CHAPTER 2

PALLIATIVE CARE - BETWEEN PAST AND FUTURE

Luminita Dumitrescu, Marinela van den Heuvel Olaroiu, Constantin Bogdan, Corneli Moisa

Published in Romanian Revista Medicala Romana 2003; XLX (3):153-159
2.1 Introduction

Each minute, 288 children are born and 108 people die. By 2050, the number of people over 60 will have tripled. The number of people over 80 will also have tripled, from 600 million to 2,000 million. During the first half of the twentieth century, the major causes of morbidity were infectious and parasitic diseases, acute respiratory and digestive illnesses, and prenatal illnesses. During the second half, these illnesses continuously decreased and were replaced by chronic diseases as the major cause of morbidity, a phenomenon also known as “health status transition”.¹

Chronic diseases cause half of the 57 million deaths recorded in the world. The number one killer is heart attack and cerebral stroke, followed by cancer. Every hour, 360 new cancer cases are diagnosed, of which 240 will end in death. The annual rate of increase is 5%, which will lead to 15 million new cases in 2020.

Cancer, together with HIV-AIDS, leads to the highest percentage of terminal patients without hope of cure. Patients in the terminal stage of their disease offer a heartrending “show” as a result of their and their families’ suffering. Many clinical specialists prefer to forget them, viewing them as desperate cases and medical failures, thereby abandoning the fight and the human aspects of this problem.²

The need for action to reduce cancer-related morbidity and mortality and to provide specialized care aimed at improving the quality of life of cancer patients is mentioned in official reports by the WHO. These issues also concern many people in the world today.

In the following sections, we will present the most important landmarks in palliative care development, both at an international level and in Romania.
2.2 International palliative care development: the nineteenth and twentieth centuries

For centuries, human communities have been trying to develop specific methods to take care of dying persons and their families. Charity actions can be traced back to ancient China, where the “house of dead” offered a refuge to dying people. In New Zealand, Maori customs gave practical support to the mourning family and encouraged the community to take part in the mourning rituals. In Eastern Africa, the village elderly gave practical and spiritual support to the dying person and the mourning family.3,4,5

Care in the terminal stage of life was also mentioned in Ancient Greece, where the word “xenodochium” signified hospitality for protection and care of the poor. In the Eastern Roman Empire, there were refuge houses called “hospitium”, which were shelters for sick or dying people as well as for orphans, pregnant women or starving people.3,4,5

In Western Europe and in North-America, taking care of the dying and their family was seen as a church problem until the 19th century. Many documents from the Middle Ages and from the time of the Crusades mention refuge houses, similar to the hospices, which provided care and shelter for pilgrims and ill people, and which were built at cross-roads to religious shrines. Such places of refuge included Santiago de Compostella, Chartres and Rome.3,4,5 From the sixteenth to the eighteenth century, religious orders offered care to sick people (including the terminally ill) in regional or local shelters. But most people died at home, cared for by a female family member.3,4,5 In the middle of the nineteenth century, such shelters reappeared in Europe. One of the most famous was in Lyon in France, where Madame Jeanne Garnier opened a “calvaire” together with the “Dames du Calvaire” society. In London, the first hospice, “Saint Joseph”, was built. In Dublin, Ireland, in 1879, Sister Mary
Aikenhead of the “Irish Sisters of Charity” opened a shelter named “Our Lady’s Hospice” providing care only to terminally ill people.\textsuperscript{3,4,5}

The above trend, also referred to as the “medicalization” of death, continued, and the recorded number of deaths in medical centers increased e.g. in the middle of the twentieth century, almost 80% of the U.S.A. population died in hospitals and nursing homes.\textsuperscript{4} During the first years of the twentieth century, the hospices of “St. Luke” and “Hospice of God” were built in London. In 1905, the Irish Sisters of Charity built the “St. Joseph” hospice in East London (the poorest side of London). Gradually, interest in the psycho-social aspects of death and the associated period of grief increased.\textsuperscript{5} In 1935, the first publications by Alfred Worchester – “The Case of Aged”, “Dying” and “Death” - appeared, describing aspects related to taking care of dying people and to death. In 1953, other publications for nurses were published via the “Marie Curie Memorial” Foundation.\textsuperscript{5} The first half of the twentieth century was characterized by progress in specific etiologic treatments and the discovery of new medical technologies which guided the medical world to preventive/curative medicine. Now, we are witnessing a “withdrawal” from the incurable patient, with death being considered a medical failure. In contrast to the effective treatments discovered for most infectious and parasitic diseases, the rising incidence of cancer has resulted in increasing numbers of terminal patients.\textsuperscript{6}

