Coming home to go...
Heest, Flora Bastiana van

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2009

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):

Copyright
Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

Take-down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): http://www.rug.nl/research/portal. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.
Chapter 3

Historical review of seven Dutch theses by general practitioners about patients with cancer (1918-2006)

“If you want to look forward it helps to look back.”
W. Churchill

Introduction

Family Practice and Palliative Care are fields of interest and specialization in medicine that have an overlap in their patient group, the patients with incurable conditions. They also share the need for a combination of the use of evidence based medicine to achieve the best quality of life given the medical condition and of attention to the unique narrative of the patient. This requires optimal communication skills and courage to find the appropriate solution for a specific problem in an individual patient. Palliative care itself grew out of the dissatisfaction of doctors and nurses caring for patients dying in hospital or at home, with doctors uninterested or unintentionally incompetent in the relief of suffering and in helping patients achieve a good death (1). Family Practice resulted from the home visiting doctor living in his community; he helped patients with giving birth and dying and with all kinds of diseases that bothered them in between. The discrepancy between the diseases he was taught by specialists in hospital during his training and the ailments he met in practice also played a role as described by Hodgkin in “Toward earlier diagnosis”. Family practice by doctors who did not want to narrow their scope, became a specialization of its own, with the personal relationship with the patient as its main characteristic. Dying at home has become a patient's choice with the care needed provided at the bedside. Many patients express a preference for dying at home, when asked (2,3).

In the Netherlands many more patients with cancer do die at home under the care of their GP, compared to other European countries (4). As a GP with a fascination for palliative care I am interested in the history of research by Dutch GPs in patients with cancer. The profession and position of the researcher within the medical system influences the research
questions asked and the way the research is done. Combining a practical job as a GP with some research is common, but writing a thesis as a GP is still quite rare. GPs’ knowledge is often based around practical aspects of care, their stories are about cases not about numbers or researchable questions. In these narratives, it is the individual who plays the leading part. It is circumstances, families, relationships, narrow escapes, dramatic accidents, untimely dying that brings the doctor close to the different players – the patient and those important to the patients – with the doctor helping whenever possible.

“For physicians who dwell too much in the particulars, there is a risk of missing the forest for the trees. For those who dwell too much in abstractions, the risk is detachment from the patient’s experience and a lack of feeling for his or her suffering.” (5)

It is about finding out the meaning in what patients experience and present, and about making the doctor-patient relationship a creative alliance, where possibilities outweigh the imperatives (6).

These days it is common to write about research in the English language and to publish the results in peer reviewed journals. In olden days, the thesis was only published in the Netherlands, often written in Dutch, sometimes with a summary, in French (19th century), in German (beginning of the 20th century) and later in English. In the time of Erasmus and Paracelsus all scientific writing was in Latin which made it accessible to the international scientific community.

A problem with theses is that there is no systematic way in which you can find them as they enter the grey literature. I fully agree with Professor Bremer that it is important to know the history of research in your own country and in your specific area (7).

This leads to my questions for this chapter:
• What research has been done by GPs in the Netherlands leading to a thesis about patients dying of cancer? (subject, type of research)
• Does it tell us something about the history and the position of the GP and the Dutch health care system?
• What can be learned or anticipated for the future from this research?

Method

Bremer, the former professor of general practice in Groningen (1980-1990) with an interest in history published a second thesis after his retirement with an overview of all theses by GPs from 1900 until 1995 (7).
We made use of his definitions. We speak of a “thesis author”, when the author got a PhD at a Dutch university with this book. We speak of a GP when the doctor publishing the thesis was working as a GP for a considerable time before, or at the time of, the promotion ceremony.

From Bremer’s publication four new theses could be identified (8-11). A further two were already known (12,13). A seventh one was identified by personal communication (14). An electronic search was done to discover any missing theses from recent years without new results.

A form was developed to describe these theses in a systematic way.

| Author, title, publication details, personal details, details of promotion |
| Research question, study population, method, results and Conclusions |
| Discussion |
| Position Dutch GP |
| Role of suffering, of science (evidence based medicine and narrative medicine) |
| Future implications |

Results

An overview of all theses can be found in Table 3.1. They will be discussed in the following paragraphs.

