Summary

This thesis describes the development of palliative care in Romania and evaluates a new service, i.e. palliative home care by multidisciplinary teams. This study is based on the results of the Romanian-Dutch Matra program, called PACARO (PAlliative CAre for ROmania), which was supported by the Dutch Ministry of Foreign Affairs. Five multidisciplinary teams were trained in the palliative field and these teams provided palliative care at home to 129 patients suffering from incurable diseases in different terminal stages, both in urban and rural areas.

Chapter 1 gives a short description of the health care system and health care facilities in Romania. Before the 1989 revolution, the Romanian health system was characterized by hospital-oriented medical services. The modernization of the health system mainly started with the reform of primary health care and the introduction of social health insurances in 1999. The number of hospital beds has decreased during the last decade, but the mortality rate is increasing. The incidence of cancer is high, and it is one of the main causes of death. Large differences exist in availability and accessibility of medical services between urban and rural areas.

There is a great need for palliative care, but this service is still scarce. The development of palliative care during the last decade followed the recommendations of the World Health Organization. Palliative care aims to improve the quality of a patient's life through specialized medical services. The following research questions are also presented in Chapter 1:

1. How did palliative care in Romania develop over time?
2. What are the experiences and opinions concerning palliative care among general practitioners (GPs) in Romania?
3. Which patients enroll in the new palliative care program?
4. Is the delivery of palliative care at home effective from the perspective of the professionals involved and the family members as well as in relation to the services offered by the teams?

During the research period of 24 months 129 patients enrolled in the new palliative care program. The effectiveness of the service was analyzed for deceased patient with cancer during the 24 months (n=102).

The evaluation from the perspective of the professionals involved was executed after 18 months and included 80 deceased patients. The perspective of the family members was investigated after 24 months in four teams, including 89 deceased patients.

Chapter 2 describes the development of palliative care in Romania. First, a historical overview is given with special attention to international developments during the last thirty years. In Romania, palliative medicine was recognized as a “special competence” by the Ministry of Health in 1999, and in 2003. In 2003, the Patients’ Rights Act granted the right to care to terminal patients and the Hospitals Act introduced this service among other hospital services. However, palliative care has developed mainly within non-governmental organizations founded and financed by foreign organizations. One of the consequences is that today only a small part of the population benefits from this type of service.

Specific professional organizations in the field of palliative care have appeared as well as various facilities such as hospices, hospital departments, day centers, multidisciplinary mobile teams etc. Increasingly, professionals have shown interest in palliative care methods, and in order to support them, two training centers were founded in Bucharest and Brasov.

The chapter concludes that palliative care is still in development in Romania, that the need for palliative care is high, and that palliative care at home is the preferred option.
The experience and opinions of the Romanian GPs regarding palliative care are presented in Chapter 3. It analyzes the answers of 914 GPs who were asked about their experience and knowledge in the palliative care field, about the possibilities for delivering palliative care in Romania, and about the need for and methods of organizing such services.

Although over 98% of the GPs had provided services to incurable or terminal patients, the majority stated they had limited experience and knowledge regarding palliative care. Experience and knowledge were positively associated with age, gender and urban/rural environment they worked in. Older persons, males and doctors working in rural areas reported greater experience and knowledge. It is believed that GPs do not have any alternative in rural areas; they simply have to deliver such care.

Most GPs believed that the development of at-home palliative care services was necessary, in view of the Romanian tradition of dying at home instead of in an institution. Most of them saw the GP as coordinator of the palliative care team. They expressed the wish to be trained in palliative care aspects, such as pain treatment, communication, special techniques, etc.

Chapter 4 deals with the characteristics of the patients enrolled in the new at-home palliative service developed by PACARO. A total of 129 patients were included in the new service: 119 cancer patients and 10 patients with other diagnoses like dementia or HIV.

The socio-demographic data, functional status, psychological state, and medical data obtained after the first examination as well as further progression, and interventions by members of the palliative care team were recorded on a standard registration form, which was filled in by the team coordinator and the nurse.