The history of the movement for palliative care began in earnest in the 1940s in Great Britain. The “British Hospice Movement” led to the renaissance and consolidation of palliative care, though the first ideas about palliation were born in France.\textsuperscript{6}

Today, “hospice” signifies a place for medical care. “Palliative” means shield or mantle, and it signifies symptom management in the terminal phase of an illness. Cicely Saunders is unanimously considered to be the founder of modern palliative care and promoter of the hospice movement. Born in 1919, gifted by nature with dynamism and creativity and also with great sensitivity to human
suffering, this young doctor was initially trained as a nurse and social worker at St. Joseph Hospice. She also specialized in pain control in advanced cancers. Although people have been interested in alleviating human pain and suffering since time immemorial, the modern history of pain research and treatment started in the 19th century. Until then, various substances obtained from plants individually or in combination in order to alleviate the pain associated with illness: opium (as laudanum, an opium and alcohol mixture) obtained from the opium poppy (*Papaver somniferum*), alcohol or wine, mandragore obtained from *Atropa mandragora*, belladonna, and marijuana or *Cannabis indica*. In 1804, a medical student identified the active ingredient in opium and named it “morphine”, after the Greek god of dreams *Morpheus* (he became the first morphine addict in history and died because of it). *Heroin* also became known in England and was initially considered to be a panacea for pain treatment, which is why its name was based on the Greek word ‘herous’. Unfavorable side effects led less favorable opinions being formed regarding this drug. The discoveries of both these substances have nevertheless had a great impact, which is felt even today, as they became part of street culture and resulted in a modern-day plague: drug addiction.

Dr. Saunders pioneered the modern method of opioid analgesic pain treatment through her research. Administering the drug at specific hours instead of “at need”, the scheme conceived by her is still considered the standard one for hospices and palliative care. The “St. Christopher” Hospice in London, built in 1967 by Dr. Saunders, took palliative care to a new level by building on previous results, applying a multidisciplinary approach in treating dying patients, regularly using opioids for pain control, and also focusing on the social, spiritual and psychological needs of patient and family. This hospice represents an important milestone in palliative care history. It was the first medical institution dedicated to terminal patients, providing a model and a
training ground where, in time, various specialists from the United Kingdom and elsewhere would be trained.

In the same year that “St. Christopher” opened its doors, across the ocean in Chicago, a Swiss psychiatrist, Elisabeth Kübler-Ross, started down a road which would make her famous and revolutionize our understanding of death and the way in which we cope with it. Her unique experience in researching human psychological feelings before death lies at the basis of her masterwork “On Death and Dying”, whose influence is now seen in hundreds of hospices in the U.S.A. It was Elisabeth Kubler-Ross who introduced the palliative care approach to AIDS patients and who gave them her new masterpiece ‘The Last Moments of Life”. This work, which made her even more famous, describes the last moments of life in terms of stages which have become archetypal in palliative medicine.

Between 1968 and 1975, many hospices and palliative care programs were established in the United Kingdom, adapting the “St. Christopher” model to local conditions and providing palliative care at home or in hospices. Following the British model, the “Calvaire” hospice opened its doors in France, the “St. Jean” in Belgium, the “St. Luke” in Canada, etc. In 1975, Balfour Mount (who later became the first professor of palliative care) founded a palliative care unit in the Montreal Royal Medical Center in Canada. It was the first palliative care unit which used the term *palliative care*, thereby referring to the care of patients with advanced illness for whom healing is no longer possible but pain alleviation is. Later, synonymous terms such as *palliation*, *hospice care* and *supportive care* appeared.

