Palliative care in Europe: experiences and the future

Lukas Radbruch, President of the European Association for Palliative Care (EAPC), looks at what needs to be done to set up common goals and norms for palliative care in Europe

Fifteen years ago, at the age of 35, Gisela was treated for cancer of the choroid membrane of the left eye. She had been disease-free after surgery, with enucleation of the eye, until liver metastases were discovered a year ago. Surgery and multiple courses of chemotherapy did not prevent progression, and lung metastases were discovered a few months later. She lost weight and suffered from severe fatigue. She was admitted to a palliative care unit because of severe pain from bone metastases in her lower back and left hip.

Pain management included low-fraction radiotherapy, an increase in the dosage of transdermal fentanyl from 125 to 150 µg per hour and the addition of a non-steroidal analgesic. This regimen resulted in significant pain relief. However, there were other problems that distressed the patient. She complained of severe fatigue, but rejected treatment of anaemia (7.6 mg per 100 ml) with blood transfusions. She wanted to go back home, but her GP had made it clear that he would not continue treating her because there were some unpaid bills. Her husband was not informed adequately about her diagnosis and prognosis, but she did not want him to be given more details as she thought he would not be able to cope. She was worried about the future of her two children, aged 14 and 29. She said that she wanted to be fully informed, but had suppressed her own knowledge of her lung metastases. These problems were addressed by repeated talks between the staff, Gisela and her husband. Home care was organised by the palliative care team before she returned home.

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In 2008, the European Association for Palliative Care (EAPC) had collective members from 41 national associations representing 50,000 healthcare workers and volunteers

Key points

- Palliative care is about management of pain and other symptoms, but also about psychological, social and spiritual problems. It is about co-ordination and continuity of care in different settings and across the disease trajectory.
- The lack of a common language and differences in the understanding of key concepts of palliative care have recently been identified as major barriers to the development of palliative care in Europe.
- Working closely with the national palliative care associations, the European Association for Palliative Care (EAPC) intends to define common goals (the Budapest Commitments), as well as common norms and a common language for palliative care in Europe.
- An ethical framework supported by the European institutions is required, for example establishing a right for care leave, rejecting legalisation of euthanasia or providing clear guidance on treatment withdrawal.

She was discharged home after 17 days of inpatient treatment, but had to be readmitted eight weeks later because of recurrent pain and dyspnoea. Opioid dosage was increased significantly, to 400 µg per hour of transdermal fentanyl. In addition, she required rescue medication, with a bolus dose of 60 mg oral morphine for breakthrough pain and dyspnoea repeatedly. This time she did not want to go back home, and was transferred to an inpatient hospice after 15 days. She died in the hospice four days later with good symptom control.

What palliative care is about

This case report – based on a presentation given at the European conference, 'The burden of cancer – how can it be reduced?', organised under the Slovenian presidency of the European Union in Brdo, Slovenia, on 7–8 February 2008 – emphasises what palliative care is about. It is about management of pain and other symptoms, but also about psychological, social and spiritual problems. It is about co-ordination and continuity of care in different settings and across the disease trajectory. It is about interdisciplinary and cross-sectional teamwork involving staff from different healthcare professions as well as volunteer services. It also includes carers, both in their role as partners in the team and as family members who require care and support.

Palliative care needs

Data from several surveys show the wide range of palliative care needs. A survey of German palliative care units showed pain (58% of patients) and other physical symptoms (55%) as the most frequent reasons for admission, but problems with nutrition (36%), nursing (15%), social or psychological problems (14% respectively), terminal care (16%) and other problems (19%) were also documented. Most importantly, 74% of patients had reasons for admission documented in more than one area.[1] Most patients suffered from cognitive or physical impairment, or a combination of both.

Caring for patients with complex needs and a multitude of symptoms and problems requires a holistic approach, using multiprofessional teams with good knowledge of symptom control, adequate communication skills and an attitude focused on patient empowerment.

