CHAPTER 8

CONCLUSIONS, DISCUSSION AND RECOMMENDATIONS

8.1 Introduction

The need for palliative care is growing worldwide due to the ageing of the population and developments in medical technology, both resulting in a change of morbidity and mortality. In Romania, the development and rise of palliative care has occurred fairly recently, making it an interesting case study for this thesis, which describes developments in palliative care in Romania and evaluates a new care arrangement for palliative care at home.

This closing chapter will first attempt to answer the main research questions formulated in the introductory chapter and highlight the lessons learned from this study.

Next, the results as well as the methods used will be discussed. Finally, recommendations are presented for practice, research and policy.

8.2 Answering the research questions

In the introductory chapter, four research questions were formulated, which were then answered in some detail in the following chapters. Here, the overall findings are presented in brief.

The first research question was: “How did palliative care in Romania develop over time?”

As in the rest of Europe, care for poor and suffering patients was left to charity for a long time. In Romania, the development of palliative care had to
wait until after the revolution in 1989. Before the revolution, individual pioneers in palliative care focused attention on the care of terminally ill patients.

Romanians have a long tradition of dying at home, but primary health care and home care were not developed until after the mid 1990s. The first hospice-oriented palliative care was started in 1992 in Brasov with the support of foreign charity foundations, followed by a hospice in Oradea in 1996. In 1997, a first international conference on palliative care was organized in Romania. Legislation recognizing the necessity of special care for terminally ill (cancer) patients and recognizing palliative care/medicine as a “specialty competence” was introduced in 1999. In 2003, the right to obtain (terminal) care at home and to die in dignity was legally recognized.

In 2003, two training centers for palliative care were recognized by the Ministry of Health in Bucharest and Brasov.

In short, the development of palliative care in Romania was and is characterized by an emphasis on providing the needed care at home and allowing (terminally) ill patients to die in dignity at home. Palliative care was formally and legally recognized as a necessary health care service in 2003.

The second research question was: “What are the experiences and opinions concerning palliative care prevalent among general practitioners (GPs) in Romania?”

A survey among GPs in five districts in Romania showed that most GPs have limited experience in dealing with palliative care and terminally ill patients. Also, most GPs recognize that their medical knowledge is insufficient for providing palliative care to these patients at home.

Given their awareness of such “shortcomings”, it should not be surprising that most GPs were interested in the development of palliative care, agreed that they needed training in such care for terminally ill patients, and were willing to follow such training. Two thirds of GPs see a coordinating role for themselves in the delivery of palliative care at home.
The third research question was: “Which patients enroll in the new palliative care program?”

Between October 2002 and September 2004, five multidisciplinary teams delivered palliative care at home in two districts in Romania and Bucharest. These teams were trained to deliver such care at home, which was a rather new phenomenon in Romania. A registration form was developed to assess the health status and the need for service of patients who were referred to this new service. Patients were eligible for the service if they had a disease (usually cancer) in an advanced stage, their prognosis for life was less than nine months, and they lived in the area served by the teams and agreed to receive the service via informed consent. A total of 129 patients enrolled in the palliative care service at home during the research period.

Since such service was new, little information was available about the characteristics of these patients. Mostly, elderly patients enrolled in the new service, the average age being 66.7 years. Most patients lived with others, and most received informal help. About one in ten patients did not receive any help. Most patients were (very) poor.

Three quarters of the patients were restricted in most of their activities, and many needed permanent care. All patients except ten were diagnosed with cancer. Co-morbidity was frequently reported (91%), and metastases were found in over two thirds of the patients.

Patients reported many symptoms; the average number of symptoms was 13.4 per patient. Pain was the most frequent symptom, and about one third reported a high intensity of pain. Over half of the patients reported psychological problems.

An analysis was carried out as to which social and medical characteristics were related to functional status, showing that living in urban areas and many symptoms were strongly related to a very dependent functional status.
It was concluded that the patients who enrolled in this new service had a high need for care, especially patients living in rural areas.

The fourth research question dealt with the effectiveness of the new at-home palliative care service and was formulated as: “Is the delivery of palliative care at home effective from the perspective of the professionals and family members involved and in relation to the services offered by the teams?” This question was tackled in various ways.

