Coming home to go...
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Summary

1 Introduction

Research in general practice has the opportunity to combine various disease characteristics in different phases of life with the continuity in relation with the doctor. This discerns research in general practice from disease related research in other settings where continuity of the relationship of the patient with the doctor is not a key element.

A main part of palliative care in the Netherlands is delivered by GPs. A majority of patients with cancer dies at home under the care of their GP. Cancer is the main cause of death in patients in the age groups of 40 to 70 years. The Dutch government stimulated the further development of palliative care in the Netherlands by instituting and subsidizing Centers for the development of palliative care in 1998. In the north east of the Netherlands this resulted in the project of the GP advisor in palliative care, collaboration between medical faculty and cancer institute. My personal interest - and the project I was participating in - resulted in the following research question:

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

An overview of the different chapters of the thesis is given in the introduction.

2 Background information

In this chapter different aspects are analysed in relation to optimization of palliative care. An overview of deaths in my general practice in Schoonoord, Drenthe is given, including the cause of death and place of death. The role of symptoms as key to diagnosis and experience of disease is discussed and a circle model is introduced. A comparison is made between primary care and secondary care on different aspects e.g. the cooperation of the GP and the medical specialist, from the patient's point of view, the doctor's point of view, the diseases and end of life care. Thereafter the phases in palliative care are reviewed and the symptom circle in relation to palliative care is discussed including the influence of feelings. Symptoms of anxiety overlap with symptoms due to bad condition and may complicate correct interpretation. Then
aspects influencing end of life are reviewed. The paragraph ends with [a discussion] of the needs of the GP.

3 Historical review

In the seven theses written by GPs who got their PhD in 1918, 1970, 1981, 1986, 1999, 2001 and 2006 different aspects of patients with cancer in general practice were researched. The first thesis (1918) looked at the local epidemiology of cancer to discover whether an infectious cause played a role.

In the next five theses the GP was at least one of the subjects of research. The dying patient himself was difficult to reach but through the GP the story of his death was accessible. The next thesis from 1970 reported the stories of the GPs about his patient dying at home to give other GPs support. At that time there was nothing to rely on for a starting GP; he had to find out all by himself, having the full responsibility for the patient’s care.

In 1981 the GP helping patients to die was studied. In this thesis the term appropriate dying (a way of dying which the patient experienced as most consistent with his personal situation, his needs and wishes) was used and euthanasia also came up as a theme. The author advocated a participation model for the relation between doctor and patient (and not a paternalistic or mechanistic model).

In 1986 the histories of 223 deceased patients with cancer were studied. In practically all patients the GP was involved in the care. In a third of the cases the GPs did not experience problems during the course of disease and the dying of the patient. Participating GPs experienced more deficiencies with respect to the medical somatic part of the care, than with the psychosocial part.

In 1999 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. Patients in the palliative phase of disease were asked about their symptoms. Their GPs were unsolicited informed about possibilities of improvements in symptoms management. Part of the study also dealt with education of GPs about pain management and the use of morphine.

The study in 2001 was about what a GP does from the moment he knows that a patient is going to die for cancer until the hour of his death. At the same time the experiences with palliative care and their doctors of patients and their caregivers were evaluated. In this study 82% of the patients died at home. The way of working and the time involvement of the GP were described. This study showed that there was no great difference between the needs of the patients and the expectations and capabilities/skills of the GP. The conclusion was that a dying patient needs a good relationship with his doctor, close attention and personal support.
In the last study from 2006 four validated instruments were developed to assess needs, a long and a short version for patients and for caregivers. An additional instrument, developed to assess loss of autonomy, was a novelty and could 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.

The message from these theses for education and optimization of palliative care 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.

4 Case report

A fifty year old patient with renal cancer developed ascites without therapeutic options. In the end he needed ascitic puncture every two weeks with removal of 10-12 liter bloody, jelly-like fluid, this was done six times. Through the internet an article about inhibition of tumour growth by captopril was found and treatment on N=1 base of this patient was started. The patient did not need removal of ascites anymore and lived another 8 months. The question remains why captopril worked so well in this case.

5 Consultative palliative care for nausea and vomiting in the home setting

Two patients with terminal cancer, a 46-year-old man with intestinal obstruction and a 12-year-old boy with a brain tumour, were suffering from vomiting and from headaches and nausea, respectively.

Their general practitioners consulted the general-practitioner adviser about palliative treatment. After the recommended changes in medication the symptoms decreased in both patients. They died some weeks later. Nausea and vomiting may be treated when one takes into account which centers in the brain and neurotransmitters are involved, together with the site of action of the medication. The medication may be administered by subcutaneous infusion.

This study describes a novel type of support for GPs caring for patients dying at home: the establishment and evaluation of a telephone advisory service for GPs run by GPs with a special interest in palliative care (GPwSIs) in the Netherlands 2000–2003. A growing number of GPs called for advice, 10% during out of hours. Prognosis of the patients was generally short (days to weeks in 70% of cases). Most advice sought by GPs concerned symptom management and on evaluation, 85% of the GPs followed the advice.

7 Changes in the palliative treatment of patients (dying at home) suffering from nausea and vomiting: consultation by a GP advisor

In 1999, four GP advisers in palliative care were appointed, enabling all GPs in the Northern Netherlands region to access advice when caring for patients dying at home. Pain was the most frequent reason why GPs needed specialist advice; nausea and vomiting were the second most frequent reason; delirium was the third and dyspnoea the fourth. Every consultation was documented on a standardized form. Registration forms with nausea and/or vomiting as the subject for advice were individually analyzed.

