

Palliative care in Europe: an emerging approach to comparative analysis

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ABSTRACT – At the national level, hospice and palliative care activities have been developing in Europe since the late 1960s. International organisations to support palliative care have been in existence since the late 1980s. It was only in the late 1990s, however, that the first comparative studies of European palliative care development were conducted. This article reviews this history and highlights the main studies and initiatives that have focused on the growth of palliative care in Europe. Evidence to date shows huge variations in the levels of palliative care provision that exist in different countries, as well as some differences in the preferred models of care. The extent to which palliative care provision is integrated with wider health and social care policies appears to be a crucial determinant of success. A sustainable evidence base on palliative care provision in Europe is needed, and there are encouraging signs that this is beginning to develop through close cooperation between key organisations and initiatives in the field.

KEY WORDS: development, Europe, history, hospice care, palliative care

The World Health Organization's (WHO) European Region stretches from the Atlantic shores of western Ireland to the north-east waters of the Bering Sea. It contains 52 countries and has a population of around 879 million people. Some nine million die each year, 24% of them from cancer.¹ European countries generally have ageing populations – every seventh person is aged 65 years or over and this proportion is growing. In general, the process of population ageing is further advanced in the western parts of the region and it is now widely acknowledged that this ageing profile has many implications for the provision of palliative and end-of-life care in Europe.²

A society to promote palliative care in the European context was first formed in 1988, when the European Association for Palliative Care (EAPC), with headquarters in Milan and supported by the Floriani Foundation, came into being. Professor Vittorio Ventafridda became its first President the following year.³ Trained in anaesthesiology, Professor Ventafridda had earlier been instrumental in

assisting the development of the WHO Cancer Pain Relief Programme. The EAPC began with 42 founding members and aimed to promote palliative care and act as a focus for scientific, clinical and social interest in the field. It held its first major congress in Paris in 1990 and established the *European Journal of Palliative Care* in 1993 to provide an information and communication resource for palliative care professionals across Europe. By 2005, the EAPC had individual members in 40 countries, with collective members from 32 National Associations in 21 European countries, representing a movement of some 50,000 healthcare workers and volunteers engaged in palliative care.⁴ In 1999, under the leadership of Professor Jacek Luczak, the Eastern and Central European Palliative Task Force (ECEPT) came into being at an EAPC congress held in Geneva,⁵ aiming to gather data on hospice and palliative care in the region, share experiences of achievements and obstacles, influence the institutions of government, set standards to meet local needs, and raise awareness.

At the national level, however, the history of palliative care in Europe significantly pre-dates that of these organisations. In 1967, Cicely Saunders founded St Christopher's Hospice in South London as the first modern hospice in England, combining clinical care, education and research. Trained as a nurse, social worker and physician, Dr Saunders' work was widely acknowledged as a source of inspiration to what, after 1967, became recognised as a worldwide hospice and palliative care movement. Ten years later, services began to appear elsewhere in Western Europe: in Sweden (1977), Italy (1980), Germany (1983), Spain (1984), Belgium (1985) and

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Key Points

The palliative care needs of the European population are increasing

Palliative care development in Europe is still inconsistent

A clear evidence base about the provision of palliative care in Europe is needed

International collaborations are underway to provide research evidence on the opportunities for, and barriers to, palliative care development in Europe

the Netherlands (1991). In the former communist countries of Eastern Europe and Central Asia, there were few palliative care developments during the years of Soviet domination. A volunteer hospice service began in Krakow, Poland, in 1976. Lakhta Hospice opened in St Petersburg, Russia, in 1990 and a service started in Budapest, Hungary, the following year. After that, initiatives were started in:

- Bulgaria, Romania, the Czech Republic and Slovenia (1992)
- Albania, Kyrgyzstan and Lithuania (1993)
- Belarus and Croatia (1994)
- Ukraine (1996)
- Estonia and Latvia (1997)
- Azerbaijan, Bosnia, Macedonia and Moldova (1998)
- Armenia (1999)
- Slovakia (1999)
- Serbia (2000)
- Georgia (2001).