The development of modern hospice and palliative care was initiated in 1967, when Dame Cicely Saunders founded St Christopher's Hospice in London. Since then, palliative care has been introduced in most European countries. However, there is a wide variety in the degree of implementation, and few countries have reached the stage of development that has been achieved in the UK. The lack of a common language and differences in the understanding of key concepts have recently been identified as major barriers to the development of palliative care in Europe.[2]

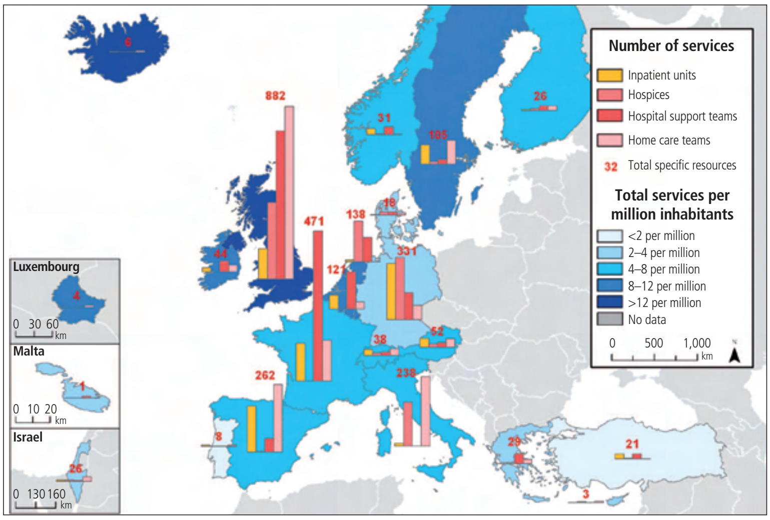

Figure 1. The number of palliative care services in Western European countries (taken from the *Atlas of Palliative Care in Europe*[4])

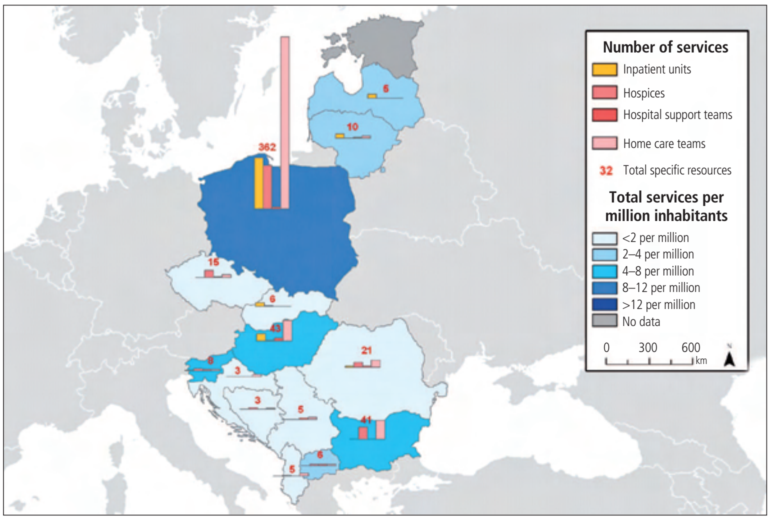

Figure 2. The number of palliative care services in Central and Eastern European countries (taken from the *Atlas of Palliative Care in Europe*[4])

Palliative care at a European level

The European Association for Palliative Care (EAPC) was established in 1988 with the aim of promoting palliative care in Europe and acting as a focus for all of those who work in, or have an interest in, the field of palliative care at scientific, clinical or social levels. In 2008, the EAPC had individual members in 40 countries and collective members from 41 national associations in 25 countries, representing 50,000 healthcare workers and volunteers. It is a non-governmental organisation recognised by the Council of Europe.

Every second year, the EAPC organises palliative care congresses with more than 2,000 participants. In the intervening years, it runs a Research Forum with a high scientific standing [see pages 179–181 the report on the 5th Research Forum]. The EAPC has commissioned several task forces, such as the Task Forces on

Ethics and on Medical Education and the Task Force for the National Associations. It has also prepared curricula in palliative care for training nurses and undergraduate medical students.