The first hospice in the U.S.A was founded in 1974 in New Haven, Connecticut, followed by other centers for cancer as well as AIDS and other incurable illnesses. In 1977, only ten years after the first hospice was built in the United Kingdom, there were already 26 hospices in Ireland. Their number was
also increasing in other European countries as well as the U.S.A., Canada, New Zealand and Australia.

During the 1970s and 1980s, a revolution in cancer pain treatment was also taking place. This involved improving the methodology of drug treatment according to the principles recommended by Cicely Saunders, which modified opioid therapy by adjusting the way the drug was administered, the dose required and the time intervals. The WHO and EAPC nominated groups of experts to establish the main guidelines in cancer treatment, using simple and cheap methods. Morphine, which controls 80% of the pain via oral use, is recommended as the first option in severe cancer pain. Pain in cancer is recognized as one of the major problems in public health by the WHO. The Public Health Committee of the European Council dealt with the issue of death and the care of dying persons at Strasbourg in 1981. Around the same time, the concept of the palliative care team was born, and other aspects of the new care concept came into focus: bereavement management during the mourning period, family support, religious support, etc.

Various organizations which aimed to support hospices and palliative care appeared: the Cancer Relief Macmillan Fund, the Marie Curie Cancer and Sue Ryder Foundation in the United Kingdom, the National League against Cancer in France, the National Hospice Organization and Hospice Education Institute in the U.S.A., and the Center for Hospice and Palliative Studies in Perth, Australia.

At the initiative of Dr. Thelma Bates, palliative care teams were formed within the hospital at “Saint Thomas” Hospital in London. The first palliative care university chair in England was also created here, and its first holder was Dr. Geoffrey Hanks. Thus, the term hospice was separated from the actual building and its meaning was expanded to include the palliative care concept. Palliative care then began to diversify. In England, the first hospice for children appeared, followed by five other such hospices which were also capable of
providing care for severe childhood pathologies other than cancer. A new organization also appeared: *Association of Children with life-threatening or terminal conditions and their families*. In 1990, in Eastern Africa, the *Nairobi Hospice* was founded near *Kenyatta National Hospital* and it became the first hospice in the region. This hospice is a charity-funded organization which provides palliative care for terminal patients with cancer or AIDS as well as providing support for their families.5

Extending palliative care to the home, as anticipated and encouraged by Cicely Saunders, was becoming a reality and spreading around the world. The trend was to develop palliative care for dealing not only with cancer and AIDS, but also with degenerative neurological diseases, Parkinson, senile dementia, and cardiac, pulmonary or renal sufferance. Care which responds to the needs of the specific local community increased as did the number of palliative care units and teams available.

After the 1990s, palliative care also spread to Russia, Bulgaria, Romania, Zimbabwe and Taiwan. Today, in south-eastern Europe, there are 220 palliative care centers in Poland, 20 in Hungary, 10 in the Czech Republic and 29 in Romania.5 Increased awareness of terminal patients’ care needs underlined the need for palliative care and hastened its introduction into the academic world. Accordingly, training centers for doctors and nurses have sprung up in larger hospices all over the world.

The definition given by the WHO Experts Committee in 19907 formulated the goal of palliative care and described its various aspects. It was assigned a higher priority, as witnessed by the construction of the Palliative care center (where training modules, study groups, cancer and palliative care programs were developed) and by the recommendation to introduce such services in public national health care systems.
Scientific organizations devoted to this sector appeared in an increasing number of countries including: France - the French Society of accompaniment and palliative care; Belgium - the Belgian Federation of Palliative Care Associations; England - National Council for Hospice and Specialist Palliative Care. The first European Congress dedicated to palliative care took place in Paris in 1988.

The year 1990 marks a milestone in modern palliation as several important events took place, including the formulation by the World Summit of the Declaration of principles about providing care to patients with chronic violent pain or terminal patients. The European Association for Palliative Care – EAPC, which unites the national associations – was formed in 1990. In that same year, the first EAPC Congress took place in Paris.

