

University of Groningen

Palliative care in general practice. Research and education.

Schuit, Karel Willem

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:

1999

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Schuit, K. W. (1999). *Palliative care in general practice. Research and education*. s.n.

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).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

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.

In this thesis several research and educational activities of a project for palliative care for patients with cancer in general practice carried out from 1993 to 1998 are described. The project was initiated by the Comprehensive Cancer Centre North Netherlands in cooperation with the Department of General Practice, University of Groningen. Central in this project was the appointment of a general practitioner facilitator who had received extra training in palliative cancer care. This general practitioner facilitator, being a generalist, was able to identify the specific problems of palliative care in the home care setting. The facilitator was available on a part-time basis for consultation in case of problems in complicated palliative care at home and took part in the development of protocols and clinical guidelines for palliative care. Moreover the facilitator attended peer group discussions on palliative care in general practice and organized educational workshops for colleagues as well as trainees of the Department of General Practice.

In **chapter 1**, the general introduction, some historical aspects of palliative care for cancer patients in the Netherlands and abroad are described. Moreover the motives for the various research and educational projects are outlined. The introduction ends with a structured overview of the research questions of this thesis.

In **chapter 2** literature on the actual role of general practitioners in symptom management of cancer patients is reviewed and the question of whether there are gaps in the knowledge considered essential in this field is considered. On the basis of literature data, an attempt was made to identify the most commonly occurring symptoms. The results of this literature review revealed that the role as well as the knowledge of the general practitioner in palliative care can be improved. It is recommended that the general practitioner should become more active in his approach towards the cancer patient. The literature revealed that cancer patients in the palliative phase suffer not only pain but also many other symptoms. However most of the data derived from our literature search concerned patients in the final stages of their disease who were referred to palliative care services. These patients are not representative for the total group of Dutch cancer patients cared for by general practitioners and medical specialists. Therefore this chapter ends with the conclusion that it is necessary to investigate the prevalence and severity of the symptoms of cancer patients in the Netherlands in the palliative phase of their disease.

To perform these investigations we had to select measurement tools available in the Netherlands at that time. In **chapter 3** a literature search for the necessary measurement tools is described. Finally the McCorkle Symptom Distress Scale for the investigation of the prevalence and the severity of symptoms was selected. This distress scale included the symptoms constipation, nausea, loss of appetite, coughing, vomiting, pruritis, dyspnoea, urinary incontinence and hiccups. For the assessment of pain the numerical rating scales (0-10) were used. In addition we selected the COOP-WONCA charts to determine the functional status of the cancer patients.

In **chapter 4** the investigations into the prevalence and the severity of pain and other symptoms as well as the functional status of cancer patients in the palliative phase of disease are described. For that purpose we designed a cross-sectional study of consecutive patients visiting oncology outpatient departments for follow-up. Cancer patients for who were no longer eligible for curative therapy and who had a life expectancy of more than one month were included. The study population consisted of three different groups: group I, patients whose symptoms were assessed by means of a structured interview given at home by the general practitioner facilitator; group II, patients who received self-administered questionnaires via the mail; group III, non-cancer patients of the same age, randomly selected from two general practices, who also received self-administered questionnaires via the mail. The results of symptom assessment revealed that between 30 and 40% of all cancer patients reported the symptoms constipation, nausea, loss of appetite, coughing and dyspnoea. These percentages were about 50% lower when only moderate, severe or extremely distressing symptoms were included. The symptoms of the non-cancer patients were significantly less frequent and less severe. The study also revealed that 60% of all cancer patients suffered from pain. According to the numerical rating scale for daytime pain, 20% of patients indicated a pain score of 5 or more on a scale of 0 to 10. It was remarkable that 18% of the control group of patients without cancer reported pain of the same severity. Finally the results of some of the COOP-WONCA charts revealed a decline in functional status of the cancer patients compared to patients of the control group. Moreover some of the COOP-WONCA charts correlated significantly with some pain and symptom scores, indicating that impairment of the patient's functional status was associated with symptom distress.

