

Palliative Care in Europe

Vittorio Ventafridda, MD, Franco De Conno, MD, and Heidi Blumhuber

European Association for Palliative Care and National Cancer Institute, Milan, Italy

In Europe, the development of palliative care started with the hospice movement in the United Kingdom, which offered continuous care for incurable patients in their terminal phase. Since then, the palliative care movement has grown through various local and individual initiatives in all countries. The discussion of the problem of cancer pain relief on an international level has been emphasized by the World Health Organization (WHO) since 1982, when guidelines were drafted and distributed.

In 1988, the European Association for Palliative Care (EAPC) was created (a) to spread knowledge and awareness about palliative care throughout Europe; (b) to bring together already existing groups and thereby promote an exchange of experience on this matter between the most- and the least-advanced countries or regions, as the realities are very different between them; and (c) to encourage initiatives for the official recognition of palliative care. The association, which has doctors, nurses, and social workers on its board of directors, started its activities with the organization of its first congress held in Paris in 1990. The congress was inaugurated by French President Mitterand, was attended by 1700 persons, and had a very big impact on public opinion.

This first event gave a vital impetus to the effort of the various French associations in the field of palliative care. This led to the start of new groups and the formation of seven university diplomas in palliative care. The rapid growth was also helped by the existence since 1986 of a ministerial document on the care of the terminally ill. According to an inquiry made on behalf of the French Ministry of Health in 1990, there are approximately 450

beds distributed among 40 hospital centers and 180 beds in various religious institutions. Furthermore, home care is actually operative and more new services of this kind are being set up; recently, geriatric services are turning toward palliative care.

The second congress of the EAPC was held in Brussels, Belgium, in October 1992 and was attended by 1300 participants from 26 different countries. In Belgium, about 15 palliative care units exist, with the primary activity focused on home care. As in other countries of Europe, there are doctors working full time in palliative medicine, though it is not yet a recognized and approved medical specialty. The Brussels congress was honored by the participation of the Belgian Minister of Public Health, whose interest in the problem promises good progress for the development of palliative care in the health care system.

In Italy, palliative care also has developed in the last 10 years. The existence of palliative care units is completely dependent on local and individual initiatives, the good will of the hospital directors and financial support by private charities such as the Floriani Foundation and the Italian League Against Cancer. The operative part is particularly directed towards the care of patients in their own homes. The Italian Society for Palliative Care (SICP) has been trying for several years to get official recognition by a governmental body, but national legislation is still lacking and only local resolutions authorize the task of many clinicians, rarely employed full time, who work as a team supported by the above-mentioned private organizations. Two private hospices have been set up, one with 30 beds and the other with ten beds, and a wing with eight beds has been opened in a public geriatric structure.

In Spain, a very advanced and structured 5-yr program for the implementation of palliative care was started as a WHO demonstration project in Catalonia in 1990. Adequate financ-

Address reprint requests to: Vittorio Ventafridda, MD, Istituto Nazionale dei Tumori, Via Venezian 1, 20133 Milan, Italy.

ing and good follow-up have increased the numbers of palliative care units from two (1990) to seven (1992) and the beds from 15 to 140. In other Spanish regions, various isolated initiatives by people of good will who are particularly sensitive toward the issue of palliative care are springing up. Two important units have been set up in Madrid and Santander. In addition, there exist services for analgesic therapy that are now turning toward palliative care; this is also happening in oncology and geriatric units. Nevertheless, national legislative regulations are lacking. The Spanish Association for Palliative Care was established in 1992.

Switzerland has its association based in the French-speaking part of the country, with both Italian- and German-speaking sections. There are about ten units in Switzerland and, thanks to a widespread campaign in collaboration with the Swiss League Against Cancer, there is good awareness on the part of the public and family doctors of cancer pain and palliative care.

Germany also lacks a normative state law regulating palliative care.

