Palliative care in Romania

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CHAPTER 1

INTRODUCTION AND RESEARCH QUESTIONS
1.1 Introduction

Recent decades have been characterized by the ageing of the population in all developed countries, developments in medical technology, and an increase in medical diagnostics and medical interventions.\textsuperscript{1,2} These developments are inter-related and – taken together – have considerable consequences for morbidity, mortality patterns and the need for medical care.\textsuperscript{3,4} Each year, approximately six million cancer patients die worldwide, and ten million new patients are diagnosed with cancer.\textsuperscript{5} For 2020 it is estimated that the number of death from cancer will double (12 million). The need for care for these patients and other patient groups is growing continually, especially among the elderly. These needs include pain control, relief and support.\textsuperscript{6}

In all countries and in developing countries in particular, measures aimed at helping older people to remain healthy and active are a necessity, not a luxury. Ageing is a privilege and a societal achievement. In 2000, there were 600 million people aged 60 and over; that figure will increase to 1.2 billion by 2025 and 2 billion by 2050.\textsuperscript{7}

Consequences of the ageing population include: a growing number of persons with chronic diseases, changing medical care needs, the need to pay more attention to cost-effectiveness and evidence-based treatment in medical care, and the growth of palliative care services.\textsuperscript{8}

Although these developments are basically global in nature, significant differences may be seen between countries, i.e. differences in morbidity and mortality patterns as well as in health care arrangements and services. For example, there are striking differences in the development of palliative care services, both qualitatively and quantitatively, between European countries.\textsuperscript{9}

In recent decades, palliative care facilities have, in particular, been developed in western European countries with an emphasis on institutional care (hospice, nursing homes). Apparently, these facilities fulfilled a need, and this type
of service was expanded to other countries including those in Eastern Europe. However, it should be noted that little effort has been made to evaluate whether the services provided have actually met the needs of those concerned.

Some authors have stated that solutions for health care needs, and particularly palliative care, require different specific approaches related to the historical background of the health care system, infrastructural inequalities, culture and preferences of people etc. A “European agenda” for palliative care has been recommended.

This study describes the development of palliative care in Romania in recent decades and evaluates a new palliative care system which was recently developed.

This chapter begins with a short description of the development in health care delivery in Romania and of the health status of the Romanian population as well as an indication of the need for palliative care. Next, palliative care is defined in accordance with international definitions, thereby making it clear that such a definition does not lead to only one type of palliative care service. The reasons why a new type of palliative care service was developed in Romania are then explained, followed by a presentation of the main research questions. The chapter ends with an outline of the thesis.

1.2 A brief history of health care delivery in Romania

After the Revolution in 1989, Romania inherited an exclusively public medical service, strongly centralized, sustained by the state budget, and coordinated by the Health Ministry and territorial inspection. As in other Eastern European countries, it was a hospital-based health services model. One consequence of the model was unequal access to health care facilities in rural areas, where health care professionals and facilities were lacking. On the one hand there was over-bedding in hospitals and on the other hand a lack of primary health care services.
After the revolution, various plans to change the health care system were prepared, based on reports by the World Bank and other international agencies. These plans and recommendations, mostly recommending privatization of the health care system, could have been opportunities to introduce new care services in the health care system. However, the quality of the health care services and health care equipment has generally been poor due to the low budget available for health care.\textsuperscript{12} During the sixteen years after the revolution, Romania had the lowest health care budget (3.7% of Gross Domestic Product in 2004) in the EU and EU candidate countries (both before 2004), i.e. less than half the budget of EU candidate states and four times less than the average budget in EU states\textsuperscript{16}. After 1996, primary health care started to develop as an independent, i.e. not hospital-funded, specialty. However, changes imposed after the Revolution did not really improve the situation until 1999, when the health care system became based on health care insurances.\textsuperscript{17}

As a result, the health care needs of the population were not met. Due to the lack of an adequate public health care system, various services – including home care, residential homes, and palliative care – have developed in the nongovernmental sector. Today, the majority of services can be found in this sector. It should be noted that private foundations from abroad also developed some new services prior to 2000, including home care and palliative care. Such services targeted local populations.