The effectiveness of the service provided was analyzed by considering the activities and interventions taken by the (members of the) five at-home palliative care teams and analyzing the relationship between these activities and interventions and outcome measures. We used reduction of symptoms and decrease of intensity of pain during the palliative care process as outcome measures. Number of symptoms and intensity of pain were measured at enrolment in the palliative care service and at last consultation. For reasons of homogeneity this analysis focused on cancer patients who had died during the study period. A total of 102 patients were included in this part of the study.

During the at-home palliative care delivery period, the number of symptoms as well as the intensity of pain and other symptoms decreased considerably. The number of interventions by team members, in particular the team doctor, showed a statistically significant relationship with reduction of intensity of pain and an almost significant relationship with a reduction of the number of symptoms. Living in an urban area and being poor were related to a (greater) decrease in the number of symptoms, while strong social support was associated with a (greater) reduction in intensity of pain. Except for the number of symptoms and the intensity of pain at enrolment in the palliative care service, medical, functional and psychological characteristics were not related to the outcome variables, but as previously stated social factors were.

In conclusion, the at-home palliative care service delivered proved to be effective.
The professionals involved in the palliative care process evaluated this process. We focused the evaluation on the care process for patients who had recently died. The survey included 80 deceased patients, covering the period of October 2002 - May 2004. The professionals involved were asked to fill out an evaluation form on the care for a specific patient. A total of 96 forms were received from nurses, 61 from general practitioners and 24 from oncologists.

About one third of the professionals reported an emotional burden in delivering the palliative service to the patient. GPs and nurses experienced such a burden more frequently. This was especially true when a case was felt to be different from other cases, which often happened when (unexpected) complications occurred. In such cases, GPs often felt they lacked adequate knowledge to care for the patient involved. Overall communication was judged positively as was the care delivered. In conclusion, the professionals involved judged the treatment provided as being effective. In cases which posed an emotional burden, discussing the case with team members proved an effective way of dealing with the burden.

Family members of deceased patients were interviewed to evaluate the care process. This was done with family members of patients treated by four of the five teams, since in one team the interviews could not be planned in time. During the research period October 2002 – September 2004, a total of 89 patients died, and 74 families participated in the interviews. The expectations of most families (80%) were fulfilled, and two thirds of the families thought they were well informed about palliative care. Half of the families reported that family conflicts were prevented through the care provided by the palliative care team. A total of 11 family members reported that they were not satisfied. The main reasons for dissatisfaction were disappointment in expectations and difficulties in obtaining medication. When close family members were involved in the care process, satisfaction with the service was higher.
In conclusion, most family members were (very) satisfied with the at-home palliative care service in all of its aspects.

8.3 New findings

This is the first time that palliative care at home was developed systematically in Romania by training specific teams. Prior experience with palliative care was mainly limited to institutions. Delivering palliative care at home not only proved to be feasible in Romania, it also proved to be effective and satisfactory according to the professionals and family members involved in the process. This type of data was not previously available in Romania. It is also the first time that this type of new service was systematically evaluated.

The training process was evaluated by the participants (details of which are not reported here) and judged very positively. The systematic evaluation of such courses is also new for Romania.

Survey-based assessment research is not yet common in Romania, and people may be suspicious of the results obtained in this matter \(^1\). This study shows that such research is “feasible”, also among “lay people”. Asking the opinion of patients, families or the public is – still all too often in policy processes – considered “not done”. After all, “the doctor knows best”.

We demonstrated that palliative care at home is related to better outcomes for patients regarding reduction in intensity of pain and number of symptoms. These are new data for Romania.

Patients living in urban areas seemed to profit more from palliative care at home than those living in rural areas. The same was found to be true for poor patients as compared to “rich ones”. These findings may be due to the disadvantaged position patients in rural area still find themselves in.

