Coming home to go...
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Chapter 11
Discussion

This thesis reports about observational research in general practice. It is comparable to a kind of careful systematic listening to the patient and his doctor with the aim to write about the observations and to catch this reality in words. This work has been done with the intention to optimize quality of palliative care as delivered by GPs and other doctors and the quality of life of patients with cancer who cannot be cured. Spending the last phase of life including dying at home under the care of the general practitioner is common in the Netherlands, especially in our area in the north east.

Dying at home

Dying at home surrounded by close relatives with personal care by the own GP and nurse - to be called in when necessary - gives a familiar and intimate context to the dying process. The end of life will come for everybody and is a life event much more than an outcome of disease. This is the reason why dying at home under the care of the GP is a good option. Symptom management and counselling during life events are typically tasks of the GP and in my opinion GPs must continue to optimize the quality of palliative care at home.

The leading theme for research in this thesis was

“How can GPs be supported to optimize palliative care for patients with cancer (or other diseases) dying at home?”

In every article of this thesis is written about opportunities, achievements and possibilities of improvement. In the following overview the accent is on ideas and suggestions for further research.

In the introduction (chapter one) and background information (chapter two) the importance of and developments in palliative care as an area with knowledge, skills and attitude relevant for general practice is illustrated. In palliative care just like in family medicine a humanistic approach and science are combined by the doctor to achieve the highest quality of care for the patient. In general practice the focus is on continuity of care for that patient as a person; in palliative care the focus is particular on the last phase of life.
when the patient and family know that death is not far away any more. Palliative care and general practice meet at the home of the patient. An important part of palliative care is delivered there, by the GP in cooperation with nursing care.

In the hospital, specialist care and palliative care meet when the diagnosis is given to the patient that the palliative phase has started. The definition of the start of the palliative phase is not unambiguous, for research and improvement of care agreements on this definition and the registration of it would be relevant.

Optimization of palliative care for the patient, in communication, in symptom management, in discussing end-of-life issues at any place is important to achieve the best quality of care and death with dignity. The focus of this thesis is on the GP and the needs of the GP.

From the historical overview of the seven theses analyzed, it is obvious that GPs have played an important role in end of life care for patients with cancer in the Netherlands. A returning theme is how to improve cooperation between the specialist caring for the patient and the GP involved in the care for that same patient. This could be subject of further research.

In the Netherlands we have a unique position for studying patients dying in their own environment. For the individual doctor we should make it easier to take part in research projects. Most GPs are involved in improvement of care but the fine tuning of researchers and practitioners could be improved leading to more (evidence based) research and a higher quality of care.

The case study showed that one visit to the internet could make a difference, sometimes. Maybe we should do more mapping of stories (like the gene mapping) to keep an enthusiast and inspiring spirit as doctors. Often cases that were explained fully are chosen to publish but maybe we should start with open ended cases as well to keep the art of asking questions and critical thinking alive.

In the “case study about consultation” the advices of a GP advisor to colleagues changed a lot for the patients after they were carried out. This might be an effective way of support and of upgrading of knowledge at home in difficult cases to supply patients with the best care of that moment.

How to lower threshold fear of doctors to persuade them to phone for advice? How to reach doctors not motivated for this type of care? How to create personal continuity for the GPs phoning? How to create awareness for possibilities of care not known by doctors thinking they do the best possible?

All these questions should be taken into account when considering how to continue and improve the advisory role of the GP advisors.

In the consultation project one of the key aspects was not measured. This is the interaction between the doctor phoning for advice and the GP
advisor. In the evaluation GPs were very positive about this service. This might partly be due to social desired answering. Not much is known about consultation of one doctor by another.

Generally there is an inequality in knowledge, but in case of consultation of a specialist there is also inequality in education, network and context and in organisation of care. With consultation of one GP of another the context is the same, the relation is more balanced and the way of thinking about the best solution for this problem in this individual patient is more comparable. The goal of the consultation is support of the GP caring for the patient.

Consultation of specialists often ends in the specialist wanting to see the patient himself or asking for more investigations. In end of life care this is often not appropriate or not wanted any more by the patient.

Research to discover the best form of support for the GP attending to patients dying at home should continue so that more patients can have an appropriate dignified death in the place they prefer. Even if there is no other solution than admitting the patient to a hospital for the last days it is still important for patient and caregiver that the best possible quality of care was given at home until that admission.

Advices on the treatment of nausea and vomiting of patients dying at home showed that in a short time a new technique of administration of medicine ‘subcutaneous infusion’ can be introduced in the home situation. This subcutaneous infusion of medicine - in patients that cannot make use of another route - either by syringe driver or by CAD PCA pump has changed and improved symptom control at home enormously. Which medication or combination of medicines is best and what dosages are to be preferred could be a subject for research in the future.

With the subcutaneous route, primary care has gained a very simple and useful method to control symptoms until death in patients that cannot swallow any more

Evaluation of the advices on sedation and euthanasia showed how involved GPs are in the care of their patients. They delivered personal and continuous care for the patient, but also experienced difficulties in keeping a balance between their own opinions and values and the pressure of a patient and/or family to do something. Besides that, it also showed the misunderstandings of patients and GPs around the word “sedation”. An appropriate, good, dignified death is the ultimate goal if cure is not possible. But what if the patient has finished all he wanted to do and if he only wants to die? Is that “enough” suffering? Is starving to death an alternative to euthanasia with help of a doctor to control symptoms?

