Chapter 1

Introduction

Coming home to go, the patient who cannot be cured goes home to die; coming home to go again, where the GP visits the patient who is very ill. The GP is giving care in this phase, palliative care because unfortunately curative care is not possible any more. A personal type of care adjusted to the needs of that patient and his informal carers; personal also for the GP. This GP with this patient. Personal tailored care, unique care.

This thesis deals with the patient who is dying at home, about the unique care of the GP and the support of the GP.

Going home, going to sleep for ever, euphemisms for dying referring to “everyday normality” of dying.

Personal experiences with disease

From a small child on I was fascinated by interaction between things, animals and people. Especially the power of the mind over the body (I climbed out of the playpen at 9 months) or the body over the mind, as I was ill quite often.

Some memories are very vivid. As an asthmatic child (around 4 years old) being in a tent (with oxygen?) extremely thirsty, getting only a small sip of cold water instead of the full glass that I was longing for. Then I drifted away with the picture of the caring doctor and nurse on my mind as they stood there, not fulfilling my wish but being there.

Lying in a children’s ward again because of the asthma (5 years old, yes my father was a smoker, “Miss Blanche”) with some eczema as well, seeing another child completely covered in bandages due to severe eczema. I tried not to scratch myself anymore, I realized the influence I could have by my mind over my body.

The proud and very special feeling of going to my teacher to tell that at almost 8 years I got a little brother, I had longed for that moment so very much. A permanent feeling of belonging and joy was generated by that good news.

During the recovery of my last asthma attack (I must have been 9 years old) being in bed for an afternoon nap with the radio on. The “Moldau”, classical music of Smetana, was played in parts with an explanation of the music. I remember the dyspnoea and constriction melting away on the music. I never had an asthma attack again. My mind had found a way to influence the body, to reduce the constriction and tension in my respiratory system (or maybe my airway had just grown in size, who will tell).

My parents went away for their work to Indonesia when I was 13 year old. My small brother went with them, I stayed with the sister of my mother and family. The first week of their absence I was literally sick, weak, crying inside. Besides the loving care of my aunt, uncle and cousin, friendship (especially with Ellen and tante Ger) and music were basic elements of getting through the feelings of loss and insecurity and restoring a balance.
A view from general practice

The ideal society is one in which people can develop inborn qualities of body and mind up to the limits of their possibilities to the enjoyment and benefit of all. If something goes wrong, if disease develops then there should be professional care with diagnosis and treatment. Doctors are there to treat patients but also to search for the origin of disease and the improvement of treatment.

My contribution to research as a GP lies in (epidemiologic) observations to describe the importance of some aspects of palliative care at home. The aim is to assess quality of care and to contribute to improvement. From my position as a doctor in the community I have a different view on the factors involved in development of disease, on quality of care and interactions with patients than doctors working in a hospital or researchers without practical experience or working in a laboratory environment. (1,2)

In 1998 Meyboom-de Jong wrote an article on “Promoveren kun je leren” (“you can learn writing a PhD thesis”) (3) This was enough for me to take the threshold fear away (I moved to a different region of the country and did not know people in the university of Groningen) and an appointment was made resulting in my diploma and masters in palliative medicine and in this thesis.

Scientific practitioner

In the science model of research you start with a “good” research question (4). The opinion about what is “good” in this question is essential; if the questions that are accepted are very limited this may result in tunnel vision of reality (5,6,7,8). See box on page 5.

In general practice science and a humanistic approach unite. There is ample opportunity to do observational or epidemiologic studies or to research ways of improvement of care.

Interactions

The influence of interactions between people is difficult to translate in an ethically accountable, researchable scientific question. How much does a committed positive and caring attitude of the doctor or nurse contribute to the feeling of well-being of a patient? (11) As the body cannot do without basic food and hygiene the mind cannot do without interactions in the form of love and care, either in positive way (a caress or a pat) or if nothing else in a negative way (a stroke or slap). This complicates doing comprehensive research.
Evidence based medicine with disease related experiments in large samples of patients has improved the views about what is best for the patient. It has enhanced the critical thinking of doctors. It has unmasked habits based on opinions that were not really contributing to better care (12). But there is more than that in medicine especially in general practice. How can we measure the part of the treatment described by "The doctor's best prescription is himself (13)?" Especially in walking the last part of the way of his life -with the patient and his family- personal commitment matters.

Here we come to basic values in (professional) life. Should the narrative of the patient's life end with the count of the haemoglobin or should it end with his personal qualities that made people love him and love caring for him (14)? What is the interaction between these two? Is it necessary to split it up in either-or? What is the role of creativity in bringing different elements together?

An example of a confusion about interpretation of reality is found in the thesis of Sander Borghstede - a young pharmacologist (9). He found that step two (codeine, tramadol) of the WHO ladder is not used much by GPs in the Netherlands.