In this project instruments were developed and used, which are new and may be useful for future evaluation of health care services.
8.4 Discussion Content of care

In primary health care, the need for training in palliative care is widely recognized, but a great deal also depends upon the attitudes and perceptions of general practitioners. This study reports on the experiences and opinions regarding palliative care of general practitioners in Romania. Other studies revealed the same need and the wish to be informed regarding the latest techniques and developments in palliative care. A similar survey was carried out among 333 nurses working in primary health care (results not published). This group of nurses reported a similar need for training as well as an interest in providing palliative care in primary health care setting. GPs and nurses reported limited experience with palliative care and a need for more expertise. The willingness of Romanian primary health care workers to be trained in palliative care issues is promising for the development of palliative care at home and may provide an opportunity for improving the quality of such care. It is indeed important for workers in primary health care, who are involved in palliative care, to be informed regularly about new developments in palliative care and to cooperate with experts in palliative care. This applies not only to primary health care workers but also oncologists.

The profile of patients enrolled in the at-home palliative care service indicates a high need for palliative care among these (cancer) patients in Romania. Terminally ill patients are discharged from hospitals due to lack of personnel and medicines. Also, most patients prefer to die at home, although conditions there are not good either. Patients in rural areas in particular suffer from a lack of facilities. Specialist care is far away, infrastructure is poor (bad roads, few telephones, no public transportation) and the number of primary health care workers is very limited. We had expected patients from rural areas to benefit more from the new at-home palliative care service. They did in fact benefit but not as much as patients from urban areas. Several factors contribute
to this difference. Health care facilities, including primary health care, are less accessible and personnel are scarce in rural areas. In actual fact, the members of the palliative care teams in rural areas paid fewer visits to the patients and had more problems in prescribing the necessary medicines. Also, patients in the rural area were often less informed about their (terminal) disease. Patients were not aware of or denied having the disease, while family members, if they knew of the disease, preferred not to communicate with the patient about the disease and asked health care professionals to do the same. This context made it difficult for professional caregivers in rural areas to provide the care patients needed. Family members could oppose the recommendation of the professional, and sometimes did so, leading to disruption of the care process.7

The evaluation by family members of patients of the palliative care delivered by the trained teams at home showed that such services were highly appreciated. Evaluation by the professionals involved showed that overall the palliative care at home was delivered effectively in their opinion. Both evaluations were made after the patient passed away to avoid “co-incidence” with the actual care process. Based on the method used for these evaluations and given the regular discussions we have had with the teams involved, we believe these findings reflect the quality of the palliative care delivered. Nevertheless, there is also recognition that improvement in the content of care is possible, especially when unexpected events occur during the palliative care process, such as complications.

Good symptom control, starting with an assessment of the current symptoms as done in this study, was found to be essential. However, it was not always easy to know what to monitor, especially not for family members.8 Teams reported that communication with the patient and family members was essential in such cases, a finding that is also reported in other studies.2, 5, 7, 9, 10

The need for good communication is also underlined by the finding that some families had specific (differing) expectations from the palliative care
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service. Some expected financial assistance and more material help. As mentioned earlier, most patients were (very) poor, and for some families (and patients) the suffering inflicted by the disease was less important than the financial conditions they had to live in. In this context, it is important to note that without additional financial help, a considerable number of families could not afford the medicines the patient needed.

The findings of this study show that palliative care at home reduced the number of symptoms, which was extremely high compared to several international studies. The assumption was that reduction in symptoms and intensity of pain would improve the quality of life of the patients concerned. We did not measure quality of life of patients directly. Other studies have reported on the relationship between reduction of symptoms and improvement in quality of life. The fact that we did not interview the patient does not imply that the patient’s point of view regarding health care and health is not important. On the contrary, it is part of the “new subjective medicine”. We did not interview the patients for several reasons. The service provided was very new, and team members as well as patients had little or no experience in that regard. Accordingly, we did not wish to put an extra burden on the project by interviewing the patients. In addition, interviewing patients for their opinions and experiences is not very common in Romania. We thought patients would become more confused if we did interview them. Also, we judged that family members would not be pleased by such interviews during the care process, especially since not all patients were completely informed about the nature of the disease and care by their family members.

