

## **Barriers to the development of palliative care in Western Europe**

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**Abstract:** The Eurobarometer Survey of the *EAPC Task Force on the Development of Palliative Care in Europe* is part of a programme of work to produce comprehensive information on the provision of palliative care across Europe **Aim:** To identify barriers to the development of palliative care in Western Europe **Method:** A qualitative survey was undertaken amongst boards of national associations, eliciting opinions on opportunities for, and barriers to, palliative care development. By July 2006, 44/52 (85%) European countries had responded to the survey; we report here on the results from 22/25 (88%) countries in Western Europe. **Analysis:** Data from the Eurobarometer survey were analysed thematically by geographical region and by the degree of development of palliative care in each country. **Results:** From the data contained within the Eurobarometer, we identified six significant barriers to the development of palliative care in Western Europe: (i) Lack of palliative care education and training programmes (ii) Lack of awareness and recognition of palliative care (iii) **Limited availability of/knowledge about opioid analgesics** (iv) Limited funding (v) Lack of coordination amongst services (vi) Uneven palliative care coverage. **Conclusion:** **Findings from the EAPC Eurobarometer survey suggest that barriers to the development of palliative care in Western Europe may differ substantially from each other in both their scope and context and that some may be considered to be of greater significance than others. A number of common barriers to the development of the discipline do exist and much work still remains to be done in the identified areas. This paper provides a road map of which barriers need to be addressed.**

**Keywords:** Palliative care; barriers; Western Europe

## **Introduction**

The *European Association for Palliative Care (EAPC) Task Force on the Development of Palliative Care in Europe* was founded in 2003 under the leadership of Dr. Carlos Centeno from the University of Navarra. The Task Force combines the expertise of the EAPC with that of the *International Observatory on End of Life Care (IOELC)*, *Hospice Information* (itself a partnership between *Help the Hospices* and St Christopher's Hospice, UK) and the *International Association for Hospice and Palliative Care (IAHPC)*.<sup>1</sup> A progress report on the work of the Task Force was published in 2004,<sup>2</sup> initial findings were first presented in 2006,<sup>3</sup> the *EAPC Atlas of Palliative Care in Europe* was published in 2007,<sup>4</sup> and the *EAPC Review of Palliative Care in Europe* appeared in 2008.<sup>5</sup> Associated articles have been subsequently published in peer-reviewed journals.<sup>6 7 8</sup> The work of the Task Force has also been utilised to compile a technical report for the European Parliament,<sup>9</sup> and a set of specific EAPC country reports are disseminated via the web pages of the EAPC, as well as via links from the web pages of other organisations participating in the Task Force.

The aim of the Task Force is to undertake a reliable and comprehensive analysis of palliative care developments within each European country, in order to generate and disseminate an 'evidence base' of clear and accessible research-based information concerning the current provision of the discipline across both countries and regions. It is hoped that this overview of palliative care provision, achievements and challenges will provide governments and policymakers with a new and improved understanding of the development of programmes to promote palliative care within the European region and that this will, in turn, assist the providers of palliative care services in a direct, practical way through the development of future policy and practice. The specific aim of this particular study is to identify barriers to the development of palliative care within Western Europe.

## **Methods**

From the outset, the Task Force sought to work collaboratively in a manner that would bring together experience from groups and institutions working to promote

palliative care in their own countries. The national palliative care association of each country was therefore requested to nominate someone with extensive local knowledge to participate in the project (for example, a chairperson or secretary). The EAPC Head Office, the IAHPC, Help the Hospices and the IOELC provided vital information in identifying national associations, local contacts, and key palliative care workers in each country and region who had studied the development of hospice and palliative care in their own setting and who could provide specific data to assist policy makers and planners; these organisations also provided valuable assistance in the compilation of the qualitative ‘Eurobarometer’ survey that was disseminated amongst the boards of national associations, eliciting opinions and views on opportunities for, and barriers to, palliative care development.