The ladder has 3 steps officially. If possibilities of step 1 have been used adequately (by the clock in adequate dosages) then the next step should be taken (10). For the education of GPs about the treatment of severe pain we have added a step 4 as in part of the patients the pain cannot be controlled by the oral route.

The finding that step 2 was not used much by GPs was for me the (positive!) result of years of education and training of GPs on the use of morphine as an effective controller of severe pain that should not be feared. If the pain cannot be treated anymore by paracetamol and NSAID alone pharmacologically –and if strong opiates are available as is the case in the Netherlands- the choice of a low dose of morphine can be superior to the use of codeine (same side effects as morphine, needs conversion in the body to morphine, part of the patients lack this possibility) and tramadol (has a 5 times weaker effect as morphine, often side effects like dizziness). At the same time dr Borghstede is wondering why the GPs are not making use of step 2 of the WHO pain ladder (40% did not use a weak opiate). He suggests that more research to the management of cancer pain by GPs should be done.

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What is the role of encouragement and inspiration? What is the role of philosophical or religious backgrounds (15)?

General practice gives opportunities for descriptive and qualitative research with observations, interviews and stories (case studies) to give words and meaning to aspects that cannot be captured in numbers (16,17). The development of penicillin started with an observation. However Sir A. Fleming said: “Penicillin cures but a glass of wine makes happy.” How to bring happiness together with science? How to die well?

**Palliative care**

Prolonging life is important for patients and doctors in the medical world. Some 40 years ago the optimists thought that we would be able to cure (almost) all patients with cancer by now. Although a lot has been achieved cure rates for cancer are still around 50%. However in many cancer patients survival after diagnosis is longer than before. In the older population of our society they have become part of a chronic patient population (living longer than 6 months after diagnosis) that needs substantial professional care. Attention for and improvement of the health related quality of life (HR-QOL) despite failure of cure has won in significance in the last decades. Palliative care, a medical specialty in Great Britain since 1987, originated from dissatisfaction with quality of care for patients who could not be cured (18,19). QOL is one of the key concepts in the new World Health Organization (WHO) definition of palliative care.

> “Palliative care is an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (WHO, 2002, (20))

In the three 10-years patient groups from 40 years up till 70 years, cancer is the most frequent cause of death. See table 1.1 as an illustration for patients from 50-60 years (21, CBS 2004).

Patients in this age group are active members of the society and their untimely death is a major loss and change in the life of their family. As GP you want to give the best care to both the patient and the family. These untimely deaths have many consequences for the work of the GP. GPs experience the care for these patients both as rewarding, but sometimes as difficult as well (22,23). As a GP I was challenged to improve the care for palliative patients and to evaluate these efforts in the research for my thesis.
In 1998 the “Centrum voor ontwikkeling van Palliatieve Zorg Noord-Nederland [COPZ-NN]” (Centre for Development of Palliative Care for the North of the Netherlands) was instituted. This Centre was a cooperation between the University Medical Centre Groningen [UMCG], including the Medical faculty and the Comprehensive Cancer Centre of the North of the Netherlands [IKN]. The common goal of the COPZ-NN was to optimize the quality of palliative care.

From 1986 on the IKN considered the GP as the key-player in the care for the patient in palliative phase of disease. The aim of the IKN was to improve knowledge and skills in palliative care among GPs. From organisational point of view it was stimulated to adept and support existing organisations and structures, rather than designing new ones. Guidelines for physical symptoms were written. Bottlenecks in knowledge, capabilities and organisation in palliative care at home were described.

One part of the COPZ-NN project was “the GP advisor for GPs in palliative care”, a continuation of the GP advisor project of the IKN for the province of Groningen 1994-1998. GP advisors were appointed for each of the four different regions of the IKN (one for approximately 250 GPs). The project started with a focus group interview with the four new GP advisors and a mediator to identify the needs of GPs in general and the needs of the GP advisors in particular (24). Before January 2000 forms for registration and evaluation of the advisory project were developed. To fulfil the need of education in palliative care the four GP advisors could start all four at once with the postgraduate study for the Diploma in Palliative...
Medicine in 2000 in Cardiff thanks to mediation of Ilora Finlay. Professor Finlay was appointed at the Johanna Bijtel chair of the Medical Faculty of the University of Groningen as a honorary professor around the same time because of her work as a female professor in Palliative Care at the University of Cardiff UK.

Among the four GP advisors new knowledge, cases, communication skills, emotional aspects of advising, aspects of care and practical tricks were exchanged. As different personalities each of them accentuated different aspects of care and communication. All developed a way of working with the local peculiars of the region. The project would not have been the same without this interaction among the four GP advisors.

Specific for the project in our area was the GP friendly way of working with direct access by telephone of the GP asking advice to the GP advisor. The GP advisors combined the role of advisor, preliminary administrator/researcher by filling the registration forms and educator for their region on palliative care. The continuity of advisors and advice was guaranteed by the fact that the GP advisors were appointed for one day/wk with the IKN.