<table>
<thead>
<tr>
<th>PhD student</th>
<th>Date of birth</th>
<th>Male/female</th>
<th>Date of degree</th>
<th>Promotor</th>
<th>Spec/soc/GP</th>
<th>Subject</th>
<th>Research focus</th>
<th>Publications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dam J v GeusCA de</td>
<td>23-3-1930</td>
<td>m</td>
<td>18-3-1918</td>
<td>Pel</td>
<td>spec</td>
<td>Incidence of cancer</td>
<td>Death certificates</td>
<td>no</td>
</tr>
<tr>
<td>Spreeweemb C</td>
<td>9-3-1947</td>
<td>m</td>
<td>17-3-1970</td>
<td>Horstra</td>
<td>soc</td>
<td>GP and cancer patient</td>
<td>GPs</td>
<td>no</td>
</tr>
<tr>
<td>Schadé E</td>
<td>16-12-1952</td>
<td>m</td>
<td>17-3-1981</td>
<td>Lamberts H</td>
<td>GP</td>
<td>Help by the GP with dying patients who died</td>
<td>GPs</td>
<td>no</td>
</tr>
<tr>
<td>Schuit KW</td>
<td>8-8-1956</td>
<td>v</td>
<td>3-3-1999</td>
<td>Meyboom B</td>
<td>GP spec</td>
<td>Palliative care</td>
<td>GPs, GPs</td>
<td>no</td>
</tr>
<tr>
<td>Muijsenbergh</td>
<td>20-4-1962</td>
<td>m</td>
<td>10-10-2001</td>
<td>Springer</td>
<td>GP+ethics</td>
<td>PC by GP, patient needs assessment and care</td>
<td>GPs, patients, carers</td>
<td>yes</td>
</tr>
<tr>
<td>Osse B</td>
<td>26-1-2006</td>
<td>m</td>
<td>26-1-2006</td>
<td>Grol</td>
<td>GP+GP</td>
<td></td>
<td>GPs, patients, carers</td>
<td>yes</td>
</tr>
</tbody>
</table>

Table 3.1 Overview of the theses

The first Dutch thesis about cancer by a general practitioner was written in the beginning of the 20th century. The author dr. J. van Dam, born in Leeuwarden, did his research after more than 25 years working as a GP. The setting was a rural area in the province of Friesland, on clay soil, with cattle breeding, in a water rich area.

His promotion was the 18th of March 1918 at 4pm in the University of Amsterdam with Professor Pel, professor in internal medicine.

His research question concerned the occurrence of cancer, whether there was a rise in numbers or not. To answer the question he also studied the etiology of cancer.

In his method he used mortality numbers and information about the causes of death from the community administration. He mapped the cases of cancer just like John Snow mapped the cholera cases to identify whether an infectious cause could play a role in the etiology. He compared mortality due to tuberculosis (going down at that time) to mortality due to the different types of cancer (which were possibly going up).

The results are presented in tables of which I have chosen to translate some (Tables below on deaths due to cancer).

In his discussion of the outcomes he considered different causes or influences on the occurrence of cancer: heredity, contagiousness, alcohol, other chronic stimuli, food, economic and hygienic circumstances, influence of trees and soil and the relation between cancer and tuberculosis.

His conclusions were that “there is much in favor of saying that cancer is a chronic infectious disorder” and the second “that abuse of alcohol does not play a role in the etiology of cancer”.

<table>
<thead>
<tr>
<th>Rauwerderhem</th>
<th>stomach</th>
<th>liver</th>
<th>intestines</th>
<th>lip and tongue</th>
<th>mamma</th>
<th>uterus</th>
<th>mixed*</th>
<th>unknown</th>
<th>sarcoma**</th>
</tr>
</thead>
<tbody>
<tr>
<td>1881-1885</td>
<td>2</td>
<td>6</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>1886-1890</td>
<td>12</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>1891-1895</td>
<td>14</td>
<td>7</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>1896-1900</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>1901-1905</td>
<td>4</td>
<td>8</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>1906-1910</td>
<td>6</td>
<td>6</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>1911-1915</td>
<td>12</td>
<td>2</td>
<td>7</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>total number</td>
<td>54</td>
<td>38</td>
<td>17</td>
<td>7</td>
<td>3</td>
<td>4</td>
<td>3</td>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 3.2 Death due to cancer in relation types of cancer
Discussion

The picture of medicine at the time from his thesis (less than a century ago) is one with the overwhelming presence of infectious diseases (including typhoid fever), a lot of obstetrics and with the emergence of surgery. Signs and symptoms were very important for diagnosis and prognosis and gave a lot to think about, but not much could be proven.

A curiosity in my opinion is that lung cancer was missing. Maybe it was taken for tuberculosis. The numbers for cancer of the breast and cancer of the uterus were very low compared to numbers in the city. He comments on that himself, but he did not have an explanation. It is striking that the age group in which most patients with cancer died has not changed.