The Second EAPC Congress took place in Brussels in 1992. Since then, more extended and advanced congresses have taken place every two years: Bergen, Norway; Barcelona, Spain; Lyon, France; Palermo, Italy and The Hague, The Netherlands.

At the same time, various regional organizations also appeared: ECEPT – Eastern and Central Europe Palliative Task Force, affiliated to EAPC and founded by Professor Jacek Luczak from Lodz, Poland. Today the palliative care concept has already been adopted by 40 nations, including Romania.

2.3 Development of palliative care in Romania: the nineteenth and twentieth centuries

At first, providing medical and social care had a strong religious character in Romania. For centuries, such care has been provided via monasteries and churches. In the 18th century, so-called “bolnites” were organized around the monasteries, as well as asylums for the poor, for invalids and for the ill, where they were provided with social and spiritual care as well as medical care. Taking their cue from the churches, Romanian kings also began to
show some interest in taking care of the poor. One of these was Radu Basarab, the founder of Campulung, who founded the “misery hospice” near this same town (14th century). Another was Neagoe Basarab, who told his son: “Use the abundance of your prosperity to give rest and peace to the poor”. In 1831, via the Organic Rule, the first medico-social services provided by state institutions were organized in the Romanian Kingdom(s).

In the first decades of the 19th century, especially during Alexandru Ioan Cuza’s reign, public authorities started to become increasingly involved in the field of medico-social care, which was made obvious by their building of institutions outside the Church’s control.

At the beginning of the 20th century, the increased involvement of the state in the health area led to a diversification of medical care options in: general hospitals, emergency hospitals, chronic hospitals, medico-social units, psychiatric respite homes, and shelters for the elderly initially named “asylums”. Terminal patients who could not be cared for at home were forced to seek help in hospitals oriented towards the chronically ill. Such hospitals – especially those dealing with “incurable patients” – as well as asylums and home care institutions became the preferred places for providing this type of care and support. But these places did not yet provide care in accordance with palliative care principles. These principles were introduced only later at the end of the 1980s, when the “St. Luke” hospital was built in Bucharest, which was where most of Bucharest’s other hospitals sent incurable and terminally ill patients. At the beginning of the 1990s, the first specialized palliative care services were established with the help of foreign funding programs.

2.4 Development of palliative care in Romania after 1989: legislative changes and demographic context

Romania is ranked last among European countries in terms of overall funding for health, which comprised 4.6% of the Gross Domestic Product in 1999. This is less than half the amount spent in EU candidate countries and four
times less than in the European Union.\textsuperscript{11} Because of economic and social problems, associated with historic traditional processes and efforts to build a democratic government system and a market-based economy, Romanian society has had to deal with negative consequences such as institutionalized children, HIV/AIDS infections, and violence and discrimination against children and women, as well as problems in the health care system related to the care for elderly and chronic patients.

The special situation of an ageing population - with its “specific needs” (the needs dictated by overall decline) - resulted in increasing numbers of requests for medical services both in medical facilities and at home. However, the health care system was not able to satisfy this requests.\textsuperscript{11}

The traditional pattern and the general wish of patients to die at home, in the midst of their family, kept the mortality rate in hospitals (including medical emergencies and all kinds of accidents) at the level of 0.84‰. Requests for bed facilities related to the ageing process were based primarily on a lack of care options at home.

Significant changes in the health care system were initiated with Act no.145/1997, which provided for a new form of social insurance, i.e. social health insurance, starting in January 1998. Implementing health system reform faced many obstacles and caused many problems, not the least of which were political: between June 1996 and June 1998, no fewer than six new ministers and eight state secretaries had to be appointed; between January and August of 1999, three new National Health Insurance House presidents had to be appointed. Also, the “immobility” of the 50-year-olds hindered implementation when it came to innovation in the health care field.