Because of the difficult historical transition in the health care system, Romanians have had to face a lot of problems regarding the availability and quality of health care services. For example, health care services were almost absent in poor areas, and people had to solve health problems themselves, partly using traditional methods. Health care institutions and services have recently started to change. While the population is ageing, the mortality rate of the elderly is decreasing (see Table 1).\textsuperscript{16,18} The number of hospitals beds has decreased since 1990, but the hospitalization rate has increased as has the number of doctors.
Specialized health care facilities such as those providing care for the mentally ill have increased and others, such as medico-social units or homes for the elderly, have also been erected.

The budget available for health care varied greatly during the period 1990–2004, which does not contribute to a stable development. One of the biggest health care problems of Romania is still the lack of infrastructure, modern communication, and registration and quality assurance, especially in rural areas.

<table>
<thead>
<tr>
<th>Table 1. Evolution of sanitary reform in Romania after 1989</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990</td>
</tr>
<tr>
<td>Population of Romania</td>
</tr>
<tr>
<td>Percent of population over 65 years</td>
</tr>
<tr>
<td>Birth rate per 1,000 inhabitants</td>
</tr>
<tr>
<td>Mortality rate per 1,000 inhabitants</td>
</tr>
<tr>
<td>Mortality over 65 years, per 1,000 inhabitants</td>
</tr>
<tr>
<td>Number of hospitals</td>
</tr>
<tr>
<td>Number of hospitals beds</td>
</tr>
<tr>
<td>Number of hospitals beds per 1,000 inhabitants</td>
</tr>
<tr>
<td>Hospitalization per 100 inhabitants</td>
</tr>
<tr>
<td>Number of doctors per 10,000 inhabitants</td>
</tr>
<tr>
<td>Number of GPs per 10,000 inhabitants</td>
</tr>
<tr>
<td>Number of institutions for chronic mentally ill</td>
</tr>
<tr>
<td>Number of day care centers for mentally ill in general hospitals</td>
</tr>
<tr>
<td>Number of consultations and treatment for cancer</td>
</tr>
<tr>
<td>Medico-social Units*</td>
</tr>
<tr>
<td>Number of beds in institutions for orphans</td>
</tr>
<tr>
<td>Number of homes for elderly</td>
</tr>
<tr>
<td>Public home care services for elderly by municipalities</td>
</tr>
<tr>
<td>Number of nongovernmental association / home care organization for elderly</td>
</tr>
<tr>
<td>Percentage of the Gross Domestic Product for health care</td>
</tr>
</tbody>
</table>

*For the first time in Romania medico-social institutions socio-medical institutions were built for poor people and people with chronic diseases
**The Institutions for orphans was eliminated and in their place were created Centers to admit and to place the orphans in new families
***19 homes for elderly are financed by the Ministry of Work and Family
Nowadays citizens have health insurance, which gives them the right to the services of general practitioners (GPs), hospital care with clinical services, and a pre-defined number of medicines. Access to primary health care is available if patients have registered with a GP practice. Patients are expected to be referred to the hospital by GPs except in emergencies. Home care is not part of the health insurance system.

The change from a centralized, state controlled, tax financed health care delivery system to a national health insurance system is not as big as some politicians want people to believe. In the past the health care system was accessible for everybody, but not all services, for example most organ transplantations, were not available. There were no waiting list, but the types of medicines were limited. Nowadays, health care is still partly subsidized through taxes, waiting lists exist and all medicines are present. However, co-payment for medicines is “normal” and many patients cannot afford the medicines they need.

The Health Insurance House collects premiums through employers’ and employees’ contributions. Each district has a regional health insurance house, which works under the auspices of the national one.

What really changed is that the legislative basis for health care delivery improved, patients rights are recognized, hospitals are paid for executed services and quality assurance is on the agenda. The patient rights are embedded in various laws including the right care at home and a free choice of doctor. But still most new legislation has to be implemented.

The position of the health care workers improved during the last decade. Doctors’ prestige was never high in (former) communist countries and still it is not. Their financial situation improved. Most specialists are on salary. Earnings for doctors doubled on average during the last decade. The position of nurses did not really improve during the last decade. Their work is strongly dependent from doctors’ decisions and control.
For all health care workers there are chances to work in private institutions, which mean often a higher income and better work conditions.