This thesis is an example of science research, the word suffering is not mentioned and there are no narratives, neither from patients nor from doctors.

From this thesis we can conclude that etiology can be comprehensively studied in general practice. The position of the general practitioner is unique in generating data for epidemiological research. This has been materialized much later in the Morbidity and Registration networks by general practitioners of the Universities and the (national institute) Nivel.


The second thesis from a GP about cancer patients came some fifty years later. The author (born in 1930) had been a GP since 1958 working in a semi-rural area in the west of the Netherlands (Waddinxveen Zuid-Holland).

The promotion was the 17th of March 1970 at 4.15 pm in the University of Utrecht with Professor Hornstra, a professor in sociology who had an interest in the work of the general practitioner.

The research question considered the family doctor’s share in the support given to cancer patients. GPs generally did not exchange experiences about
dying patients with each other, so the wealth of their experience was lost. A doctor starting out in practice had to find out everything for himself, being inexperienced but fully responsible for the patients.

In the introduction of this dissertation the disease cancer, its hidden origin and the emotional consequences for the patient and family suffering from it, were discussed with literature as a reference. At that time most cancers were incurable and a relevant issue was whether to tell the patient the truth or not. The drama of the cancer was a reality (a personal, an objective and subjective truth) to which the family doctor had to respond with support. Any problem could be brought up by the patient and family and support would be given in response to the most acute and grave problems. The centre of attention was the patient (and family) - doctor relationship in which professional knowledge, and also knowing each other were important. There was a trend to institutionalize incurably ill patients with a counter reaction from general practitioners and nurses. "The own home of the patient is a place to live and to die and it would be a medical, economical and social foolishness to try to change this" (page 57 Aitken-Swan).

In the theory of assistance to the patient three different levels were observed, the patient as a project of care for the doctor, the patient as an object undergoing the changes of cancer with all its consequences and the patient as the subject – a human being coming to the end of his life and his personal death.

Method
Sixty family physicians were interviewed about the assistance they gave to one of their cancer patients. The interviews were taped, transcribed and classified according to themes. (participant observational structured interview).

Results
The interviews (57 of 60 could be used) have been arranged around certain themes concerning the GP and the patient: Responsibility of the GP and trust in the GP; the patient; fitness; truth telling; attitude of mind; patient and family; patient and society; family and society; GP patient and family.

Discussion
From the title "Family physician and cancer patient" the development of the profession of family physician is obvious. In general, this research is contributing to a professionalization of the care by GPs with dying at home as a “specialization” that should be distinguished from hospital care.

In this thesis the way of writing was in a literature (subjective) style. For the purpose of giving an impression of the assistance given by GPs this seemed adequate; with words a picture was painted of the suffering with all emotions that belong to it. In contemporary terminology this research would fit in the mainstream of narrative or humanistic medicine, not in the evidence based science oriented part.

For the future it underlines the personal aspects of care (of doctor and patient) as a counterbalance to the emphasis on evidence based medicine.

The author of this third thesis, born in 1944, specialized a short time in internal medicine but decided then to become a GP. First he worked in Emmen Drenthe (the area where I work now) and from 1978 he worked for the department of general practice in Utrecht combined with a part time job as a GP near to Utrecht.

His promotion was the 17th of March 1981 at 2.45 pm with the first professor in general practice in the Netherlands Prof. Dr. J.C. van Es

His research question was how terminal care provided by the GP influenced the patient’s appropriate dying. The extent to which terminal care ensured “appropriate dying” was taken as a criterion of the quality of
care by the researcher. Appropriate dying was defined as a way of dying which the patient experienced as most consistent with his personal situation, his needs and wishes. In his preface Spreeuwenberg comments on the research problems in this area because this research not only reveals anxiety, insecurity/uncertainty and emotions of the dying but also the ones of the carers.

Method
Qualitative analysis of forty one patients who died under his care during one year in the small town where he worked (his patient population consisted of 3000 patients) and of relevant literature. He identified important aspects from these data and held explorative structured interviews under thirty colleagues working in three different regions in the Netherlands with a different “regional culture” on dying at home (the north, most patients dying at home, the south, most patients dying in hospital, and the west, in between).

The author used the place of dying as an outcome to start with. The patient to be discussed with the researcher was the last one that had a prognosis longer than 7 days and died at home. First the GP told about his experiences with the dying of this particular patient, later uncovered subjects were brought up by the researcher. Then background ideas of the GP were talked over.