Government policy aimed at protecting elderly and suffering persons created greater awareness of the need for specialized care for dying and frail elderly patients, resulting in an interest in palliative care by the Ministry of Health. Palliative care was recognized as a special competence in 1999 by
Order no. 772/2 November, appendix 7. The recognition of palliative care as a medical sub-specialization took place in 2000 by Order no. 254 of the Ministry of Health. It was recorded in specialty nomenclature by Order no. 923/2001, and in that same year the first ten specialists in palliative care in Romania were confirmed.

At the end of the same year, the government formulated the National Strategy for Reform of the health care system, and palliative care services as part of hospital services were mentioned for the first time. The year 2002 saw the restructuring of bed units, according to Government Decision no. 826. This process ended in June 2003 with the following results:

- The overall number of beds was reduced by 22,210 (987 less in Bucharest alone); the result was a change from 6.7 to 5.7 beds per 1000 people;
- The number of chronic care units and hospital wards was increased from 84 to 126, and the number of beds for chronic patients rose to 8138 (compared to 1151 beds in 2002);
- 104 institutes with 3,906 beds were identified as suitable for transformation into medico-social units.

Following the WHO recommendations given during the Budapest meeting in March 2002, the Romanian Ministry of Health organized a work group aimed to implement palliative care and pain control treatment. This group was created in September of the same year in Brasov. The group consisted of 16 professionals and adopted an action plan for the long term to optimize pain control treatment and care for terminal patients. It also developed a national strategy and aimed to change the opioid law. At present, opioid-based treatment is in accordance with Act no.73/1969 and the instructions of the Ministry of Health for drugs and opioid substances. Also, long-term treatment with morphine is recommended with reticence, with access to such drugs being too
difficult because of the bureaucracy and also because of the professionals’ limited knowledge in the field of chronic pain. It is estimated that only 15% of cancer patients receive adequate treatment (with morphine). The treatment doses and intervals are set by law and not by the professionals, which limits prescription. For example, only one product may be prescribed at one time/consultation. The mentality of the professionals involved as well as the patients and their families is dominated by the prejudice \textit{morphine = drug = addiction = terminal phase}. Only in some centers where palliative care is provided has a start been made in using opioids in accordance with a modern approach.

A study carried out in 2000 at Wisconsin University, U.S.A., showed that the ten most industrialized countries, containing 10% of the world population (Australia, Austria, Brazil, Canada, France, Germany, Japan, Portugal, England and the U.S.A.), accounted for 69% of global morphine consumption. Romania ratified the Unique Narcotics Convention in 1961. This convention declared that opioids are indispensable for pain treatment and alleviating suffering. Romania ranks 42\textsuperscript{nd} in terms of morphine consumption, at 2.17mg/person in 2002 compared to the global average consumption of 5.58mg/person (see Table 1).

<table>
<thead>
<tr>
<th>SOUTH-EAST EUROPE</th>
<th>Morphine consumption (mg/person) 2001</th>
<th>DEVELOPED COUNTRIES</th>
<th>Morphine consumption (mg/person) 2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albania</td>
<td>0.40</td>
<td>Canada</td>
<td>57.68</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>3.61</td>
<td>Denmark</td>
<td>65.62</td>
</tr>
<tr>
<td>Croatia</td>
<td>1.49</td>
<td>Netherlands</td>
<td>14.50</td>
</tr>
<tr>
<td>Czech republic</td>
<td>6.46</td>
<td>United Kindom</td>
<td>18.55</td>
</tr>
<tr>
<td>Hungary</td>
<td>4.39</td>
<td>USA</td>
<td>35.32</td>
</tr>
<tr>
<td>Lithuania</td>
<td>2.56</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poland</td>
<td>7.24</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Romania</td>
<td>2.17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Slovakia</td>
<td>3.51</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Slovenia</td>
<td>7.95</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
An analysis of the INCB reports regarding total morphine consumption in Eastern European countries shows that while Bulgaria, Croatia, Hungary, Lithuania and Poland have seen constantly rising morphine consumption levels since the early 1990s, consumption in Romania remained at a minimum level of 10 kilograms per year until 2001, when 50 kilograms/year was recorded. Poland is the biggest consumer with 275 kilograms/year, followed by Hungary with 70 kilograms/year.