As compared to studies abroad, the patients enrolled in this new service showed a very high number of symptoms: on average 12.8 symptoms per patient, with a sizable difference between the urban and rural areas (average of
14.3 symptoms per patient in urban areas compared to 10.4 in rural ones). A
similar pattern was found for the number of metastases in urban and rural areas.
This difference might be explained by the rural patients’ low accessibility to
specialized medical services and a resulting lack of information/knowledge
about the disease, which could lead to some metastases not being diagnosed as
such and a lack of treatment options.

Pain was the most frequently reported symptom and was reported by
90% of the patients. This differs from data in Western Europe. In part, this
difference might be related to the use of opioids, which is problematic in
Romania because of old legislation and some problems in providing treatment
according to the WHO analgesia diagram.

More than half of the patients indicated psychological problems. Here
too a sizable difference existed between patients in urban and rural areas (71%
in urban areas and 25% in rural ones). This finding might be explained by the
great trust in family support mechanisms and related strong support for patients
in rural areas and/or by lack of knowledge about diagnosis and prognosis in
such areas.

To evaluate the effects of the interventions by the palliative care team,
the number of symptoms and the intensity of pain were used as dependent
variables. In Chapter 5, the changes in symptoms, intensity of pain and other
medical data – including nausea, fatigue, loss of appetite and psychological
characteristics – as well as the interventions by the palliative care team are
described. For the sake of homogeneity, the analysis deals with the cancer
patients enrolled in palliative care. The changes in symptoms for 102 patients,
based on the first consultation (enrollment) and the last consultation before
death, are analyzed and related to the type and number of interventions.

After enrollment in palliative care, patients showed a strong reduction
in number of symptoms and intensity of pain. The average number of symptoms
decreased by 8 (from 13.4 to 5.4 per patient). High intensity of pain was
reported by 42 patients at enrollment and by 7 patients at the last consultation before death. Fatigue, loss of appetite and nausea also declined significantly between the first and last consultation.

Interventions by the members of the palliative care team were numerous and varied. Medication was changed for three quarters of the patients. Consultation was the intervention most frequently mentioned, followed by interventions directed at relief. Doctors’ interventions included small surgery interventions, perfusions and venous punctures. Nurses’ interventions included oral medication, artificial alimentation, injections and functional exercises. Most patients (90%) received five interventions or more.

Over half of the patients stated that the teams’ interventions provided good results for all their problems, and one third stated that the number and/or intensity of the problems were reduced.

Interventions by team members actually showed a borderline effect with regard to the reduction of all symptoms and a significant effect on reduction of intensity of pain. In the latter, interventions for relief were the most effective. Reduction of symptoms was stronger for patients in urban areas compared to those in rural ones and also stronger for poor patients compared to more affluent ones. These findings might be explained by the poor infrastructure and scarcity of medical personnel in rural areas and by the high need poor patient experienced (lack of alternatives and less family support). Reduction of intensity of pain was also related to social support, i.e. those patients who experienced strong social support showed a higher reduction in pain intensity.

The delivery of palliative care might put a burden on the professionals involved. In Chapter 6, the views of the professionals involved are analyzed after the death of the patient. During the first 18 months, 103 patients with cancer received palliative care. In that period, 80 patients died. In the second month after death, each member of the palliative care team involved received a questionnaire with questions about: satisfaction and problems with the role as
team member, emotional burden and coping, necessary knowledge, activities of
the team, communication with the patient and his/her family and within the
team, and a general evaluation of the care provided in this specific case. The
answers were recorded and related to background characteristics of the care
process and the professionals such as: duration of care, reported complications,
the team and the discipline of the team member, e.g. GP, oncologist, medical
nurse. This is the first study of this kind ever carried out in Romania, and
generally speaking, the specialized literature does not abound in this type of
evaluation.

The majority of team members gave a positive evaluation of their
activities within the team, the services provided to the patient, and their
knowledge of palliative medicine. The GPs and the nurses were more modest
about their knowledge and admitted they had to improve their knowledge,
especially in the case of complications. Relatively more problems were reported
for patients living in rural areas due to poor infrastructure, limited availability of
medical services and difficulties in communication.

Almost one quarter of respondents reported for communication
problems with the patient, which was explained by the unwillingness of family
members to inform the patient about diagnosis and/or prognosis. This made
communication for team members more difficult. Communication with family
members and communication within the team were given a positive evaluation;
this was disturbed only in those cases where the patient did not know his/her
diagnosis.