In **chapter 5** an intervention study is described in which the efficacy of recommendations for palliative care in general practice was investigated. The original background for such an intervention was insufficient treatment of pain and symptoms of patients in the palliative phase of their disease. In the intervention study the general practitioner facilitator interviewed consecutive patients visiting outpatient departments using structured questionnaires in order to establish the incidence of pain and other symptoms. After randomization the general practitioners of one group of patients received a letter reporting the results of the interviews and offering recommendations for treatment. The general practitioners of the second group received the same letter with recommendations after a second interview two weeks later. The recommendations for treatment were formulated in cooperation with an oncologist and with a specialist in the treatment of pain. The research question in chapter 5 was whether the report of the symptom scores as well as the suggestions for treatment presented in a letter to the general practitioner led to an improvement in the symptom scores after two weeks. The results show that this intervention did not cause a significant change in the pain and symptom scores of patients whose general practitioner received a letter with recommendations for treatment. Despite the negative

findings o
cer patient

In **chapter**
evaluated.
tional stud
concerning
selected 13
question v
workshop
found that
ity of cases
However t
enced by s
er doctors
tive evaluat
pose data f
tions was a

The research
workshop
included a
workshop.
prescription
workshops
changes in
bination of

In **chapter**
order to em
tance of go
though the
in the resear
importance

The genera
ommendati
coordinator
and develop
thermore th
care plans is
refer a patie

findings of the study we obtained a better understanding of the unmet needs of cancer patients in general practice.

In **chapter 6** the effects of a workshop on palliative cancer care in general practice are evaluated. The objectives of the workshop were based on the results of the cross-sectional study and the intervention study and contained several learning objectives concerning pain and symptom management. From these learning objectives we selected 18 items for a questionnaire with 5-points response scales. The research question was to detect possible changes in knowledge and attitude scores of the workshop participants by comparing the scores before and after the workshop. We found that the knowledge scores of the workshop participants changed in the majority of cases towards the desired policy, particularly with respect to morphine therapy. However the answers to the questionnaires described in chapter 6 could be influenced by socially desired answers and therefore may not indicate sufficiently whether doctors finally do in daily practice what they say they do. Therefore a more objective evaluation of the behaviour of the general practitioners was needed. For this purpose data from the regional Sick Fund prescription databank on morphine prescriptions was assessed for the general practitioners who participated in the workshop.

The research question of **chapter 7** is whether the opioid prescription figures of the workshop participants changed between 1995 and 1997. Furthermore the study included a control group of general practitioners who did not participate in the workshop. The results of these investigations revealed a small effect on morphine prescription behaviour of the workshop participants. It is concluded that single workshops can only help to prepare the ground for improvement but that substantial changes in prescription behaviour can only be effectuated by more efforts and a combination of several methods.

In **chapter 8** a case history from the practice of a general practitioner is presented in order to emphasize the necessity of exploring the psychosocial factors and the importance of good communication during the treatment of pain in cancer patients. Although the somatic aspects of palliative care prevailed over the psychosocial aspects in the research questions of this thesis, we nevertheless consider them to be of equal importance.

The general discussion described in **chapter 9** contains several conclusions and recommendations. First it is concluded that if the general practitioner wants to be the coordinator of palliative care for cancer patients, he must have an active approach and develop a more patient-oriented instead of a problem-oriented approach. Furthermore the importance of good coordination of the care and the development of care plans is emphasized. Dutch general practitioners should have the opportunity to refer a patient to an institution with special expertise in palliative medicine. For that

purpose the installation of palliative care units within nursing homes has proven to be effective. With regard to the results of the cross-sectional study it was concluded that the prevalence and severity of the investigated symptoms had a negative impact on the quality of life of the cancer patients. On the basis of our experience during the intervention study it was concluded that this particular approach to palliative care need not be pursued in the future. More impact can be expected when the general practitioner participates actively instead of being faced with recommendations he did not ask for.

The evaluation of the educational workshop on palliative cancer care for general practitioners revealed a satisfactory increase in most of the knowledge scores of the participants. However the additional research question concerning the Sick Fund prescription figures of the workshop participants only revealed a small positive change towards the desired prescription behaviour. This led to the conclusion that a discrepancy exists between medical competence, as reflected by the increase in the knowledge scores, and performance, as reflected by the Sick Fund prescription figures. Several recommendations for future vocational and post-graduate training are proposed.