Indeed, there are now only a handful of countries in the European region with no known hospice or palliative care initiatives. It is clear, however, that development in many places remains patchy, uncoordinated and poorly integrated with wider systems of health and social care delivery.

Policy recognition at the European level

In 1989 and 1992, the European Parliament adopted resolutions on counselling and on care of the terminally ill. Thereafter, however, the European Commission (EC) appeared to show little interest in end-of-life issues, until January 2005 when a question was put to the Parliament concerning what action the Commission had taken to prepare a strategy for palliative care. The ability of the EC to take specific actions on palliative care is limited by the principle of subsidiarity, but there are a number of areas where palliative care issues can be addressed. The Europe against Cancer programme did refer to palliative care, though this was never exploited. More recent public health programmes offer a number of opportunities for the funding of projects on palliative care in relation to:

- specific diseases eg cancer and HIV/AIDS
- care of older people
- exchanging information on best practices
- training for healthcare professionals
- networking of organisations.

The Council of Europe, in contrast to the European Parliament, has shown a more concerted interest in palliative care development. Inspired by its Report of the European Health Committee (1980) *Problems related to death: care for the dying*, and by the Parliamentary Assembly Recommendation 1418 (1999) on 'The protection of the human rights and dignity of the terminally-ill and the dying', the European Health Committee decided in 2001 to address the issue of palliative care by setting up a committee of experts which, over a two-year period, prepared a set of European guidelines for the field. Its

report, *Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care*, was adopted on 12 November 2003 at the 860th meeting of the Ministers' Deputies.⁶ In doing so, all 45 member countries of the Council of Europe embraced the recommendations on behalf of their home populations. Subsequently, through the efforts of the EAPC East initiative, the recommendations were made available in 17 languages (Croatian, Dutch, English, French, Georgian, German, Greek, Hungarian, Latvian, Lithuanian, Polish, Romanian, Russian, Serbian, Swedish, Turkish, and Ukrainian) and were launched simultaneously in October 2004 throughout Europe.⁷

The report saw palliative care as an essential and basic care service for the whole population, and acknowledged that in many countries the majority of healthcare budgets is spent on people in the last years of life, though it is by no means the case that they receive the care that is most appropriate to their needs. It noted the great differences in the availability and quality of palliative care throughout Europe and argued that these need to be addressed through increased cooperation between countries. The report highlighted the need to support families and other informal caregivers and saw home as often – but not always and not for everybody – the best place for palliative care. It also encouraged all countries to devise national plans for palliative care in close collaboration with professionals and patient/family representatives and underpinned by appropriate needs assessments. Good quality palliative care should be equally accessible to everyone, independent of ethnicity, age, religion, geographical location, type of disease, life expectancy, and socio-economic status. There should be no restrictions on the availability of opioids or other drugs for medical use. At the same time, palliative care services should aspire to improve quality, where policy and practice are underpinned by appropriate research evidence. The report took the view that palliative care receives insufficient attention in the medical and nursing curriculum and recommended that each country establish at least one centre of excellence in the field. These recommendations appear to have been used quite actively in Eastern Europe where they have served as a tool for advocacy and lobbying. Their wider impact on national policy-making and service development is, however, more difficult to ascertain.

Policy issues relating to end-of-life care in Europe have also been raised by both non-governmental and inter-governmental organisations. At palliative care conferences in 1995⁸ (Barcelona) and 1998⁹ (Poznan), exhortatory declarations were made, calling for government action on palliative care at the national level and drawing attention to key problems and issues facing palliative care as it develops internationally.

In 2004, the European Federation of Older Persons (EURAG) launched a campaign to make palliative care a priority topic on the European health agenda.⁹ EURAG is a non-government organisation representing the interests of older persons in Europe, with 152 member organisations in 33 countries. Its campaign has sought to make palliative care a priority at the European Union level and in every member state (including accession countries). Central to its approach is the declaration

that palliative care policies should be based on certain core values: human rights and patients' rights, human dignity, social cohesion, democracy, equity, solidarity, equal gender opportunity, participation, and freedom of choice.