1.3 Health status of the population and the need for palliative care

The average life expectancy in Romania is five years less than in other EU countries (67.7 versus 73 years for men; 75 versus 79.5 years for women). Cardiovascular and cancer diseases are responsible for more than half of the deaths among people aged 0-64 years and for more than 85% among people over 64 years. Cancer mortality has increased significantly (see Table 2). The incidence of major diseases has increased strongly (see Tables 3 and 4).16, 19, 20

<table>
<thead>
<tr>
<th>Table 2. Mortality according to the main groups of medical causes of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Per 100,000 inhabitants</td>
</tr>
<tr>
<td>Infectious disease</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
</tr>
<tr>
<td>Cancer</td>
</tr>
<tr>
<td>Respiratory disease</td>
</tr>
<tr>
<td>Digestive disease</td>
</tr>
<tr>
<td>Accident, trauma, poisoning</td>
</tr>
</tbody>
</table>

Cancer is a major health problem and is related to unhealthy living habits and pollution. In most European countries, the incidence of cancer is 0.5-1% per year; in Romania, it is 3.6% per year. The incidence increased from 110.4 new cancers per 100,000 in 1970 to 226.6 per 100,000 in 2004.16

The majority of Romanian cancer cases are diagnosed in the final stages, and mortality is very high: over 60-90% in new cases of cancer, indicating a deficiency in cancer control and prevention.19 There is a shortage of oncology services, no system for following up patients, poor management of cancer patients, and no national strategy for cancer control.
Table 3. Incidence by principal classes of disease

<table>
<thead>
<tr>
<th>Diseases</th>
<th>Per 100,000 inhabitants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1990</td>
</tr>
<tr>
<td>General morbidity</td>
<td>73,629.0</td>
</tr>
<tr>
<td>Infectious disease</td>
<td>2,839.9</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>1,660.1</td>
</tr>
<tr>
<td>Cancer</td>
<td>183.5</td>
</tr>
<tr>
<td>Respiratory disease</td>
<td>28,868.2</td>
</tr>
<tr>
<td>Digestive disease</td>
<td>18,734.9</td>
</tr>
<tr>
<td>Accident, trauma, poisoning</td>
<td>3,328.0</td>
</tr>
</tbody>
</table>

Since GP services are supposed to cover the whole country, health care statistics have been collected for a number of diseases as recorded by GPs. Only a limited number of diseases are registered in these official statistics (see Table 4). No reliable data are available based on the International Classification of Primary Care as developed by the WONCA classification committee.

Table 4. Number of cases recorded by GPs in 2004

<table>
<thead>
<tr>
<th>Diseases</th>
<th>No. cases</th>
<th>No. cases per 100,000 inhabitants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goiter</td>
<td>102,949</td>
<td>475.00</td>
</tr>
<tr>
<td>Sweet diabetes</td>
<td>370,073</td>
<td>1,707.50</td>
</tr>
<tr>
<td>Malnutrition</td>
<td>17,707</td>
<td>81.70</td>
</tr>
<tr>
<td>Rachitic</td>
<td>12,889</td>
<td>59.50</td>
</tr>
<tr>
<td>Anemia</td>
<td>122,572</td>
<td>565.50</td>
</tr>
<tr>
<td>Mental disorder</td>
<td>200,423</td>
<td>924.70</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>81,928</td>
<td>378.00</td>
</tr>
<tr>
<td>Acute joint rheumatism</td>
<td>18,434</td>
<td>85.10</td>
</tr>
<tr>
<td>Cardiopathy</td>
<td>40,280</td>
<td>185.90</td>
</tr>
<tr>
<td>Hypertensive diseases</td>
<td>1,440,355</td>
<td>6,645.70</td>
</tr>
<tr>
<td>Ischemic cardiopathy</td>
<td>819,276</td>
<td>3,780.10</td>
</tr>
<tr>
<td>Pulmonary heart</td>
<td>41,469</td>
<td>191.30</td>
</tr>
<tr>
<td>Cerebro-vascular diseases</td>
<td>175,220</td>
<td>808.80</td>
</tr>
<tr>
<td>Chronic pulmonary diseases</td>
<td>236,318</td>
<td>1,090.90</td>
</tr>
<tr>
<td>Ulcer</td>
<td>281,481</td>
<td>1,299.40</td>
</tr>
<tr>
<td>Circoza</td>
<td>208,395</td>
<td>926.00</td>
</tr>
<tr>
<td>Nephritis</td>
<td>30,288</td>
<td>139.80</td>
</tr>
<tr>
<td>Calculus</td>
<td>111,404</td>
<td>514.20</td>
</tr>
<tr>
<td>Cardiovascular malformations</td>
<td>17,087</td>
<td>78.80</td>
</tr>
<tr>
<td>Mental diseases (annual new cases)</td>
<td>54,505</td>
<td>251.50</td>
</tr>
</tbody>
</table>