The data were studied from the perspective of reflection on the ethical determinants of a doctor’s actions. The ethics of values and responsibility are regarded as particularly suitable to serve as a guideline for a doctor’s conduct. Both the patient and the doctor should be willing to accept each other as a person to function optimally in a participation model. The patient’s norms and values give direction to the care provided and the doctor’s norms and values determine the limits of his care. The participation model can be recognized by the way in which emancipation, responsibility and communication function in the relationship.

Results
GP’s basic attitude towards terminal care was an important factor in appropriate dying.

Somatic aspects like the relieve of pain could only be done by a GP understanding the principles of alleviation of pain. With psychological aspects emphasis was placed on existential anxiety and other negative and positive feelings in the dying process.

Emancipation leading to a participation model in contact with the patient-in contrast to mechanistic model or paternalistic model - and truthfulness were important aspects. Truth was a relative truth according to time and the patient’s needs. To safeguard family relationships the patient and the relatives should be informed about the diagnosis simultaneously. It was concluded that religious faith had different significance for different persons.
With requests for euthanasia the decision should be based on intersubjective assessment of all values involved. Termination of human life was considered euthanasia (a good death) only if the inhumanity of this act was outweighed by the inhumanity of preserving that life. The “humanum” encompassed anthropological categories as hope, future, freedom, signification, tolerability, dignity and relations (and if applicable also relation to God).

In the participation model the doctor could not be obliged to effect euthanasia, he was allowed to limit his actions on the basis of personal views, norms and values. Although many patients attached great value to dying at home there was not a most desirable place of dying, the most “appropriate” place could change in course of time depending on available care at home and condition of the patient.

Psychosocial care for patients was considered a task for the GP. Improved communication between hospital and home care could be more effective than shifting care to hospitals. Cooperation with the district nurse and when applicable with the pastoral worker was important for the GP working in the home situation.

The GP must have some insight in relations of the patient because particularly children who no longer lived at home often played an important role in the quality of terminal care.

Within a family caring for a dying patient the GP’s relationship had dual characteristics: in one way family members were helpful allies, in another way they needed help themselves because of the (pending) loss.

The author advised that training in the management of dying patients should be included in the medical curriculum.

Discussion

In this thesis the position of the GP has changed to a professional worker in his own field of care with his own co-workers.

The way of doing research was qualitative by an observational approach. This was closer to the narrative/hermeneutic aspects of medicine than the evidence based part. In this way insight was gained in attitudes and relations of the GP in terminal care.

For the future it implies that doctors who work with dying patients must also have developed a personal attitude towards dying to be able to handle their own emotions in this phase of life.


The author of the fourth thesis had a year of training in internal medicine before starting working as a GP, one year in Amsterdam and then for nine years (until 1984) in Hoorn, West Friesland. From 1984 he continued to work
for one day/week as a GP, while working the rest of the time for the University as a coordinator of the education for GPs.

His promotion was the 16th of January 1986 with Professor Dr H. Lamberts (department of general practice of the University of Amsterdam) as his promotor and dr C.H.N. Veenhof as a co-promotor.

In part one, the registration of accurateness of cause of death was investigated by comparing official death certificates with forms filled in by GPs. The conclusion was that GPs should be more cautious when completing the forms and that in statistics a possibility should be given for uncertain cause of death. Interesting to cite as a result: place of death of all deceased patients (including patients with cancer): home death 35%, low care nursing home with GP 16.9%, high care nursing home 7.2%, hospital 40.8% (1979-1983 N=750).

In part two, four research questions were addressed relevant for my study:

- How was the progress in the diagnostic phase in patients who died of cancer?
- Which problems were encountered by GPs in the diagnostic phase?
- Which problems were faced by GPs in the treatment, care and guidance of patients dying of cancer?
- Which conclusions can be derived from this study with regard to teaching GPs?

**Method**

These questions were answered on the base of 223 medical histories of patients (who died from cancer, 29.7% of all deaths) with additional information from their GPs.

**Results**

Only a few problems faced by GPs during the diagnostic phase of cancer resulted from lack of knowledge or expertise. Most problems resulted from the relation between the patient and the GP and were due to patient delay or communication problems and also from the co-operation between GP and specialist.

For practically all patients who died (221 of 223) the GP was actively involved in care and counseling. In 80 cases (36%) the GP reported no problems. Psychosocial care of the patient resulted in problems in 26%, with the family/informal carers in 23%. Most problems, 39%, occurred with medical treatment. Problems with cooperation between doctors was 10%.

The GPs participating in this research experienced more deficiencies with respect to the medical somatic part of the care, and less with the psychosocial part.