Also in 2004, WHO Europe produced an important document entitled *Better palliative care for older people*.¹¹ Its aim has been 'to incorporate palliative care for serious chronic progressive illnesses within ageing policies, and to promote better care towards the end of life'. Its companion volume, *Palliative care: the solid facts*, is a resource for policy-makers in a context where 'the evidence available on palliative care is not complete and ... there are differences in what can be offered across the European region'.¹² Despite the powerful symbolic language of these endeavours, unfortunately as yet there appears to be little evidence of the impact of such activities.

Key studies and initiatives

Whilst policy-making about palliative care at the European level remains under-developed, there have been some studies and initiatives designed to create an evidence base of what is occurring at the national level and some work has been done to generate comparative analyses of countries and contexts.

The first study to explore the development of palliative care in Europe in a comparative manner focused on seven countries (Belgium, Italy, Germany, the Netherlands, Spain, Sweden and the United Kingdom (UK)) and was known as the *Pallium* project.^{13,14} Reviewing palliative care provision in the late 1990s, the study showed two forms of variation. First, palliative care delivery was found in a variety of settings: domiciliary, quasi-domiciliary and institutional. Second, these forms were not prioritised equally in each country. Allowing for population differences, there were still gross variations in the numbers of palliative care services across countries, and the number of specialist palliative care beds per head of population varied from 1:17,866 persons in the UK to 1:1,913,333 persons in Italy.¹⁵ The study found examples where palliative care developments were integral to the formal healthcare system (Spain, Sweden), symbiotic with it (Belgium, Germany, Netherlands) and separate from it (Italy); the UK appeared to be a hybrid of all three tendencies.

In 2003, Clark and Wright reviewed the state of development of hospice and palliative care in 28 countries of Eastern Europe and Central Asia.¹⁶ The study covered matters of service development, levels of provision, policy implications, education and training, opioid availability, as well as local, national and international partnerships. The review

made use of a wide variety of primary and secondary data including: public health sources, more than 100 questionnaires returned by palliative care practitioners from the different countries, interviews with over 30 key individuals, unpublished policy papers and planning documents, correspondence, newsletters, professional and scientific journals, and secondary publications. Only Poland and Russia had more than 50 palliative care services within the country and five countries had no identified palliative care services. Various types of service delivery model were in evidence. Home care was the form of service most commonly found, followed by inpatient provision. There was a great absence of hospital mobile teams, as well as services in nursing homes and day care provision. Only 48 paediatric palliative care services were identified, covering just 9 of the 28 countries. More encouragingly, there were examples of outstanding success in specific locations and these were designated palliative care 'beacons'. Five beacons were identified, in four countries (Hungary, Poland, Romania and Russia). In each of these examples there was:

- evidence of the historical significance of the service within the national scheme of development in hospice and palliative care
- involvement of personnel of national/international repute
- a centre for education and training
- evidence of impacts upon national health policy.

Two comparative studies of European palliative care development have recently emerged from Germany. The first comprises a review undertaken on behalf of the German Parliament of 11 western European countries and is based on surveys of national

Table 1. The provision of specialist palliative care beds in 16 European countries.²⁰

Country	Population in millions (2000)	Number of beds	Number in the population to one bed	Beds per million
United Kingdom	58.689	3,195	1:18.369	54.44
Norway	4.473	190	1:23.542	42.51
Italy	57.536	2,133	1:26.974	37.07
Netherlands	15.898	590	1:26.946	37.11
Poland	38.671	1,268	1:30.498	32.79
Austria	8.102	190	1:42.742	23.46
Germany	82.282	1,788	1:46.019	21.73
Latvia	2.373	50	1:47.460	21.09
Czech Republic	10.269	185	1:55.508	18.01
France	59.296	772	1:76.808	13.02
Denmark	5.322	65	1:81.877	12.22
Estonia	1.367	16	1:85.438	11.70
Hungary	10.012	106	1:94.452	10.59
Ukraine	49.688	500	1:99.376	10.06
Slovakia	5.391	54	1:99.833	10.02
Lithuania	3.501	30	1:116.700	8.57
Total	412.870	11,132	1:37.089	26.96