The ageing of the population and the development of medical technology and expertise have led to an increase of terminal (cancer) patients in Romania as well. Providing care for these patients is a growing problem because of the lack of
facilities and expertise. The same applies to care for people with other incurable
disease like HIV/AIDS or dementia.21 The need for palliative care in Romania is
high, but no reliable and relevant data are available.

Terminally ill patients must stay in hospitals when no other care is
available, but they do not belong in the hospital, where they miss proper care
and attention. Also, most patients would prefer to die at home if possible.22,23,24

In the past, family members took responsibility for end-of-life care. However, due to “modern-day progress”, a transfer of this duty has taken place
from the family to special places such as hospices, nursing homes, and hospitals.25
This is especially true in industrialized nations. This trend would also be expected
to appear in Romania. However, dying alone in a strange place, with pain and
suffering, is a nightmare and not yet commonplace in Romania.26 In Romania, there
has been a strong tradition, even up to the beginning of the 21st century, of families
taking care of their family members until death.

1.4 Definitions of palliative care

Death is unlike any other life transition experienced by humans. Being
confronted with one’s own mortality, either through watching someone die from
a terminal illness or just simply thinking about it, is quite a moving event for
most people.

Cancer (which is making more and more victims despite medical
progress), AIDS and other incurable diseases like dementia or organ
insufficiency require a new orientation for medical care. Such patients need new
kinds of services, provided at home until their death, in order to ensure a
reasonable quality of life towards the end. Medical care given to terminal
patients should ensure quality of life and allow patients to die with dignity and
comfort. In the last period of their life, patients with incurable diseases need
special treatment and professional care to manage their symptoms and maintain
quality of life. This can be referred to as palliative medicine. Doyle et al. defined palliative medicine as “the study and management of patients with active, progressive, far-advanced disease, for whom the prognosis is limited and the focus is the quality of care”. Palliative medicine is part of palliative care, but the latter term is broader, as may be derived from definitions from the WHO.

In 1990, a WHO committee formulated a unanimously accepted definition of palliative care, which was modified in 2002 and recommended to all member states for introduction in their national health system. The most recent definition is:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or
radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”7

Palliative care is interdisciplinary in its approach and encompasses the patient, family and community in its scope. In a sense, palliative care offers the most basic concept of care – that is, providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.

Palliative care has been present for centuries, but it developed as a special care discipline after the middle of the twentieth century, when it developed into a special discipline starting with the hospice movement and evolved further since then. It started by changing the location of patient care before death from the hospital (or home) to a hospice, i.e. a friendly, warm place where terminal patients could go and spend their final days in peace assured of good care directed at quality of life. In the further evolution of palliative care, the exact place of care became less important, but the content of the care concept remained essentially the same.28

1.5 Development of new palliative care service in Romania

The need for these new palliative care services was recognized in most Eastern European countries after the Communist period. As mentioned previously, this need also existed in Romania, but official health policy did not really stimulate the development of palliative care. Foundations and subsidies from abroad made it possible to start palliative care in Romania about one decade ago, most of it hospice-based. Despite these initiatives, most patients did not have access to palliative care. Even the concept was (and is) rather unfamiliar to Romanian citizens, and most patients did (and do) not understand
the nature of palliative care. The majority believed that this kind of care could
cure their terminal disease.

Because of the enormous need for and limited availability of palliative
care for most Romanians, a new service was developed to deliver palliative care
at home by teams built around general practitioners and nurses. The first step
was to demonstrate the feasibility of such a service. A medical Romanian–
Dutch program called “Pacaro” was developed in two southern Romanian
regions (Olt and Ilfov) and Bucharest. It aimed to form at-home palliative care
teams which were multidisciplinary in nature and adapted to the social,
economic, and cultural traditions of Romania. The objectives were: to
demonstrate the possibilities for palliative care at home in Romania, to develop
models for such care, to establish a network of trained experts, and to evaluate
the activities of the at-home palliative care teams.