Problems between GPs and specialists were caused by failure in communication and differences in concept of professional responsibility. The GP felt responsible for continuity in care but lacked tools to achieve this and was not presenting himself enough.
The GPs wanted to contribute more to treatment, care and counseling of cancer patients than was done up till now. They were prepared to do so and time was not reported as a limiting factor.

Education about the patient with cancer should concentrate on diagnosis of patients with cancer before graduation. In vocational training as a GP or other specialization the treatment, care and counseling of cancer patients should be taught. An important aspect of post graduate training is improvement of cooperation between GPs and specialists.

Discussion

In this thesis the position of the GP is fully recognized and improvement of cooperation with the specialist is proposed. The GP is willing and able to do an important part of the work but this is not always recognized by the specialists. On the other hand the GP is not self conscious enough to advocate his share in the care.

Evidence in this thesis was provided by numbers more than by narratives.

The late Prof Lamberts excelled in the putting up of the registration of primary care problems with the International Classification of Primary Care (ICPC). This thesis showed that the general practitioner became more incorporated in epidemiologic and reductionistic research methods.

For the future we can learn from it that the relation GP-specialist has to be improved.


My colleague Karel Schuit (born in 1952) was trained as a GP before his training in tropical medicine. He worked in a rural hospital in Kenia from 1981 to 1984. He returned and started his work as a GP in Groningen in 1985 as the successor of his father. From 1993 he worked for the Integraal Kanker Centrum Noord (IKN) for one day/week.

His promotion was the 3rd of March 1999 at 4 pm with Professor dr B. Meyboom-de Jong (the first female professor in general practice) and Professor dr D.T. Schleijfer (oncology) and referees dr R Otter and dr W.J. Meijler.

The general goal of the study was to evaluate and improve symptom treatment of cancer patients by the GP at any time during the disease process. At the time of diagnosis and cancer-directed treatment (with chemotherapy, surgery and/or radiotherapy) both GPs and specialists might think that the other doctor would address these symptoms. The specialist referred back to the GP when he had neither curative nor palliative possibilities anymore for anti-tumor therapy. If a patient was referred back for terminal care in a late stage it was difficult (too late) for the GP to build an effective confidential relationship as needed for counseling and treatment during the dying phase.
The research question was what type of symptoms do cancer patients in a palliative phase of their disease have and how can symptom management be improved; do expert recommendations influence symptom scores? does a workshop for GPs on treatment of pain improve knowledge and influence use of opiates?

Methods
After selecting appropriate measuring instruments (for the prevalence and severity of the symptoms and the functional status) a cross-sectional study with three patient groups was done. Patients with disseminated cancer visiting an outpatient department of the oncology clinic were asked to participate and symptoms were measured either by interview at home or by questionnaire. A control group of patients received the questionnaire as well.

In half of the interviewed patients the results of the interview were reported back to the GP and an advice was given on how to improve symptom management.

After the second interview at home the other half of the GPs were send the results of the interviews and recommendations.

The effects of a workshop about treatment of cancer pain was evaluated by a questionnaire at the beginning and at the end of the workshop. The opiate prescription patterns of the general practitioners were evaluated as well.

Results
60% of the cancer patients suffered from pain with 20% indicating a score of 5 or higher (0-10). An unexpected finding was that in the control group 18% of patients without cancer reported pain of the same severity. 30-40% of the patients with cancer reported constipation, nausea, loss of appetite, cough and dyspnoea. Cancer patients had a decline in functional status compared to control patients. Decline of functional status was associated with higher symptom distress.

There was no significant improvement in symptom score between patients who's GP received a recommendation for treatment of symptoms and who's GP did not receive that.

Questionnaires filled at the end of the workshop on pain showed improved knowledge about pain treatment especially with morphine. Prescription behavior of workshop attendees was compared to non-attendees and it turned out that there was a small effect.

The importance of exploring psychosocial factors and good communication during treatment of pain in cancer patients was illustrated with a case history.

Conclusions
Although the outcomes of the intervention were disappointing this research increased insight in the burden of symptoms in palliative care patients. The self invited advice was not successful but the idea grew that - if advice would be available when asked for - it would be possible to make a difference.
Discussion

There may be a difference in the perception of symptoms and the wish of the patient for treatment. Actually in general practice it is quite common for patients to come to the GP with a complaint being satisfied with examination and explanation of the background of it. Many patients don’t want more treatment than explanation.

Changes in (prescription of) doctors is a slow process like any process of change.