The *Eurobarometer Survey* was developed to gain insights into the views of key palliative care leaders across the 52 countries of the WHO European region in relation to the current state of palliative care in each country. This qualitative survey included questions on the strengths and weaknesses of palliative care at the country level, and aimed to show the achievements and breakthroughs that had been made in each jurisdiction. The survey had five main sections:

- Background questions (name, contact details, palliative care organisation, etc.);
- Questions on the current state of development of palliative care in each country (has improved; remained the same; got worse, etc.);
- Questions on barriers to, and opportunities for, the development of palliative care in each country (for example, availability of opioids; other issues relevant to the development of palliative care);
- Questions on policy (for example, national health policies; euthanasia and assisted suicide; *Recommendations on Palliative Care from the Council of Europe* (2003)<sup>10</sup>);
- Questions on the future of palliative care in each country.

A caveat was included within the survey to ensure that the participant was aware that the responses they provided would be assumed to reflect the vision of the palliative care organization that they represented; participants were therefore encouraged to

discuss details of the survey and their responses to it with colleagues prior to submission in order to provide as balanced a view as possible.

The resulting data were analysed thematically by geographical region and by the degree of development of palliative care. A thematic mode of analysis allows the participant to be centre stage, and as such was considered a suitable choice for this particular study.<sup>11</sup> Common themes were revealed in the survey through qualitative secondary analysis, data synthesis and ‘meta analysis’ of data findings. Initially, the survey responses were carefully reviewed in order to identify relevant concepts; these concepts were then sorted into potential themes, data relevant to each theme collated, and theoretical categories developed. Themes were modified and developed as survey data were revisited and analysis progressed. **The aim of categorizing in this manner was to satisfy the theoretical requirement of qualitative research through the development of theoretical categories arising directly from evidence expressing personal meaning.**<sup>12</sup> The overall aim of the categorizing process was to give meaning to the voices of respondents within the survey and to represent them as accurately as possible.<sup>13</sup>

In this paper, we focus on findings concerned with one part of the Eurobarometer Survey, relating specifically to 22/25 (88%) countries in Western Europe. Each country makes a contribution to this paper, although in some cases selected parts of text have been edited to improve the English language fluency. A list of Western European countries that did and did not respond to the Eurobarometer Survey are shown in Table 1.

**Table 1 Countries of Western Europe (2005)**

Countries of Western Europe (2005) n=25
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\*Andorra  
Austria  
Belgium  
Cyprus  
Denmark  
Finland  
France  
Germany  
Greece  
Iceland  
Ireland  
Israel  
Italy  
Luxembourg  
Malta  
\*Monaco  
Netherlands  
Norway  
Portugal  
\*San Marino  
Spain  
Sweden  
Switzerland  
Turkey  
United Kingdom

\* = did not respond to Eurobarometer  
Survey

## Results

Western Europe is a region generally thought to contain countries with well-developed palliative care networks,<sup>14</sup> yet significant barriers to the development of the discipline do exist. Whilst it is acknowledged that the barriers described within this paper may differ substantially from each other in both their scope and context and some may be considered to be of greater significance than others, a number of common barriers to the development of the discipline in Western Europe do exist: (i) Lack of palliative care education and training programmes (ii) Lack of awareness and recognition of palliative care (iii) Limited availability of/knowledge about opioid

analgesics (iv) Limited funding (v) Lack of coordination amongst services (vi) Uneven palliative care coverage.