But although we do not have data directly from the patients, we believe this study has provided various indications that the service delivered contributed to the quality of life of most patients.
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8.5 Discussion Organization of palliative care

This study of the development of palliative care in Romania concludes that delivery of such services at home is characteristic of Romania and that palliative care was formally recognized as part of the health service system in Romania in 2003. The study also presents an overview of palliative care facilities in 2002. A recent update does show an increase in palliative care facilities, especially in at-home and day-care facilities (see Table 1).

| Table 1. Palliative care facilities in Romania in 2002 and 2006 |
|-----------------|-----------------|
| 2002            | 2006            |
| Hospice (free standing) | 1 | 5 |
| Hospital ward/hospice | 7 | 14 |
| Mobile teams in hospitals | 0 | 1 |
| Nursing home | 0 | 0 |
| Palliative care at home | 10 | 24 |
| Day care | 11 | 23 |
| **Total** | **29** | **67** |

Other studies on palliative care services in the western world indicate a tendency to de-institutionalize palliative care and expect a further increase in palliative care services.\(^{18,19}\) Apparently, developments in Romania are in line with international trends.

The Health Insurance House Act mentions palliative care only as part of hospital services. During the last three years, organizations that offered home care services in general could also enter into a contract with the Health Insurance House for home care services, including palliative care. The law now permits paying some specific services related to palliative care, such as counseling, punctures and perfusions. These specific services can be delivered under the supervision of doctors with competences in palliative care. No competence in palliative care for nurses is yet required, nor is it formally recognized. In practice, some nurses are specialized in palliative care.
Despite the increase in palliative care facilities, it should be noted that developments in health-related policy and health insurance have stagnated. A special committee on palliative care, established in 2003 by the Ministry of Health, was disbanded in 2005. Financial resources and reimbursement policies for palliative care did not increase, and regulations governing the development of new palliative care services were not really facilitating new initiatives. There were and still are several barriers to the further development of palliative care in Romania. These barriers are not in the legislation and regulations themselves but in the implementation. As in other places and other sectors in society resistance to change exists often based on vested interests.

There is a certain amount of resistance present among clinical specialists and hospitals naturally wish to retain as many beds as possible. A decade ago, Romania started on the development of primary health care by creating one association and training for GPs in accordance with European standards. The association of GPs supported the development of palliative care. In theory, palliative care could have spread through all regions of Romania via the GP network, including rural and remote areas within the primary care system. Although the right to terminal care and home care was formally established in 2003, relevant legislation is still incomplete and contradictory. The standard forms of the National House of Health Insurances cover the reimbursement of home care services given by medical nurses, but this does not include specific palliative services. At the same time, Ministry of Health legislative guidelines contain a list of palliative care services in primary health care that applies to both doctors and nurses.

Another barrier is related to the medical specialists at the hospitals. On the one hand, oncologists and other specialists know little about palliative medicine (as is the case for general practitioners), and they do not recommend such services for incurable or terminal patients. On the other hand, oncologists were, till recently, the only ones permitted to directly describe opioid-related
medicines. General practitioners may also prescribe them but only after a great deal of paperwork. In addition, a large gap exists in Romania between secondary health care and primary health care.

Communication is poor between medical specialists in the hospital and specialists in primary health care, and referral at home of the patients is often unnoticed to the GP. However, most patients are registered with a single general practitioner, as was legislated in 2000.

The gap between clinical care and primary health care also impacts the prescription of analgesia. As mentioned above, primary health care workers find it difficult to prescribe proper drug treatment against pain, and it is expensive for patients to obtain such drugs.

Although Romania has trained doctors and nurses in palliative care, the number involved is still small. Only two centers are recognized as training centers for palliative care, which implies a lack of postgraduate training in this field. Most importantly, the curricula for medical schools do not include formal training in palliative medicine. There are simply no professors in palliative medicine.

Postgraduate education in Romania is a request from the College of Physician for each doctor, who must demonstrate every five years that he trained 200 hours, for accreditation. A form of continuous education could be the achievement of a competence on a specific field, for example in a palliative care. Especially GPs, oncologists and nurses expressed their interest in training in this field.