Position of the GP

In this thesis there was no doubt about which doctor should get the treatment advice in a palliative patient, it was the patient’s GP. This confirmed the leading part the GP was playing in caring for the patient with incurable cancer. It was seen as essential that this GP is equipped well enough to perform this task. This thesis was the first using the term “palliative care” in the way we use it now for a field of care.

This study was also the first study with the use of measuring instruments, with evaluation of symptoms in patients with cancer in the palliative phase of disease and with an intervention. It is also the first study to measure effects of education on pain treatment especially morphine in the Netherlands. The balance of emphasis on measurement tools and attention to physical symptoms is corrected in the last chapter with the narrative of a case illustrating the importance of psychosocial end communication issues in relief of suffering.

This research project was at the base of the Groningen consultation project of which is reported in chapter six.


The sixth thesis is the first in this area by a female author, born in 1952. She worked as a GP from 1985 until 1995 in Leiden and moved to Nijmegen in 1996. She is involved in education at the university of Nijmegen as well.

The promotion was the 10th of October 2001 at 4.15 pm with Professor dr M.P. Springer (general practice) and Professor dr H.M. Dupuis (ethics) Other members of the promotion committee were prof dr E. Schadé (reviewer), prof dr F.J. Cléton, prof dr P. Spinhoven, prof dr C. Spreeuwenberg, prof dr C. van Weel.

In her introduction she described the difference in perception of an acute problem between the patient and the doctor. The doctor had a lot to offer as treatment of pain due to fracture of a vertebra (tumour metastasis) in a 43 year old woman with breast cancer; but the patient did not want any of these treatments for several reasons.

Her research questions: “What does a GP do from the moment he knows that a patient is going to die until the hour of his death? What are the experiences with palliative care of patients, their cares and their doctors?
Method
In this prospective qualitative research project for two years (1995-1997) a selected group of in total 19 GPs were involved with a population of around 36000 patients.

102 patients with cancer were included in the study by their GPs; some GPs hardly ever considered a patient fit enough to be included while other GPs included most of their patients. Analysis revealed that the 30% of the patients that were not included had different reasons for exclusion. The GP was interviewed after including a patient and after the patient died. The patient kept a diary and was interviewed by the researcher as well (26 patients were interviewed). After the patient died the carers were interviewed, this was possible with 13 carers.

Results
The palliative stage of the patients with cancer lasted on average seven and a half months (<1 month up to >3 yrs). The GP had an average of 26 contact of 16 minutes with each patient. Contacts were most on initiative of the doctor. A GP spend an average of 45 minutes per week on these contacts. 95% of the care was delivered personally, compared to 80% in ordinary care. In one in every three contacts medication was prescribed, generally consequences of the illness both physical and emotional were discussed. In the last days 80% of the patients knew that their GP was available at any time. In the last week before dying contacts were generally daily. 82% of the patients died at home.

Severe complaints seemed not very important for most patients; in the last three weeks there was an increase in amount and severity. Pain, tiredness and dyspnoea were the most frequent complaints. Patients did not want to relieve their symptoms at all costs, they were convinced that some problems could not be helped. Doctors were aware of 82% of these complaints. The GP was not able to relieve 30% of the complaints especially tiredness and anorexia. In 5% of the cases the doctor considered treatment of physical complaints problematic. Half of the patients were hospitalised once for a short time.

GPs were satisfied with their performance and did not consider specialists to be able to do better. Co-operation between the specialist and the patient was problematic in more than a quarter of the cases.

Patients reported not having any mental complaints, carers did not report any about them either. Emotions were interpreted as normal for the situation. Doctors registered fear in half and sadness and gloominess in a quarter of the patients. 10% of the patients were extremely anxious and 7% were depressed according to the GP. Treatment was not very specific, not all patients with depression were started on antidepressants and sedatives were given to both anxious and to no anxiety reporting patients.

Carers considered the GP important for monitoring the care and the burden on them and if necessary to suggest or arrange extra care at home.
The GP discussed the end of life several times in 91% of the patients, usually on their own initiative. Euthanasia was discussed with about half of the patients. For GPs a request for euthanasia was disturbing, they were in doubt about the term “unbearable suffering” and about how to respect to their own values.

20 out of 83 patients asked their GP for euthanasia. In four cases the GP declined the request because a lack of unbearable suffering in his opinion. Euthanasia was done in 16 patients. The most important reasons for the request for euthanasia by the patient were fear of dependence and the wish not to deteriorate further. There seemed to be a difference between GPs in the preparedness to agree with euthanasia. All GPs were deeply moved by performing euthanasia.