Overall, the advice given most commonly involved a radical change in treatment, both of medication and route, followed by the addition of an extra drug. The telephone consultation between the GP and the GP adviser avoids having to take the patient to see a specialist (in a hospital, nursing home or hospice) by providing the GP with the necessary knowledge. This may be valuable in helping the patient to achieve a good death at home.

8 Telephone consultations on palliative sedation therapy and euthanasia in general practice in the Netherlands 2003: a report from inside

General practitioners with a special interest and with specific training in Palliative Medicine (GP-advisors) supported professional carers (mostly general practitioners [GPs]) through a telephone advisory service. Each telephone call was formally documented and subsequently evaluated. Data from 2003 was analysed independently to reveal how often and in what way palliative sedation and euthanasia were discussed.

The telephone documentation forms and corresponding evaluation forms of two GP-advisors were systematically analysed for problems relating to the role of sedation and/or euthanasia both quantitatively and qualitatively.
In 87 (21%) of 415 analysed consultations, sedation and/or euthanasia were discussed either as the presenting question (sedation 26 times, euthanasia 37 times, both 10 times) or arising during discussion (sedation 11 times, euthanasia 3 times). Qualitative analysis revealed that GPs telephoned to explore therapeutic options and/or wanted specific information. Pressure on the GP (either internal or external) to relieve suffering (including shortening life by euthanasia) had often precipitated the call. On evaluation, 100% of the GPs reported that the advice received was of value in the patient’s care.

9 Educational needs of general practitioners in Palliative Care: Outcome of a focus group study.

The objective of this study was to identify the general practitioner's perception of educational needs in palliative care. A qualitative study with focus groups was performed.

General practitioners estimate palliative care as an important and valuable part of primary care. Nevertheless, they consider their coordinating role as a course with increasing obstacles. Pain, nausea, dysphagia, delirium, insomnia, anxiety, and depression were mentioned frequently as symptoms difficult to deal with in palliative care. Also, psychosocial issues such as communication, bereavement, and defense mechanisms were subject to discussion in the focus groups. Ethical issues such as euthanasia were mentioned as the most complex subject in palliative care.

In conclusion, general practitioners experience difficulties with their coordinating role in palliative care. With more basic knowledge and skills in communication, but also with consultation, their roles as coordinators of palliative care in primary care will improve. Reflection and deepening of ethical values are necessary conditions for an optimal functioning.

10 Mental symptoms in patients with cancer from general practice

Many patients with cancer have been found to have mental symptoms and syndromes such as anxiety and depression; these are often poorly recognized and therefore may be undertreated. However, the reported incidence and prevalence vary depending on the setting and the research method used. We were interested in data from primary care.

In a registration network of 17 GPs (30,000 patients) all cancer patients were identified by the International Classification for Primary Care (ICPC) codes. Registration for psychological complaints or psychiatric syndromes (P domain) in these patients was compared to matched control patients. Prescriptions issued to the patients were also compared.

Although GPs recorded more psychological complaints in relation to the stressful life event of the diagnosis, the overall incidence of P domain syndromes
was not much higher in patients with cancer. If the mortality due to the cancer was higher, there were more registrations in the P domain and more prescriptions. Prescriptions of anxiolytics, sedatives and antidepressants increased at time of diagnosis of cancer and remained at a higher level than pre-diagnosis. 117 of these patients (14%) discussed considering euthanasia but only 22 died of euthanasia.

GPs recorded symptoms in the P domain, especially sleep problems, more often than syndromes like depression and anxiety disorders in patients with a diagnosis of cancer. Symptomatic treatment with prescriptions by GPs was common (almost in 50% of the patients). It is unclear whether it is easier to discriminate (anticipatory) grief from depression in primary care or whether assessment in the home environment alters the outcome of a diagnostic interview with a patient.

The interpretation of symptoms and suffering by the GP in the home setting might also differ from other assessments.

11 Discussion

In the Netherlands many patients die at home under the care of the GP. As GPs in the Netherlands we should make use of that situation and try to do more research. Suggestions for new research topics are done.

The strength of the GP advisor project is the length of the study (four years), the coverage of the GPs, the discussion of problems during the last days of life of the patients, the positive evaluation, the discussion revealing more problems than initially mentioned and continuity in GP advisor.

The strength of the other projects were: giving a historical background to the research in the care of GPs in the home situation; an evaluation of the needs of the GPs in the area; the confirmation of the hypothesis that around the diagnosis of cancer psychological symptoms resulting from stress rather than psychiatric syndromes like depression are registered during the counseling of the GP.

A weakness of the GP advisor study is that improvement of quality of care at the bedside was not be measured, no non-response research was done with the evaluation, there were slight differences in registration among the GP advisors, generalization of the findings to other parts of the Netherlands is not possible because of different traditions in dying at home and no research was done among GPs about the reason of not consulting a GP advisor.

For a more complete historical picture of patients dying at home in the Netherlands also research of others than GPs should be included. The evaluation of the needs of the GPs is getting outdated after eight years and should be redone. A coding system like the ICPC always can lead to differences in interpretation of the codes by different doctors and so the findings may not represent reality exactly. However anxiety and depression in palliative care is a broad subject and complicated matter. More research is needed to clarify the findings anyway.
Care, education and research
Continuity of medical care, nursing care and access to subcutaneous route at any time is of key importance for the care of patients dying at home.

Every doctor should be educated about the meaning of loss and dying in his professional life.

GPs should be trained in the basics of palliative care and know how and where to ask for help if necessary.

Enough GP advisors should be trained and be organised in a way that every GP knows who to phone for advice. Evaluation of quality of advices and of the consultations should be arranged.

GPs should get easy access to help with and involvement in research and medical writing.