At the end of 2002 and the beginning of 2003, new changes occurred in palliative care. Government Ordinance no. 150, which modifies the Health Insurance Act, emphasizes for the first time the patients’ right to obtain care at home in any illness circumstances (art. 11.1 and art. 27), and the Frame Contract for 2003 refers to palliative care as a medical service provided to hospitalized patients. Act no. 46, the Patients’ Rights Act adopted at the beginning of 2003, defines terminal care for the first time and emphasizes the patient’s right to terminal care so that he/she can die with dignity (art. 1 and 31).

Moreover, the Ministry of Health elaborated rules about the organization and functioning of home care (Order 318/7), allowing independent persons or organizations to provide care at home, including services like communication and counseling, symptom management, therapeutic intervention, rehabilitation, kinetotherapy, speech therapy and psychological assessments. These services could be reimbursed by social insurance funds through a contractual relationship. The Hospital Act of June 2003 introduced palliative care services (art. 1, paragraph 2) among other medical services.

Every year, 181.4 new cancer cases, 3,023 new cardio-vascular cases and 3,565.2 new neurological cases are recorded in Romania per 100,000 inhabitants; and every year, 75,000 to 78,000 cases require palliative care, of which 30,000-35,000 cases involve cancer. Regarding cancer, 90% of deaths due to cancer occur at home; 15% get morphine; 50% have uncontrolled pain.
As far as deaths due to AIDS are concerned, there are almost 500 deaths per year (2.2 per 100,000 inhabitants), and practically all cases need palliative care in terminal phases (95-100%).

The need for terminal care in Romania is certainly much higher than previously estimated, but the number of people requesting such care will continue to be limited due to factors related to addressability, accessibility, and the reduced resources of the present health services, which cannot always provide such medical care.13, 14

2.5 Important moments in the development of palliative care

Before 1989, isolated initiatives drew attention to the special care needed by elderly patients, by those suffering from chronic diseases and patients in the terminal stage of their disease. The increased need for such services also became more evident. In 1980, Professor Constantin Bogdan presented the work “The Doctor and Death”, which compares curative-prophylactic practice and terminal phase care practice. The same author continued to promote palliative knowledge and in 1988 produced the book “Death and the Dying Care”. These two works reflected the author’s experience and opinions acquired as a doctor in units for chronic patients (cancer in terminal stage). In the monographic work, “Elements of Practical Geriatrics”, produced by the same author in 1989, a chapter titled “Terminal stage and specific care provided to the dying” appeared for the first time in the Romanian medical literature.13

After 1990, under the influence of the development of this kind of care in western countries, palliative care started to receive increasing amounts of attention. In 1992, the “St. Lawrence” hospice for children with AIDS, including children in terminal stages, was built at Cernavoda with the support of Reverend John Walmsley from Glasgow, Scotland. Similar institutions were also built in Bucharest and Curtea de Arges. Also, the first non-governmental
initiatives started to appear – initiatives which would not have been possible before 1989.

At the initiative of Dr. Sandu Lucian, the “Romanian Association for Pain Study” was founded in 1991. Another important moment was the establishment in the same year of the “Romanian Association for Palliative Care Development”, at the initiative of a group led by Dr. Maria Lungu (after a study at Hotel Dieu in Paris), directed at the development of palliative care in a multidisciplinary context.¹⁵

Another independent initiative took place in Brasov in 1992, when the “Hospice Casa Sperantei” Foundation was established with the support of the “Hospice Eleanor” Foundation from Kent, England. It provides palliative home care to patients with terminal cancer. Thus, the first palliative home care service was born (over 2500 terminal patients have received care until now, and professionals like Dr. Daniela Mosoiu and Professor Malina Dumitrescu invest time and effort in the development of this hospice).¹⁵ “Hospice Emanuel” was built in Oradea in 1996, and a palliative care team which provides care at home was formed.