In contrast with most other European countries, a national association for palliative care does not yet exist, although the *Deutsche Hospizhilfe* (German Hospice Society) has been promoting the hospice concept since the 1980s. According to information obtained from the Minister of Labor and Social Affairs, a pilot project with 13 palliative care units has been established by the government, mostly financed by private foundations. Together with this project, the feasibility of a future program, to be developed and endorsed by the *Krankenkassen* (the German health service), should be studied.

In 1991, the Nordic Association for the Care of the Terminally Ill organized a conference for the Scandinavian countries; approximately 1100 delegates attended. To increase the exchange between the nordic countries and the rest of Europe, the third congress of the EAPC will be held in Bergen, Norway, in June 1994.

In Sweden, there were four hospices at the end of 1992. About 20 hospital-based home care teams are working in the field of palliative care and, in the Stockholm area, there are also about 15 long-term-care hospitals with special wards for cancer patients. A medical society for palliative medicine was inaugurated in May 1992.

Palliative care has a long history in Ireland. Currently there are three hospices and over 20 home care teams operating in the Republic of Ireland. In the last 2 yr, two different associations came into being in Ireland. Recently these two associations were amalgamated into one umbrella association, which will be called the Irish Association of Palliative Care.

In Poland, there exist two organizations represented by the Polish Society for Palliative Care and the Hospice Forum under the auspices of the Roman Catholic church. These two organizations embrace the 26 hospices that have been active throughout Poland for many years. The forum also includes the eight communal hospices.

The Greek Association for Palliative Care was recently founded and held its first conference in Athens last October. Athens and Kardites hospitals have established groups for palliative care. A course in palliative care has been organized at Athens University.

Other groups are taking shape in many of the countries not mentioned above, such as the Netherlands and Austria, where the first hospices were opened in 1992. In all other countries, national associations have been created.

Even if implementation of palliative care needs to be adapted to the different cultural and religious situations, the United Kingdom remains the reference for all European countries. It is surely the country where palliative care is the most widespread. In 1991, there were 151 inpatient units, 231 home care services, and 140 hospital symptom-relief teams. To our knowledge, it is the only country where palliative care has been recognized as a medical specialty for 5 yr and where a chair has been created. In 1992, the National Council for Hospice and Palliative Care Services was set up to provide the movement with a body able to represent its views and interests, to coordinate the existing and developing units and resources, and to publish guidelines and standards. In November 1992, a paper on quality, standards, and organizational and clinical audits for hospice and palliative care services was published. Also in 1992, the Association for Palliative Medicine for Great Britain and Ireland published an official curriculum.

The EAPC regards the education and training of professional health care providers as of the highest importance and is committed to encouraging it in every possible way. In view of

this, EAPC organized a workshop in March 1993 for the education and training of physicians in palliative care in Europe. This was done with the financial support of the "Europe Against Cancer" program of the Commission of the European Community, to elaborate recommendations for member countries for the inclusion of courses on palliative care in doctors' medical education. The reports of the representatives of the various countries showed that, with the exception of the United Kingdom, education for medical students and postgraduates is still very incomplete and is mostly left to the choice of the deans of the universities. Education in palliative care is often taken over by private initiatives, for example, the Italian Medical School for Palliative Care (SIMPA). Further recognition of palliative care by the program "Europe Against Cancer" has occurred through a subcommittee on palliative care.

Education on palliative care remains the first target to achieve in order to change the

attitudes and behavior of the public and health care workers. The different cultures existing in Europe vary considerably with regard to communicating the truth to sick patients and the use of certain medical treatments, such as opioid analgesics. In fact, according to WHO statistics, the average consumption of morphine in kilograms per million of inhabitants per year goes from 24 for Denmark and the United Kingdom to 1 for Greece. According to the latest report of the International Narcotics Control Board in Vienna, such use has increased thanks to our continuous efforts in ten developed countries, especially in the United Kingdom and Italy.

Finally, another important point is the persistent belief among physicians of other specialties that palliative care is unreliable as a science. From this stems the necessity to improve research through controlled studies focused mainly on the impact of the different aspects of suffering and quality of life and the measurements taken to control them.