More research should be done to learn the opinions of elderly people about this subject and to organize care in the way that their wishes on end-of-life care can be fulfilled.
The educational needs of GPs are related to their role as doctors responsible for the care for the dying patient. On all aspects of care they considered improvement necessary and possible. Coordination of care was an issue, symptom treatment, but also communication skills, and aspects like anxiety and depression. Euthanasia was experienced as a complex and difficult issue needing more attention. They valued the possibility of consultation of a GP advisor. It would be interesting to redo these focus groups after eight years. Needs may have changed by now due to more attention for end-of-life care.

Psychological symptoms in patients around the time of the diagnosis of cancer were increased compared to symptoms of control patients, but a new diagnosis of depressive syndrome or anxiety was not common. This supports the idea that the GP in the home situation noticed coping problems but hardly new psychiatric syndromes or diseases. It would be interesting to compare mental symptoms of patients at home to mental symptoms of patients who receive institutional care. Possibly mental problems predispose to admission to institutionalised care in end-of-life. Or patients institutionalised because of end-of-life care could have more symptoms due to the fact that they lost their home.

Strengths of the research project about consultation by a GP advisor in palliative care

This is the first longitudinal descriptive research about consultation by telephone of GPs and advices of GP advisors in palliative care. There is not much research about consultation between doctors, especially not consultation between GPs up till now (1). In the field of general practice this is a new development in possibilities of support.

Around two third of the GPs in the area made use of the service at least one time; this means that a considerable number of GPs were reached and overcame the threshold fear of asking advice.

A third of the consultations took place because of problems during the last days of the patient.

The last 48 hours of a patient can be difficult (2). Problems can emerge suddenly and need control at that very moment. Anticipation does not always work. Instant support by telephone helped most colleagues as evaluation showed.

On evaluation, 85% of the GPs who made use of the service was satisfied and put the advice in practice. They had the impression that the quality of care was raised by the advice.

Our way of working, direct contact with the GP advisor and, if possible, advice at the very moment probably contributed to this high percentage.

During the telephone consultation often more problems were revealed
than the initial problem for which the GP called. To discuss the problems with an experienced colleague can be clarifying and supportive for the person asking advice and this can lead to a higher quality of problem solving than would have been achieved otherwise.

The fact that GPs in their own region had continuous access to the same GP advisor possibly also helped to gain trust.

**Other research in this thesis**

An historical overview of theses by GPs about patients with cancer, dying at home has not been given before. This overview gives insight in the Dutch culture of dying at home and the themes that were studied by GPs during the past years.

The study on educational needs by the focus group method identified quite some needs of GPs. Advice by telephone from the GP advisor was also seen as a contribution to improvement of care and a kind of education about that patient's situation at that moment. This finding (in 2001) supported the way of working by the GP advisors (3).

In the research about anxiety and depression, an existing longitudinal database of a considerable number of GPs and patients was used. This resulted in data of a high number of patients with a new diagnosis of cancer. Prescription rates were coupled with diagnoses so actually there was a wealth of research information while there was no bias that researchers or the existence of the research project altered reality by giving attention to a special aspect of care.

**Weaknesses of the research project about consultation by a GP advisor in palliative care**

The ultimate aim of the advisory project was to improve quality of care at the bedside. GPs phoning to ask for advice were a self selected group. At the time of the start of the project there were no time and researchers to realize a design that also measured quality of care at the bedside. In retrospect it would have been interesting to know whether advices prevented admissions in hospital.

The calls for advice were registered by the GP advisers themselves. There was no researcher to help with lacking data or to do non-response research with the evaluation forms. Although the method of registration was discussed and agreed upon, some differences remained in the method of registration between the GP advisors.

The possibility of generalization of the results of this project is limited. In the north of the Netherlands -compared to other parts- more people died at home, years ago already. This tradition may have influenced outcomes in certain ways, like more willingness of caregivers to look after the patient at home and to accept the care of the GP. In other parts of the Netherlands caregivers are possibly less able to stay at home with the patient.
A third of the GPs in our region never phoned for advice. It would be interesting to know why. It is not realistic to think that in four years, they never had a problem with a patient dying at home. How did they solve their problems? Maybe other strategies apart from the GP advisor were also effective and should be supported. Or maybe they were unaware about new developments in possibilities in palliative care.

Other research in this thesis
In the historical overview only theses of GPs were included. This is a considered restriction. For a complete overview of the field all research and other publications should be evaluated. This would be very interesting but also time consuming. Maybe a research project for someone with a background in history.

In the evaluation of the needs of the GPs by the focus group method only the opinions of the attending GPs (who were interested in the field) was taken into account. It would be interesting to redo a focus group on this subject or a research by questionnaire to a larger group of GPs. The plans to do this have not been put into practice up till now.