After the COPZ-NN project phase a new period started (2004) with departments for palliative care in all regional cancer centres in the Netherlands. In our region the organisation changed and the way of working was slightly adjusted because the possibility for consultation of a nurse specialized in palliative care was added. These nurses fortified our team.

During the project with the GP advisors the leading research question of this study was developed and formulated as follows:
"How can GPs be supported to optimize palliative care for patients with cancer (or other diseases) dying at home?"

The chapters of this thesis describe different aspects of the problems of patients diagnosed with a life threatening form of cancer or other incurable disease, of patients dying at home and of support to GPs to improve palliative care.

In chapter two more background is given to the relevance of symptoms, the differences between primary care and secondary care, the place of death and the dying process and the needs of the GPs.

The Dutch history of research in general practice concerning cancer is given in chapter three with the analysis of seven PhD theses by GPs. The first thesis dates from 1918, the last one from 2006. The research done by the GPs covers a wide range of subjects.

In chapter four and five cases are presented about the possibilities of palliative care for patients staying and dying at home. In the case study in chapter four information was found on the internet by the GP and trying this actually changed the course of disease for that patient. In chapter five two GPs made use of the possibility to consult a colleague by telephone for a case of end stage disease with uncontrolled symptoms. With the advice symptom control was achieved in both patients and they continued to live for some weeks with quality of life. One of the problems of GPs and specialists was a lack of knowledge about possibilities of symptom management in palliative care, especially the use of a subcutaneous infusion was new.

The core publication concerned the analysis of the results of the COPZ project Groningen. It forms an important part of this thesis (chapter six). Every consultation had a narrative of a doctor about a case he/she had difficulties with in managing, ending in a question for support. In this chapter the aims of the project and the research method used are described; the data from registration by the GP advisors and the evaluation forms are analyzed.

After three years by the year 2003 the consultation project had become quite successful. In that year 574 consultations were given. This gave us the opportunity to analyze different aspects of the consultations about palliative care resulting in chapter seven about consultations on nausea and vomiting and chapter eight about consultations concerning euthanasia and sedation.

The educational needs of the GPs in our region were investigated in 2001. Four focus group sessions - one in every region of the GP advisors - were organised and resulted in the publication presented in chapter nine. These results were important for the planning of continuing education.

A new diagnosis of a life threatening disease like cancer is a stressful life event resulting in symptoms of anxiety, depression or sleeping problems. In chapter ten the incidence of anxiety and depression in patients with a new diagnosis of cancer as registered in general practice was compared to control patients without cancer. Our hypothesis was that GPs would registrar more
symptoms in the psychological axis but not more psychiatric syndromes like depression or anxiety disorder.

In chapter eleven the findings of this thesis and the strength and weakness of the research methods are considered. Suggestions for care, education and further research are done.

One important finding is that advice by a GP advisor seems time efficient and satisfies the needs of the GP.

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**My choice to become a GP**

When I choose to work in the tropics I was very happy with the need to specialize in basic skills of all medical specialties. The combination of practical skills - in surgery and gynaecology - with the skill of clinical thinking on basis of history of the patient and observation with all senses about the signs and symptoms of disease suited me and taught me a lot. Every morning on weekdays we had a meeting at the superintendent’s office to take part in the report of the doctors who had been on call and we shared thoughts on the difficult cases or had a look at a specific patient together. These multidisciplinary meetings with a paediatrician, a surgeon, two or three general doctors, some housemen and some students often from very different backgrounds were inspiring and stimulated reflection.

I had not been able to make a choice about my further education as a doctor before I went to the tropics. There I came to the conclusion that I wanted to discriminate between normal and abnormal, that I wanted to work with all age-groups and that I wanted to be in the place where the disease developed. I preferred generalization over specialisation: the overall excellence over the concentration and development of one special talent (did I have any?)? I preferred the primary care over secondary care; the close relationship with the patient over the fascination for certain diseases. ‘Answering ‘Why’ the Ghanaian concept of disease’ written by Bishop Peter Sarpong was very interesting to read. ‘The plain truth is that man has never found the answer to the question: “Why?”’. All our scientific explanations answer the question: “How”. Causes of death or illness are often explained by the western-trained person on the basis of how they happen, but not why.” This question is essential in life, also during palliative care. The Ghanaian culture with proverbs (in word and stamp/drawing), symbolic colours (red and black for bereavement and white and blue for new life) and customs (out-dooring at sunrise) was rich although in terms of purchasing power people were poor. Social interactions in Ghana were at a high level of development (25)

The suicide of a good friend during this time, partly determined by heredity and childhood loss, who was a medical doctor as well, gave my fascination by the interaction of body and mind a personal drive. A gifted and sensitive young person with a disorder of the mind leading to his death. The sustainability of life was not determined by financial possibilities as such, neither by physical health but by a delicate balance in his case between mind and body. (26)

So I choose for general practice and I never regretted that.
1 INTRODUCTION

Literature

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