*(i) Lack of palliative care education and training programmes*

Lack of palliative care education and training opportunities is the most frequently reported barrier to the development of palliative care in Western Europe (39 references by 19 different countries). In Finland, Austria, Belgium, Greece, France, Italy, Norway, Luxembourg, and Turkey, it is reported that an insufficient focus on palliative care within both undergraduate and postgraduate medical education results in a lack of University curricula and training programmes for health care professionals and medical students. **A similar situation exists in Malta, where it is reported that the lack of formal education for undergraduates combined with a lack of clearly defined career progression for doctors often results in medical graduates choosing not to enter palliative care. In Germany, it is reported that palliative care is not integrated into the obligatory syllabus for medical or nursing students, and that the majority of medical universities do not have their own university palliative care unit and are not obligated to organise tuition in the field of palliative medicine.**

Against this backdrop, shortages of a skilled palliative care workforce resulting from a lack of education and training are reported to be affecting the delivery of palliative care; for example, in Norway the lack of palliative care personnel is acknowledged, and in Ireland there is a shortage of certain grades of staff with specialist palliative care training. This is also the case in the United Kingdom, where difficulties are reported in the recruitment of doctors, nurses and allied health care professionals:

‘The UK is currently facing shortages of healthcare staff and this is affecting palliative care amongst other specialisms. Even when funding has been made available to support palliative care, services are not always able to grow as quickly as they would like because of the time and resources required to train new specialists. There is also a need for more training for generalist healthcare staff in palliative care’ (United Kingdom)

Lack of palliative care education and training programmes is reported as resulting in a dearth of research at the national level within Israel and also Iceland, where only a very limited number of journal articles have been published on palliative care and pain control. In Germany, research activities in the field of palliative medicine and palliative care are increasing, but still remain at an insufficient level with improved networking and increased funding and education in research required.

*(ii) Lack of awareness and recognition of palliative care*

Across the Western European region, respondents report a lack of awareness and recognition about issues of palliative care (19 references by 14 different countries). In Turkey and Greece, people are not very well informed about the discipline, with a similar situation existing in Denmark, where many people, including politicians still think it is about 'loving tender care' as opposed to highly qualified professional care. Even in countries where the public has developed an awareness of the discipline of palliative care, problems of perception remain:

'Even though there are information programmes of hospices and palliative care/medicine representatives, public awareness of palliative care services is not as good as it should (be)...According to a poll in 2004, only 3% of the public know what the term palliative care means' (Germany)

A degree of passivity on the part of medical professionals in many areas continues to be a potential barrier to the development of palliative care, and, as we have reported elsewhere,<sup>7</sup> the discipline lacks recognition in several Western European countries. Although there is limited palliative care accreditation provided by Universities and other academic organisations, policy makers and government departments fail to recognise the discipline as a medical or nursing specialty in Austria, Cyprus, Greece, and Netherlands. In Israel, although discussions on the certification of palliative medicine as a sub-specialty are progressing,<sup>15</sup> it has yet to be fully embraced into the traditional health care system. A similar situation is reported from Denmark, Iceland and Sweden, although there is some evidence that a process of palliative care certification is being developed in these particular countries. In Finland, it is reported that despite similar progress in relation to the certification of palliative medicine,

Ministry of Health recognition of the discipline remains essential to clarify the process of definition:<sup>7</sup>

‘Palliative medicine should have a (sub)speciality to be able to state what it is. One can not organise something which does not exist. So far anyone or any unit can call themselves a palliative care unit or specialist if there is no official recommendations and requirement. In general opinion, so far, all health care professionals can give palliative care – no need for specialised knowledge and organisation is needed. Therefore we need the speciality to be able to organise education and a specialised palliative care service’ (Finland)

Whilst there is information to show that there are some palliative care postgraduate courses and University diplomas in Italy,<sup>7</sup> the difficulty in providing services to a homogenous standard without adequate professional certification for physicians and nurses remains a potential barrier to the development of the discipline; **it is suggested that this virtual absence of professional certification fails to guarantee patients high quality palliative care services.** In Portugal, it is reported that there is little political will to implement palliative care, whilst in Spain a lack of political commitment to palliative care from some regional health ministries is described. The medical model was perceived as dominant according to most respondents in the survey, and was often seen to take priority over care for the dying patient; for example, in Turkey, a predominant focus on curative treatment is reported, whilst in France, the biomedical model is pre-eminent in medicine and in the plan against cancer. A similar story emerges from the United Kingdom:

‘The main barrier to the development of palliative care is also the reason it developed as a distinct specialism in the first place. It is the tendency of mainstream health services to focus on curing disease and saving lives and for this to mean that care of the dying is not given priority. Because improvements in quality of life are difficult to measure, palliative care has tended not to feature in national NHS targets...The tendency to focus on curing disease has also meant that many healthcare professionals perceive death to be a poor outcome and may not be comfortable discussing palliative care with patients because it is associated with dying’ (United Kingdom)

*(iii) Limited availability of/knowledge about opioid analgesics*

A frequently reported barrier to the development of palliative care in Western Europe is the limited availability of/knowledge about opioid analgesics (14 references by eight different countries). In Greece, Portugal, and Turkey, the lack of availability and choice of opioids is identified as a problem; the situation is similar in Malta **where diamorphine is available in state hospitals but not in privately owned pharmacies because of the fear of theft**. In Portugal, the prohibitive cost and the lack of available funding streams for the purchase of expensive opioids is perceived to be a significant barrier, whilst restricted availability of certain opioids in Greece is often related to issues of cost-effectiveness:

‘The pharmaceutical companies are not interested in distributing different kinds of opioids (newer agents) because [the markets] are not [profitable] for them’ (Greece)

**Both the United Kingdom and Ireland report a lack of availability of a range of opioids outside of standard working hours, whilst problems relating to legislation and government ‘bureaucracy’ concerning opioids come from Cyprus and Greece. A similar situation exists in Austria, where prescribing strong opioids requires the completion of a number of different forms and the provision of rigorous safeguards in relation to storage and distribution.**

**Lack of professional knowledge about the prescription of strong opioids amongst physicians and other health professionals is reported to be a problem in Austria, Cyprus, Finland, France, Germany, Israel, Italy, Netherlands, Norway, and Spain. In Luxembourg, despite optimal national availability of strong opioids, there is a lack of knowledge about their prescription and use amongst both doctors and nurses. The lack of knowledge relating to the prescription of opioids results in prejudices and an ‘opioid mentality’ among healthcare professionals in a number of countries (for example, Austria, Luxembourg, and Switzerland); this often results in reluctance and fear on the part of doctors to prescribe the necessary doses of opioids to patients, such as in Turkey, and also in the United Kingdom, where the high-profile conviction of Dr**

Harold Shipman, a GP who had murdered over 215 of his patients, may have made GPs more reluctant to prescribe diamorphine for their patients.

Respondents from nine countries (Austria, Belgium, France, Luxembourg, Netherlands, Norway, Switzerland, Turkey, United Kingdom) suggest the lack of knowledge about the use of opioids may result in irrational myths and negative stereotypes about the dangers of abuse; the close association between the use of opioids in palliative care and the psychological or physical problems of drug addiction/dependence has been prevalent for many years amongst members of the general public in these countries. The stigmatizing and taboo status of opioid use is reported as a barrier to the development of palliative care in Belgium, where there is a long-standing perception that the use of morphine inevitably leads to the death of the patient:

‘...a mental barrier is the taboo on morphine (as many times emphasised by Twycross); this is a vicious circle: “morphine is a killer” so we start too late due to the resistance of the patient, the family or the doctor; then the patient dies soon after first admission because death was so near and subsequently the reaction often is: “I told you the morphine would kill him”’ (Belgium)

#### *(iv) Limited funding*

A lack of sufficient funding for the provision of palliative care is perceived as a barrier to the development of the discipline in Western Europe (11 references by ten different countries). For example, lack of state funding is described as a barrier in Belgium, where there is insufficient financial support by the government for local and national initiatives and hardly any money for research in the field of palliative care. In Ireland, Israel, Netherlands, Switzerland, and Turkey, there is a reported lack of sufficient public funding for the provision of palliative care, with a similar situation in Germany where there exists a need to find funding from private and charitable sources to pay for establishing and maintaining palliative care services. Some respondents highlighted funding difficulties due to political bureaucracy; for example, in Austria where the necessary political motivation to spend more money on hospice and palliative care services is reported as being a very slow process. Insufficient

funding of palliative care services concomitant with a lack of clarity and transparency in the way in which funding is made available is reported from the United Kingdom:

‘Palliative care in the UK was pioneered by local hospice charities and was originally funded entirely from voluntary income. Over time, palliative care services have developed in both the NHS and the voluntary sector and the NHS has increased the contribution it makes to palliative care services. However, services in both sectors still receive a significant proportion of income from charitable sources. The NHS contribution is variable around the country, and tends to be a contribution towards costs rather than payment for a specific level of services...more resources will be needed to really mainstream palliative care practice across generalist healthcare’ (United Kingdom)

A number of respondents report that limited funding often results in education and training initiatives being abandoned; this may, in turn, result in a deterioration of service provision. In Greece, slow development and expansion of palliative care services in primary, secondary and tertiary health care due to limited funding is perceived to be a barrier to the development of the discipline; a similar story emerges from Belgium:

‘We try to develop guidelines, standards for (nurse) education and a national registration system. Due to lack of means most of this is executed by a few enthusiastic people in their spare time. The danger is that lack of means leads to the development of systems that are not sufficiently professional based’ (Belgium)

*(v) Lack of coordination amongst services*

The lack of effective coordination amongst different bodies responsible for the delivery of palliative care services is often reported as a barrier to the development of the discipline in Western Europe (11 references by nine different countries). For example, in Austria there a number of different authorities responsible for implementation of the required services (federal and regional authorities, social health insurance and retirement pension insurance companies). In Ireland, the lack of

coordination amongst palliative care providers may make it difficult to deliver an integrated health care service and homogeneous standards of palliative care in the future. The lack of a coordinated referral system to access palliative care services is a potential barrier to the development of the discipline in Malta, where reluctance on the part of doctors to refer patients to palliative care services is deemed to have an adverse affect on patient care. Lack of coordination between state and voluntary services is reported in Greece, Finland, and Italy:

‘The devolution of many political decisions concerning health care from the central government to the regional government had made it difficult to propose homogeneous standards for the provision of palliative care with the development of very different reimbursement and accreditation models all over the country...In some cases this leads to different attitudes of non-profit organizations which have been developing models of care providers in competition with and in substitution to hospital-based and NHS professionally driven models’ (Italy)

There is a lack of a national coordination board in Luxembourg, whilst in Portugal it is reported that although there is a pain network and a palliative care network written into public documents, these are not adequately implemented in the field. Inadequate national standards to regulate and determine the quality of palliative care provision are also reported as a barrier to the development of the discipline in the Netherlands.

Lack of coordination between different medical specialties and disciplines is a barrier to the development of palliative care in a number of countries; for example, in Italy:

‘[There is] strong debate among oncology, anaesthesia and other medical specialties to keep control of palliative care services...At the moment depending on regional differences palliative care services are directed by oncologists or by anaesthesiologists...[there is] continuous debate with GPs about their role in palliative care in integration with specialist services...There is a danger of bureaucratization...in a way that the revolutionary role of palliative care within modern medicine is lost or is confined in few “excellence” centres’ (Italy)

*(vi) Uneven palliative care coverage*

Uneven palliative care coverage is the least reported barrier to the development of palliative care in Western Europe (seven references by seven different countries). In Germany there are a considerable number of palliative care services, though not enough to cover the needs of the population; the distribution of services is also uneven, and in some areas there exists a substantial number of 'blind spots'. The inability to provide comprehensive coverage is also reported from Greece, where it is stated that at a national level, much still needs to be done to achieve the required coverage. Similar problems in relation to the distribution of palliative care are being experienced in Finland, and also in Switzerland, where many cantons do not have any palliative care services. In Turkey, it is reported that a wider range of palliative care programmes is of paramount importance, whilst in Denmark, palliative care appears to be occurring spasmodically across the country, rather than according to any specific strategy; this often results in counties with little coverage:

‘...the development (of palliative care) has been very unevenly spread in the country, in some counties there is still no specialist palliative care service, in some the so-called specialist palliative care service is very far from WHO and international standards...It is a good thing to have hospices, but the government seems to believe that the palliative care needs are covered by 12 hospice beds in each county’ (Denmark)

One of the reasons why there is uneven coverage in a number of countries in Western Europe is an absence of sufficient public funding. In the United Kingdom, this factor is reported to affect the ability to provide comprehensive palliative care coverage:

‘The level of investment through personal giving has enabled palliative care services to develop more rapidly than they would have done if they had been entirely reliant on public funding. The disadvantage has been that these developments have been located where there was a public will and the means to do so, rather than following any strategic plan. This may leave some areas underprovided for compared with others’ (United Kingdom)

## Conclusion

Data collected in the Eurobarometer survey reveal a number of barriers to the development of palliative care in the countries of Western Europe (Table 2).

**Table 2: Most frequently reported barriers to the development of palliative care in Western Europe**

<b>Most frequently reported barrier to the development of palliative care</b>	<b>Number of references by number of different countries</b>
Lack of palliative care education and training programmes	39 references by 19 different countries
Lack of awareness and recognition about palliative care	19 references by 14 different countries
Limited availability of/knowledge about opioid analgesics	14 references by eight different countries
Limited funding	11 references by ten different countries
Lack of coordination amongst services	11 references by nine different countries
Uneven palliative care coverage.	Seven references by seven different countries

The barriers identified differ considerably in scope and context, and of course some are more significant than others. For example, in countries where palliative care is not integrated into undergraduate and postgraduate education and training programmes for medical students and other health professionals, lack of awareness and recognition of the discipline may continue unabated, and the discipline is thereby rendered ‘invisible’ amongst other medical specialties. This lack of education and training programmes, combined with the absence of clearly defined career progression for doctors within palliative care, often results in medical graduates choosing not to enter the discipline. In turn, an inability to deliver homogeneous standards of palliative care in a country due to the lack of suitably qualified staff may result. A lack of palliative care education and training programmes may also result in limited knowledge about opioid analgesics amongst health professionals (for example, in the prescription of opioids for pain control) and in a dearth of research at the national level.

Similarly, limited funding impacts upon the provision of palliative care in a variety of ways; for example where a lack of coordination between services leads to different reimbursement and accreditation models being developed. Inadequate funding often results in palliative care services occurring spasmodically across the country, rather than according to any specific strategy or plan, and this may leave some areas underprovided for compared with others. Limited funding also circumscribes the availability of opioid analgesics in some countries, and may lead to the development of education and training systems that are not sufficiently professional-based or that are abandoned completely.

There are a number of instances where barriers may intertwine and interconnect with each other. For example, a lack of palliative care education and training concomitant with a lack of knowledge about the use of opioids may result in the promulgation of irrational myths and negative stereotypes about the dangers of opioid abuse amongst health professionals. A lack of awareness and recognition of palliative care can result in uneven coverage in countries where services that are promoted as ‘specialist palliative care services’ are far removed from established international standards, or where governments consider that the palliative care needs of the population are covered by a small number of hospice beds in each area. Within this context, the restricted focus on resources allocated solely for hospices may be a potential barrier to the provision of palliative care for the wider population; for example, in some Western European countries, palliative care is still rarely integrated into hospital departments or nursing and care homes. Lack of government awareness and recognition of palliative care often means that the political will necessary to generate funding is absent or that palliative care does not feature in government financial targets.

Findings from the EAPC Eurobarometer survey suggest that barriers to the development of palliative care in Western Europe may differ substantially from each other in both their scope and context and that some may be considered to be of greater significance than others. A number of common barriers to the development of the discipline do exist and much work still remains to be done in the identified areas. This paper provides a road map of which barriers need to be addressed.

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The following countries in Western Europe were invited to participate in the Eurobarometer survey but returned a nil response:

- Andorra
- Monaco
- San Marino

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