Barriers to an effective organization of palliative care – especially in rural areas – also include poor health care infrastructure and a lack of information and expertise. Regional expertise teams for consultation, advice, information, training and discussion are needed to support professionals in primary health care who want to deliver palliative care at home. The poor
infrastructure might be compensated by such regional expert support teams, which could lead to improved quality in palliative care for the future.

We have shown that primary health care professionals are interested in delivering palliative care services at home. However, policy makers have not yet leveraged this interest to establish a new service. On the contrary, after promising initiatives at the start of this century, the interest demonstrated in palliative care by policy makers and health insurance bodies has diminished. This may be due to various factors. Experts in palliative care have not been able to agree on how to develop such a service. The main discussion lines involve institutional (hospice versus hospital) and de-institutional (at-home) palliative care. The financing of palliative care (foreign foundations, prescription allowance) provides the background to this discussion.

8.6 Discussion Methodological issues

As mentioned earlier, health care evaluation studies are not common in Romania. Nevertheless, it was relatively easy to survey the opinions of the professionals involved in delivering the service. They were very motivated to participate in the new service and realized the importance of the evaluation.

For family members of patients, it was a different matter. Romanian citizens are not used to this type of research. For the sake of objectivity we decided that a skilled person, i.e. a social worker who was unknown to the families and not directly related to the care provided should execute the interview. The co-operation given by the families with regard to the interviews was surprisingly high. The reasons for not responding made it clear that dissatisfaction with the service was not a significant reason. In one rural team, family members could not be interviewed due to planning and travel scheduling problems.
An evaluative study in families after their beloved one passed away is not always easy. In Romania, the mourning period is rather structured. In the first weeks after the death of the patient it is not appropriate to interview family members. Therefore we choose to contact the family after one month.

The opinions of the family were rather positive. It should be kept in mind that these data may picture a too positive view of the palliative care. Romanians will not easily criticize in public when asked by a stranger neither on such services (medical services, free services). Also many family members were also grateful for the services they have experienced and might have hesitated to be more critical.

Of course we asked for written informed consent of all patients as is required by medical ethical committees in the Netherlands. Also the oncologists did so to exchange information and data. This study showed that patients and families accept such procedures. We did not investigate what the motives were of the patients to cooperate in this project neither or they understood the protocol completely.

A registration form was developed for this study for monitoring developments in symptoms, medications etc. and for measuring the activities of the team members. The form was based on registration forms used abroad. However, team members discussed the first draft of the form and added elements which they considered relevant to the Romanian situation (for example: measurement of mental status and an extensive inventory of social support). The registration form was well received and usually filled in completely.

The registration form was also intended to supply data for a case control study: from various hospital registrations, patients would be selected with the same diagnosis, stage of disease, gender and age. These patients were treated by hospital specialist and/or general practitioners and not by a palliative care team. The goal was to compare the course of the disease process, the number of
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admissions to hospital, prescriptions, medical interventions etc. for the “care as usual” group and the new at-home palliative care group. After selection (matched control group) of the patients, the hospital medical records proved to be too incomplete to make a reliable comparison.

We believe that the use of “special” registration forms in Romania is needed at the moment to acquire reliable data on the course of diseases and medical interventions. In general, most medical case studies in Romania are based on selecting patients from the same clinic \(^{21, 22}\). There is no continuity in registration between the case files of the GP and hospital registration files. There is legislation requiring continuous communication between the two sectors by means of “medical letters”, but this communication does not take place in practice. The existence of separate registration systems in itself leads to misunderstandings, and the way data are collected has not changed for over 30 years.

Another methodological challenge was the analysis of the various opinions of the professionals, who were asked to evaluate the case after the patient died. We decided to use the number of professionals involved e.g. the number of received questionnaires as basis for the analysis and not the number of patients (80 patients). Nineteen professionals sent in 181 evaluation forms. But not for all 80 deceased patients we received evaluations forms; the evaluations are directed at 62 patients. Some forms were not sent in since patients had died too long ago.