Five teams were formed and each team developed its own structure for
care delivery to terminal patients in different regions. The members of the teams
included physicians (GPs and oncologists), nurses and social workers. The
teams consisted of three to six members each depending upon the region. The
professionals involved worked as volunteers. They did not receive extra
compensation, and a large part of their work had to be done outside regular
working hours.

Before starting the actual care, the team members were trained by
Romanian and Dutch experts in five training sessions covering a total of 18
days. The training sessions included the content and organization of palliative
care, i.e. history, main concepts, symptom treatment, drug prescription,
technical skills, team work, communication, registration, presentation of cases
and division of tasks. In between sessions, the teams also presented several
cases, which were discussed with the experts via Internet.

All training courses were evaluated in two ways. First, trainees
discussed their experiences and reported to the teachers. Secondly, all trainees
filled in a brief questionnaire after the training on what they thought of the training content and methods.

During the training the team members recognized the need to use standard registration forms to monitor activities and agreed to use a common form. It also became evident that the members would need additional medicines, equipment and a reimbursement for travel expenses. Arrangements were made for these requisites, including an emergency bag for each team. All team members would be able to communicate with each other and with the teachers via intranet. This tool was used to spread information and to discuss cases if a team member felt the need to do so.

1.6 Research questions

The development of the at-home palliative care project raised some preliminary questions. After all, no overview was available on the development of palliative care in the past in Romania. And how did professionals, in particular general practitioners, view the need for palliative care? The initiators of the at-home palliative care project had based the need for such a service on observations in patient care environments and on discussions with interested general practitioners, geriatricians and oncologists. It was felt that a more systematic survey was needed to learn about the current situation in the primary health care environment.

It was evident that the new service needed to be evaluated from various perspectives. The feasibility and effectiveness of the new service had to be demonstrated. In addition, a patient profile for the patients enrolling in the new program had to be formulated, as no relevant data were available.

Based on the above considerations, the following research questions were formulated:

1. How did palliative care in Romania develop over time?
2. What are the experiences and opinions concerning palliative care among 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, and in relation to the services offered by the teams?

To answer these research questions a subsidy was received as part of the Pacaro program. Within the Romanian context research like this without support from abroad would be impossible. It is still a big difference how research topics are designed and executed in Romania as compared “Western” countries. Large research programs as formulated by national states in Western Europe and being part of EU research policy have still to be developed in Romania, concerning content and procedures. The European regulation on clinical research is not introduced yet in Romania.

Before the project started the Ministry of Health was asked for permission to perform this study and cooperation of the Health Insurance House was requested as well as their offices in the regions and territorial hospitals. At that time an ethical committee did not exist to approve the research in Romania. In the middle of 2006 the Ministry of Health submitted a proposal to create a new law to establish an ethical committee in every medical institution\textsuperscript{29}. The research project was approved by the medical ethical committee of the institute for Rehabilitation Research (iRv) in the Netherlands.

1.7 Outline of the thesis

Chapter 2 presents a short history of palliative care in Romania, starting with a description of the development of palliative care around the world and describing the beginning of palliative care in Romania.
The experiences and opinions of the general practitioners and whether they would accept this kind of services in Romania are discussed in Chapter 3, based on a survey among all general practitioners in five selected regions.

Chapter 4 describes the characteristics of the patients who enrolled in the at home palliative care project and presents the medical and health status of the patients. An analysis is carried out of which medical, psychological and socio-demographic factors are related to functional health status at enrollment. The activities and interventions executed by the at-home palliative care team are described in Chapter 5. Here the emphasis is on cancer patients who died during the project. The changes in symptoms and pain during the palliative care process are analyzed as well as which socio-demographic and medical characteristics are related to these changes.

The Chapter 6 evaluates the palliative care delivered from the perspective of the professionals involved. These persons, i.e. GP’s, oncologists and nurses, expressed their opinion about the service delivered by filling out a survey form after the patients died.

To evaluate the quality of the palliative care service, it was also important to analyze the service from the perspective of the families involved (Chapter 7). This evaluation included communication, fulfillment of expectations, accessibility, conflicts and overall satisfaction of deceased patients’ families.

The last chapter of this thesis presents the answers to the research questions and discusses the results. Finally, recommendations are given for practice, research and policy within the Romanian context.
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