The doctor was present in the house at the moment of death or shortly after it with 90% of the patients.

This study showed that there was no great difference between the needs of the patients and the expectations and capabilities of the GP. The conclusion was that a dying patient needs a good relationship with his doctor, close attention and personal support.

This thesis gave insight in the everyday care of GPs to patients in the palliative phase of cancer in the Netherlands.

Generalization of the study was limited by the convenience sample of doctors who agreed to participate in the study but it gives a peak behind the curtain of the work of the GP for patients who are dying.

Discussion

This study gives insight in the practical way of working of the GP in end of life issues in the Netherlands.

The narrative of the doctor, the patient and the carer are brought together in this study in trying to get a full picture of what is happening in end of life care by GPs. The experience of suffering of the patient but also of the care giver and the difficulties for the doctor are described.

The personal aspects in the interpretation of suffering remain an important aspect for general practitioners involved in end of life care for the future. Maybe the continuity in care and personal relationship by GPs is the most essential to offer in relieving suffering.


The author of this thesis (born in 1962) had to wait for four years before he could start with the training as a GP (1993-1995). He is working in his own practice since 1997 together with his wife, also a GP.

The promotion was the 26th of Januar 2006 at 1.30 pm with Professor dr R.P.T.M. Grol (general practice, UvN) and Professor dr. E. Schadé (general practice, UvA). Co-promotor was Dr. M.J.F.J. Vernooij-Dassen.
The ultimate goal of this researcher was to give the best quality of care to patients in the palliative phase of disease in response to the needs and problems of patients and caregivers. It is essential to be aware of the exact needs and problems of the patient before providing care.

The question of the researcher was “is it possible to develop instruments for use in palliative care that can systematically assess the problems and the needs of patients and their families?”

**Method**

First, a literature review was done, none of the instruments fulfilled all the requirements. A new instrument was developed by qualitative research with in-depth interviews with nine patients and interviews with 31 patients and 15 relatives.

This resulted in a comprehensive checklist of relevant problems of patients and a separate list for caregivers. The next step was testing of the instruments for validity and reliability on 64 patients.

To assess the needs of the patients, 94 patients completed the instrument (90 items on potential problems or needs). A top 20 of problems was made. As loss of autonomy emerged as a prevalent problem, a special questionnaire was developed on that topic. Then the validity and reliability of the caregiver questionnaire with 66 items was investigated. After an assessment of caregiver problems, a short version was constructed with 33 items.

**Results**

Four validated instruments were developed, a long and a short version for patients and a long and a short version for caregivers. An additional instrument, developed to assess loss of autonomy, was a novelty and can be used in addition to the other instruments.

An important inter-individual variation in the number of problems and unmet needs was found, both for patients and caregivers. Many patients had fears that should be talked over. The loss of autonomy also needed professional attention.

**Conclusions**

The developed questionnaires (Problems and Needs in Palliative Care - patient [PNPC-p] and - caregiver [PNPC-c]) can help to map problems and needs in a valid and reliable manner.

With this instrument, professionals can gain insight in a structured way and give support tailored to the needs. Patients have a responsibility in answering the questionnaires, can direct their care in this way and maybe the instrument helps them to reflect over their situation. More attention might be given to the caregivers when the questionnaires are used because that seemed a weak point.
In this thesis the GP is an important provider of palliative care. The structured needs assessment could maybe improve the care provided. However to use questionnaires is often not the first choice in the way of working of a GP. During a consultation or visit of the doctor the talking with the patient and the care giver is a very important part of the gathering of the information and the assessment of the situation. Also for the author of this thesis the question whether such an instrument will really improve quality of care has not been answered. And it is not sure whether it is time efficient.

This study is well done methodologically. Items are tested for validity and to improve the questionnaire it is shortened. But the main question is whether suffering from pain or other symptoms can be captured in a questionnaire. Should not always (enough) time be reserved for listening to the unique story of that patient? Maybe in addition to that the questionnaires can be of help.

These instruments for needs-assessment may play an important role in research or treatment in palliative care in the future.

Conclusions and discussion

In general

In these theses from GPs about cancer patients the research they did covered the whole field of general medicine, from etiology of cancer to a diagnostic tool to measure problems in the last phase of the patient’s life.

While reading these theses a wealth of information and critical thinking about themes concerning patients with cancer in general practice is disclosed. In this time of social devaluation of values like prudence, fidelity, temperance, endurance and humility, the general practitioner is maybe one of the carriers of these values because of his position: beside his patients not at heroic times but rather during the deceptions, difficulties and addictions of everyday’s life (15).