In the project about anxiety and depression the interpretation and time of registration of the ICPC coding could be different between the doctors. In the RNG registration project the GPs had regular meetings with the epidemiologist to evaluate differences in registration frequencies and to guarantee uniform coding. This helped of course but cannot exclude small differences between doctors.

Recommendations for care
It would be desirable if specialists would be specific about the start of the palliative phase of the disease both to the patient and the GP and would give an estimated prognosis, although this is very difficult (4).

In earlier stage of disease of palliative care patients a team of oncologist, radiotherapist, surgeon, anaesthesiologist, lung specialist, psychologist, oncology nurse, home care nurse, pharmacologist, hospital reverent and general practitioner specialized in palliative care could discuss patients to anticipate problems, to estimate prognosis, and to support all involved with the care. This might be especially helpful for patients who are admitted in an institution.

At any time both the GP and the specialist should be informed about the latest developments and problems with their patient.

For optimal palliative care continuity of care is essential (5). Many GPs stay available and visit their palliative patients during out-of-office hours. It is essential and a logical consequence of the duty system that if a GP has problems during out of hours he can call for advice in palliative care.
In case the own GP cannot be reached during out of hours a short report about the situation of the patient (a kind of referral letter with diagnosis, treatment, wishes about end of life like no reanimation or no admittance in hospital any more) should be formulated for the doctor on duty.

Care at home under responsibility of the GP depends also on the possibilities of nursing care and volunteers, who fill the gaps that family and friends cannot fill. Availability of professional nursing care is a prerequisite. Availability of all kinds of aids (like an electronic adjustable bed) for safe care delivery is just as important.

It should be possible to realize a subcutaneous route for medication in the home situation on short notice, also during the weekend.

GPs should impeccable assess problems in the home situation and continue to think about solutions. They should implement and share creative solutions, after adjusting them to the local possibilities.

For GPs it is suggested that they make registration of patients in palliative phase of disease a habit (adjustment of ICPC codes) and have an active approach towards symptom management of patients with cancer.

GPs could inform their colleagues in hospital about every patient who died under his care.

Since 2001 there is a training for GP advisors in palliative care in the Netherlands. There is an association for palliative care physicians and a registration system with the Dutch association for general practitioners (the CHBB with the LHV). For optimal palliative care at any time every GP should know how to reach a GP advisor to discuss his problems. GP advisors should be part of a network that gives advices regularly and updates knowledge and skills and guarantees continuity of the advisory service. In my opinion one GP advisor for 100 GPs would be a realistic estimation, the GP advisor would then be consulted 2 times a week on average. This would mean training of around 60 to 100 GP advisors (6-10 per University or per cancer centre). A system to control the quality of the advices given and a system of evaluation should be developed and maintained. The GP advisors should also be involved in education (of GPs but maybe of nurses and others as well) and the improvement of the providence of palliative care in their region for instance as a member of a palliative team in the local hospital or the hospice.

More attention for care of the dying in the literature

In medical journals the art of helping people to die well should also be described and illustrated with case studies on how to achieve a good death after an incurable disease.
Recommendations for education

Every doctor who is regularly or incidentally responsible for a dying patient should acquire adequate knowledge, skills and behaviour concerning the end-of-life issues and dying. He should become familiar with loss and dying in his professional life.

Communication skills are especially needed in end-of-life care and deserve extra attention.

Literature or books with narratives of patients or caregivers can be a valuable source to develop empathy and understanding (6,7,8,9,10,11).

The vocational, postgraduate training of GPs should include a basic training in palliative care and care for bereavement. The education should also include coping mechanisms (both adequate and inadequate), basic insights about personality disorders (12) and counselling skills (13).

Apart from the important changes brought about by the Can Meds framework on the physician competencies and roles, the development of the personality of the (general) practitioner should be stimulated as “het Raamplan” states at page 38 and 39 (14). Successful methods for further development are Balint groups, “intervisie”, “supervisie” or peer groups (15,16).

Recommendations for research

All disease starts with a patient in his context experiencing some symptom and presenting his complaints to the GP. To maximize benefit from his scientific training easy access to a university library should be realized for every doctor, including all GPs. This would also include access to literature with the latest development in palliative medicine.

GPs have a wealth of epidemiologic data to their disposal. If these data were made accessible for research they could contribute to the body of knowledge and the development of guidelines for general practice, either by GPs combining doing research and working in general practice at the same time or by GPs supplying data to projects like with the Nivel and the RNG.

Easy access to join in research projects (about palliative care or other subjects), easy access to help with the proposal of a new research project, help with methodology of research, with statistics and writing an article is essential for general practitioners.

More research should be done about patients dying at home, the psychological aspects, the symptom control, the social and ethical aspects like the feeling of autonomy and self-determination (17).

If patients prefer death above life how can this be brought about in the most merciful way, should this be physician assisted (euthanasia or suicide) or is the decision to die by starvation a milder and more natural death? (18)
More research is necessary about what elderly patients want at the end of their life and how that should be realized (19).

Conclusion

The composing of this book, this thesis has taken quite some time and energy. At the same time it has given a lot of pleasure and satisfaction. I hope it will be of benefit.

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