The year 1997 marked a milestone for palliative care education in Romania due to the building of the first Palliative Care Study Center in Brasov. This center organizes courses in palliative care for doctors and nurses, with experienced lectures coming from countries with a rich tradition in this field. In 2002, 120 doctors, 76 nurses, 13 aid nurses and 15 volunteers participated in courses.¹⁵ In 1998, two courses in palliative care were given for the first time in the “Carol Davilla” nursing school network. Since June 2002, palliative care courses have been organized at the “St. Luke” hospital by Professor Constantin Bogdan and Dr. Gabriela Rahnea for the participants in the Romanian-Dutch
MATRA-PACARO program, which targets the development and implementation of palliative care in Romania. Over 30 doctors and 50 nurses were trained here. The same team also provided palliative care training courses for family doctors in Dambovita and Galati counties.11

At Tg. Mures Superior Medical School, pain and analgesia lessons have been introduced into the curriculum. The school also provides post-graduate courses for general practitioners in the field of palliative care. Home care nurses have trained at this school since 2000.

The existing associations have become very active in recent years. They are now better organized, are continuously improving themselves by exchanging information with similar foreign associations and organizing symposiums, workshops and training activities, in addition to providing care.

At the suggestion of Dr. Constantin Bogdan, the first ward of Palliative Oncology with 51 beds was started at the Hospital for Chronic Ill and Geriatrics “St. Luke” Hospital, which was added to the Geriatric palliative ward. The Palliatology and Thanatology Romanian Association was founded in June 1998 at the initiative of Dr. Constantin Bogdan. It was established as a professional and scientific society, which functions alongside other associations within the Romanian Doctors Association.

The first hospice unit with beds (for adults and children) was officially opened in Brasov in 2002: the “Casa Sperantei” (“House of Hope”) Hospice. Today in Romania, palliative cares is provided as home care but also in general hospitals (in oncology and chronic wards) and in hospices (see Table 2).
Table 2 Palliative care services in Eastern Europe

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>Hospice (Freestanding)</th>
<th>Hospital</th>
<th>Mobile teams in hospitals</th>
<th>Nursing home</th>
<th>Home care</th>
<th>Day care</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albania</td>
<td>3</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bulgaria</td>
<td>1</td>
<td>21</td>
<td>22</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Czech Republic</td>
<td>6</td>
<td>1</td>
<td>10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Estonia</td>
<td></td>
<td>9</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hungary</td>
<td>4</td>
<td>2</td>
<td>5</td>
<td>13</td>
<td>2</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Lithuania</td>
<td>1</td>
<td>5</td>
<td></td>
<td></td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poland</td>
<td>23</td>
<td>50</td>
<td>1</td>
<td>177</td>
<td>8</td>
<td>259</td>
<td></td>
</tr>
<tr>
<td>Romania</td>
<td>1</td>
<td>7</td>
<td>10</td>
<td>11</td>
<td>29</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Slovakia</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Slovenia</td>
<td></td>
<td>1</td>
<td>5</td>
<td></td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>32</td>
<td>61</td>
<td>5</td>
<td>5</td>
<td>244</td>
<td>12</td>
<td>371</td>
</tr>
</tbody>
</table>

Today, the most significant palliative care services in Romania are:

- 1 hospice with adult and children wards at Brasov, namely “Casa Sperantei”;
- 4 specialized services in palliative care at home: Brasov (“Casa Sperantei”), Oradea (“Hospice Emanuel”), Bucharest, Sibiu;
- 8 home care foundations which provide palliative care via their trained teams: Cluj (“Asistmed” and “Elder Care Foundation”), Bucharest (“Communitarian Care” Foundation, “Mobilmed”, “White-Yellow Cross”, “Alzheimer” Romanian Society), Piatra-Neamt (“Communitarian Care” Foundation), and Bacau “Communitarian Support” Foundation;
- 11 associations for children with HIV-AIDS, which provide palliative care in day centers or at home: “St. Lawrence” in Cernavoda, “St. Margaret’s Hospice” in Bucharest, “St. Christopher’s Hospice” in Curtea de Arges, “Sf. Mary’s” Pediatric Hospital in Iasi, in Tg. Mures, Constanta, Bacau, Giurgiu, Galati, Craiova and Petrosani;
- 7 hospital wards: “St. Luke” in Bucharest, Tg. Mures, Cluj-Napoca, Campina, Miercurea Ciuc, Birlad and Ploiesti;
5 palliative home care teams with a multidisciplinary approach within the framework of the Romanian-Dutch program PACARO, which started working in October 2002 in Slatina, Caracal, Bucharest (2 teams) and Ilfov. Starting in June 2003, six other “volunteer teams” were formed and trained within the framework of the same program: two teams (rural and urban) in Alba county, one team in Dimbovita (Tirgoviste) and Dolj (Craiova), one team (rural) in Olt county and one team in Bucharest in “St. Mina” Civil Society.