As we mentioned professionals differed in their evaluation. Since we concentrated on the received questionnaires, we did not report about incongruence per patient neither about the number of questionnaires or professionals per patient. No agreement between the professionals’ opinion was found in 11 cases (18%). Partly agreement was the most common (47%). The reasons for these differences deserve further study. Of the 62 patients who were “evaluated” by the involved professionals 24 were evaluated by all
professionals. Oncologists did not often send back the evaluation form. This may indicate oncologists experience a larger distance to the patient in the palliative care process.

8.7 Recommendations

Practice

Evaluation of the care delivered by the professionals involved, based on surveys taken after the patient was deceased, shows that unexpected events are not easy to cope with. For such cases in particular, a regional expert team may be able to provide useful advice and consultation services for the at-home palliative care team. We recommend establishing such regional expert teams in Romania, similar to those used in other countries.

This study shows that discussion with other team members about the emotional burden experienced can be helpful in dealing with such burdens, which may be seen as quite normal. We recommend that “difficult cases” be discussed with team members and/or other experts in palliative care. Here too the regional expert team could play a useful role.

More postgraduate training facilities for palliative care should be created in Romania. We recommend linking such training centers to medical faculties. The appointment of professors in palliative care could be useful for realizing such training centers and would enable undergraduate training in palliative care in medical (and nursing) schools.

The medical service available to people living in rural areas is insufficient in Romania, including care for incurable and/or terminally ill patients. To improve this situation, we again recommend the establishment of regional expert teams to support palliative care at home in rural areas as well.
Palliative care is a relatively new service in Romania. Citizens are not familiar with the service or its contents. They are also not familiar with their rights or aware of the options available. It is therefore important to inform the public about the service as well as its content. Information material should be made available to laypersons.

**Research**

This study is the first research project in Romania in which a health care service has been investigated from various perspectives. This type of study is very much needed in Romania. Such research should be embedded in a program for evaluation research of (innovative) health care services.

This study in palliative care is still incomplete. Patients’ opinions and cost-effectiveness are examples of topics which should be investigated. We reported about the differences in the evaluation of specific cases among professionals. It is recommended to investigate what reasons professionals had to differ and how this might be related with professional knowledge and involvement and with characteristics of the disease and care process.

Generally, more research is needed to compare various palliative care service options with each other with respect to quality, effectiveness and efficiency.

Various new initiatives are under development in the field of palliative care in Romania. Evaluation of these initiatives is strongly recommended. Instruments used in this study might be used for this purpose and would enable comparison of the outcomes of the several initiatives.

The registration of care processes is fragmented in Romania. We recommend the development of various specific registration forms, including forms for home care, palliative care and primary health care. Such registration forms would be helpful in collecting reliable information about patient
characteristics and care processes. Such information could be helpful for monitoring quality of care. The registration forms developed should be tested further for completeness and reliability.

More research is needed into the role, significance and influence of social support in palliative care\(^\text{28, 29}\). Family-based support is common and very important in Romania. Knowledge of what it does and how it works could be useful for other European countries.

**Policy**

We recommend that the WHO guidelines for prescription patterns and prescription of opioids be implemented in Romania.\(^\text{20, 30}\) The relevant documents and guidelines are available. A task force of the Ministry of Health and the College of Physicians should be established to implement the guidelines.

Palliative care at home should be part of the reimbursement package of the Health Insurance House. We recommend that a special committee be formed to work out the details of such a reimbursement. General practitioners, district nurses and home care organizations should provide the majority of members for such a committee. Multidisciplinary teams are a prerequisite for palliative care in Romania, as in other countries.\(^\text{3, 4, 31, 32, 33}\) The above committee should be able to give a binding advice to the government and the Health Insurance House. The question is not whether but how the reimbursement process can be optimized to support multidisciplinary palliative care.

We recommend that the Ministry of Health start an experiment with regional expert teams to support palliative care in various districts. Such an experiment is needed to determine the exact functions, costs and fields of expertise within the regional teams, to realize a package of instruments (information packages, training modules, quality assurance), and to analyze the number of regional expertise centers needed.
We also recommend the development of quality assurance indicators for palliative care by organizations and professionals involved in palliative care and by the College of Physicians together with the Ministry of Health.

All the above activities should be coordinated and stimulated by one influential and powerful project organization within the Ministry of Health, possibly within the framework of a national program.
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