Over one third of the professionals reported an emotional burden and
discomfort caused by the patients’ suffering, but most did not consider this an
unreasonable burden. GPs and nurses reported an emotional burden more
frequently as compared to oncologists.

Generally, only a few team members (GPs) stated that they would
behave differently if confronted with the same case again, adopting a different
approach to both communication and treatment. GPs most frequently mentioned (38%) that they had experienced a lack of knowledge, followed by nurses (29%) and oncologists (14%). This was mostly related to cases with unexpected development and complications.

The quality of palliative services provided to the patients can also be measured by asking the family members involved about their satisfaction and opinion regarding the service. The results of such an analysis are reported in Chapter 7, based on data of family members of patients treated by four teams. For organizational reasons the data of the fifth team could not be collected.

Family members of the deceased patients (involving 89 patients treated by four teams) were asked to allow a visit by a social worker for an interview and to fill out a short questionnaire. Most of these family members were approached six weeks after the patient’s death. Seventy four family members agreed to take part in this study.

The questionnaire involved issues like communication, the patient’s and the family’s expectations about the care provided, accessibility to services, possible conflicts, and overall satisfaction. When necessary, the family members could expand on their answers.

Family members expressed satisfaction with the care provided to the patient. This was especially true for family members who played a role as central caregivers. The information received was qualified as (very) good by most family members and the communication with the team members was judged as good.

The care provided did not generate family conflicts or conflicts with team members. On the contrary, family members reported that such care reduced the risk of family conflicts.

The accessibility to the team members was seen as important and evaluated positively. All teams were judged as very accessible regardless of the differences in infrastructure between the regions.
Generally, the family’s expectations were fulfilled, but there were cases where the family had higher expectations from the team. This occurred when family members asked for help in obtaining the drugs needed. As mentioned previously, drugs are still difficult to obtain in Romania because of prescription procedures (for opioids) or for financial reasons (too expensive).

Altogether, 84% of the patients’ families receiving at-home palliative care services were satisfied or very satisfied with the services received. Overall satisfaction was related to communication, information given by the team members, family members’ expectations and the absence of conflicts.

Most of the families would recommend this type of service to other terminal patients or to their families.

The last chapter, Chapter 8, presents an overview of the answers to the research questions, discusses the outcomes, and makes recommendations for practice, research and policy. This study answered some very important questions about the feasibility and effectiveness of palliative care at home. The answers are considered important for the future evolution of palliative care as well. The study also provides information about the need for palliative care and evaluates this new service from various perspectives. Such an approach is new for Romania. Data dealing with a systematic evaluation of the quality of such services have until now been non-existent in Romania.

The development of palliative care has started recently in Romania and strongly supported by foreign expertise and grants. The need of palliative care is clearly recognised by Romanian GPs. They showed limited experience in this field and needed more knowledge and skills.

Patients, enrolling in the new palliative care at home, presented many symptoms. Their needs were high. The evaluation has demonstrated positive effects of palliative care on patients’ quality of life, has shown (high) satisfaction among family members involved, and has shown that the
professionals involved were able to deal with the new service effectively. It has also demonstrated the great need for this type of service, especially in disadvantaged areas.

The issues discussed include: the need for additional services and for adapting regulations; methodological problems obstructing such studies in Romania, including a lack of registration data and lack of experience with evaluative research among citizens and policy makers; whether carrying out this type of evaluative research among this type of vulnerable population (patients and family members) puts restrictions on methodology and perhaps the reliability of the findings.

In the last chapter also the development of more training centers for palliative care as well as regional expertise (consulting) centers are discussed and recommended.

It is clear that the Ministry of Health needs to become directly involved in organizing this type of service, whereby the professionals involved could be compensated via the health insurance system. This might provide all terminal patients with access to specialized services, which could improve their quality of life and alleviate their suffering.

The further development of palliative care in Romania is a necessity from both the patient’s and the health professional’s point of view. Success will depend on cooperative efforts by the Ministry of Health and non-governmental organizations acquainted with this field. It will also require a significant material, legislative and human investment.