The Second National Training Center in the palliative care domain for doctors and nurses has recently been built in “St. Luke” hospital, with the logistic support of the specialists of the Matra - PACARO Program.

2.6 Conclusions

1. At the international level, Romania is in the middle of the development range of countries with regard to health status and health care system, in terms of mortality and morbidity, as compared to other countries in the Balkans and Western Europe. Decreasing birth rates and increasing rates of mortality and morbidity have characterized Romania during the last decade. The result, as also seen worldwide, was an increase in the numbers of elderly and chronically ill patients as well as a decrease in overall population from about 23 million in 1989 to 21.7 million in 2002.

2. An unhealthy life style, deficiencies in the illness prevention policy, a high rate of inflation and poor quality of life have led to a larger number of chronic patients and to an increase in the specific care needs of these patients. The structure of the healthcare system in Romania, as in most eastern European countries, is still based on historical disease prevalence, especially the acute ones, but it has been changing during the last decade in favor of chronic diseases.
3. The health care reform, which started in 1997 – in particular, in primary health care – continues today in the secondary line: the hospitals. Present policy in Romania is characterized by reductions in numbers of beds available and the use of hospitals only for emergencies and acute illnesses. This policy causes problems, especially due to the lack of alternatives. The small number of hospitals for the chronically ill, crowded asylums, and the lack of involvement by the Ministry of Labor and Social Protection in providing care to the elderly and chronically ill are a few of the problems which will cause an increase in the cost of health care and a need for extra investments.

4. Although medical professionals in Romania have been interested in providing specialized care to the terminally ill since the 1990s, this type of care was developed mainly within NGOs in an isolated fashion and was unknown to the general public, as it provided care only to a small number of patients. A characteristic feature of Romania is the emphasis on home care, the formation of multidisciplinary teams, and the acceptance of this type of care by patients and families.

5. Until now, government bodies have not really been involved in organizing palliative care services or establishing a national program for palliative care and pain control treatment. Nevertheless, 2003 can be considered a milestone in palliative care, due to the creation of an appropriate legislative environment expressing the will to develop this kind of service.

6. Twentieth century medicine will discover new values and new possibilities. But one thing will remain the same: death will remain inevitable. Professionals will have to learn about and reconsider care options for the terminally ill. They will have to explore the human soul and human suffering in order to become more human themselves. Palliative care will become one medical specialty among others, but it will not become independent of the others. Professionals from any single specialty will have to learn how to approach the terminally ill patient at any given moment.
References

1. Heuvel WJA van den, Palliative care: an European dimension, [In Romanian], Revista Medicala Romana 2001; XIVII(3):3-4
4. www.worldrtd.org 2003 - Definition & History of Hospice & Palliative Care
5. www.hospicebc.org 2003 - History of Palliative Care
9. Mincu M, Theoretical and practical bases to care healthy and sick men, [In Romanian], Editura Universul, Bucuresti 2000:477-495
10. Mincu M, Cringulescu N, Internal medicine, Medicine specialty and palliative care, [In Romanian], Editura stiinta si tehnica, Bucuresti 1998:569-620
15. Lupsa R, Csiki C, Palliative care in medical practice, [In Romanian], Editura Alutus, Miercurea Ciuc 2003:11-17