Actually it is a pity that not every GP writes about his experiences and findings either in a scientific or a narrative way; what a wealth of stories and information we would have then by now.

For the identity of general practice as a medical specialization and the self-consciousness of GPs it would help as well.

Cooperation with specialists

One of the themes emerging more than once is the cooperation of GPs with specialists.

“In the modern university, abstraction and disengaged reason reign supreme. Knowledge has been separated from experience, thinking from feeling”... “In medicine, the standard diagnostic method is an outstanding example of the imbalance. The physician is required to categorize the illness, but not to attend to the patient’s feelings or understand his experience” (5).
This is the culture of medicine the specialist is working in every day. Of course there are differences in personalities of specialists and the way they cope with this culture. Part of the attending to feelings has been passed on to (oncology) nurses in counselling patients for instance during chemotherapy; but then there is discontinuity in person and in professional background.

It might help to specify the qualities and difficulties that general practitioners experience to specialists to improve cooperation. From recent research it turned out that specialists had difficulties in reaching the GPs by phone while GPs had problems with the long time it took the specialist to send a discharge letter (16). How to change these obstacles and improve the care? There are no instant solutions.

One proposal I would like to make is that the responsible GP writes a letter to the involved specialists after the death of a patient at home with a summary of the course of the end of life. This would acknowledge the roles of both the GP and the specialist and maybe help in the building of a respectful relation.

**Dying at home**

Attending to patients who die at home is perceived as an important and challenging task by GPs.

This task of providing terminal care at home takes a lot of time of the GP as also was found in the study about elderly patients (over 65 years) in 1985-86. Of the 44 patients with cancer in this study 28 died at home (64%), a small group of patients asking a lot of attention while they experienced serious limitations in functional status (17).

The number of patients dying at home with cancer were relative high in all the studies. In the Netherlands a unique situation was created with the possibility to deliver at home and to die at home. This may have to do with cultural acceptance and the organization of the health care system.

“Complex interactions of individual and systemic attributes affect the choices people face, the decisions they make, and their ability to act on these decisions. Cultural and social values probably also guide patients, families, and care providers. Relatively homogenous and coherent sets of these values may be shared within local communities, either through a process of person-to-person dissemination of values or by people preferentially migrating to communities that manifest particular values”. In the state Washington in the USA the likelihood of home death was associated with the likelihood of home birth. Moreover, the likelihood of dying at home increased with local wealth but decreased with local hospital bed availability (18).

**Education and thoughts about the future**

The message from these theses for education is to work on both: the practical tricks (if possible evidence based) which a doctor needs when caring for a dying patient; and at the same time support of colleagues to grow as a person (in communication and self reflection) to be able to use
empathy and imagination to provide personal coaching to dying patients and their families.

To keep our profession as medical practitioners viable and prepared for the future we could take the five advices from our colleague Atul Gawande to heart who mastered the art of writing about medical issues in an inspiring way: the first is to ask a question that is not expected to make contact with that person, to get out the mechanistic everyday approach; the second is don't moan about things; the third is to start to count something, either in relation to work or anything at all, to start to improve things; the fourth is start to write, by writing you start to reflect and to take the distance to oversee a problem. You become part of the larger world with the writing. The last suggestion is change. Every choice is imperfect, sometimes it is worth to take a risk. A small idea can grow, even if you did not expect that. (19,20).

So I hope that also GPs will change and start counting for themselves whatever they like to count - in addition to obligatory so called quality indicators for insurance companies- and then write about it. Resulting in more stories and publications, more pleasure in work and more satisfied patients.

Literature

1 Richmond C. “Dame Cicely Saunders” BMJ 2005;331;238
6 Rudebeck C E. “Imagination and empathy in the consultation” British Journal of General Practice, 2002; 52: 450-453
7 Bremer G J. “Hora est, proefschriften van huisartsen 1900-1995” (dissertations by general practitioners) 2000 thesis EU Rotterdam, Panthaleon reeks nr 35 Erasmus publishing, Rotterdam
8 Dam J van, “Waarnemingen over het voorkomen van kanker ten platten lande” (“Observations of the occurrence of cancer in rural areas”) 1918 thesis University of Amsterdam; published by Meijer en Schaaftma, Leeuwarden


17 Meyboom-de Jong B. “Bejaarde Patiënten, een onderzoek in twaalf huisartspraktijken” (Aged patients, a research project in twelve general practices) 1989 thesis University of Groningen, ISBN 90-9002840-4, Krips Repro Meppel