experts, published sources and 'grey' literature.¹⁷ It is a monumental analysis of the palliative care infrastructure in these countries, including service provision, reimbursement data, and workforce capacity. Currently only available in German, it deserves to be more widely disseminated. A team of German sociologists at the University of Giessen has carried out a second study, available in German,¹⁸ Polish and French, with English and Russian versions to appear shortly. It covers 16 countries across Eastern and Western Europe, incorporating a comprehensive analysis of demographics, the history of hospice and palliative care, the number of current services, funding, education and training of professional staff and the role of volunteers, with an in-depth case portrayal of particular services. Both German projects have produced individual country profiles and for the Giessen study these are available on the internet.¹⁹ Table 1 shows the data from Giessen on the provision of palliative care beds in 16 European countries.

Within Clark and Wright's report were 10 recommendations, of which one was concerned with the establishment of an International Observatory on End of Life Care (IOELC). This would make available vital data on the current state of hospice and palliative care provision, country by country and comparatively. Following widespread consultation the Observatory was established in September 2003 at the Institute for Health Research, Lancaster University, UK, under the leadership of Professor David Clark. The Observatory can be seen as a 'community of effort' to bring together research-based activities for the improvement of end-of-life care through the provision of systematically gathered information on hospice and palliative care development at the country level. Its website currently lists detailed reports on some 60 countries around the world.²¹ The country reports reflect current knowledge drawn from needs assessments, service evaluations, historical analysis, ethical and cultural reflection, and in particular they make use of in-depth oral history interviews with key activists at the country level. The Observatory is the first ever research and development initiative to focus on comparative information relating to hospice/palliative care around the world. It generates such data from original studies as well as through the collation of material gathered elsewhere and endeavours to turn this into useful intelligence which can influence current policy and practice development. This idea builds on successful public health observatories, but is unique in being focused on end-of-life care and in its mission to go beyond a purely epidemiological frame of reference. It provides data against a common template on key structural issues facing the development of palliative care, country by country, including:

- current services
- reimbursement and funding
- opioid availability and consumption
- national and professional associations
- palliative care 'coverage'
- palliative care workforce capacity
- healthcare system issues
- partnerships and international collaboration

- material on ethics and narrative based accounts from activists.

Within the short period of time since it began, the work of the Observatory and the information on its website has gained wide recognition. It has conducted studies in Africa, the Middle East, South America and India and is working in close collaboration with partners around the world to expand its programme of research on international hospice and palliative care development.

One such partnership is with the EAPC Task Force on the Development of Palliative Care in Europe. The Task Force began its work in 2003 and will be reporting in full by the end of 2006. It is led by Dr Carlos Centeno, an EAPC board member, and is a collaboration between EAPC, the IOELC, Help the Hospices and the International Association for Hospice and Palliative Care. Its covers the whole WHO European Region and its chief goals are to assess the degree to which palliative care is developing there and to explain the current organisation of hospice and palliative care, taking into account political, social, and healthcare policy and related factors. It has four key work methods: a systematic literature review, a review of directories of palliative care, a survey of 'factual' data on current provision, country by country, and a survey of opinions among key leaders at the national level.²² In due course it aims to produce an 'atlas of palliative care in Europe'.

There is no doubt that since the late 1990s the evidence base for palliative care in Europe has improved. The studies outlined above have begun to sketch out the broad parameters of development across a vast geographic area of 52 countries and a population of 879 million people. There is still much to be done, however, if truly comparative data are to be collected and a rigorously analytic picture is to emerge.

The way forward

Comparative studies can do a great deal to advance policy-making to promote palliative care in Europe. Such work should be rooted in public health and social science models and should consider the provision of palliative care within the wider milieu of health and social care policies, as well as social, ethical and cultural factors. Such work should recognise the complex character of palliative care provision in many countries and the combination of statutory, voluntary and civil society organisations that are involved in it. There are encouraging signs of productive alliances that can produce important research evidence in a context where high quality data can be hard to obtain. The interest in studying palliative care development at the European level has never been greater.

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