The Atlas of Palliative Care in Europe

The Task Force on the Development of Palliative Care in Europe,[3] led by Carlos Centeno and David Clark, has recently released the *Atlas of Palliative Care in Europe*, containing detailed reports on the state of palliative care in all European countries (see Figures 1 and 2, page 187).[4] The Atlas presents a comprehensive review of the development of palliative care in Europe. From these data, a comparison between countries can be made. It shows, for example, that there are more palliative care services in the UK, Ireland, Iceland and Sweden than in Central and Eastern European countries – although Poland has managed to reach a state of development superior to that of many Western European countries.

More complex evaluations have also been presented by the Task Force, for example through the Euro-Barometer of Palliative Care.[5] This benchmarking system combines the level of care provision with other parameters, such as the number of publications on palliative care, the existence of a national association, the accreditation of specialty or sub-specialty training and the availability of potent opioid analgesics. Using the UK as the gold standard, other European countries lag far behind and will have to invest considerable resources to reach the same level of palliative care (see Figure 3). The Euro-Barometer shows clearly the work they need to do to achieve this.

The Budapest Commitments: set up common goals

In June 2007, at its 10th Congress in Budapest, the EAPC – in close collaboration with the International Association for Hospice and Palliative Care (IAHPC) and the Worldwide Palliative Care Alliance (WPCA) – launched the Budapest Commitments, a campaign with a political initiative.[6] Representatives of the national associations had been invited to participate in an initial meeting to reach a consensus.

They have been asked to define clear goals within a common framework, and to commit themselves to reach these goals within the next two years. The framework covers five domains: access to medication, policy, education, quality and research; it allows the national associations to focus on the domains that they deem most important considering the level of palliative care in their respective countries.

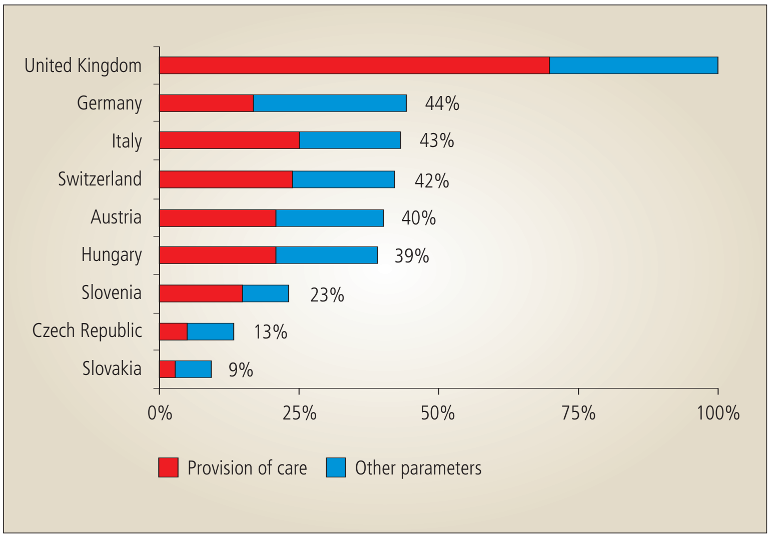

Figure 3. The Euro-Barometer of Palliative Care (adapted from[5]). The UK is defined as the gold standard with 100% of development

The Budapest Commitments campaign will benefit from the synergies and motivation arising from the collaboration between the national associations, who will be allowed to get inspiration from each others' projects and methods. The campaign will receive continuous support from the EAPC Task Force for the National Associations, chaired by David Praill, that will help the associations in their advocacy activities. First results will be presented at the 11th EAPC Congress in Vienna in May 2009.

Common norms for a common language

As a second important step, supporting and extending the Budapest Commitments and addressing the lack of a common palliative care language in Europe, the EAPC plans to produce European norms. It has given a remit for a White Paper on norms containing guidance and recommendations for service providers, stakeholders and decision-makers.

The EAPC will propose norms rather than standards. Standards (minimal norms) would set rigid limits with cut-off values, implying that services not achieving these standards would loose their specialist status. The EAPC norms (aspirational norms) will affirm how things ought to be in order to provide high quality palliative care, but services that do not meet them – because of local or regional situations – will not be discriminated against. Considering the different healthcare systems and cultural backgrounds, it does not seem possible to agree on standards in 20 countries or more. But a consensus on norms does seem a realistic goal.

The EAPC will develop these norms in close collaboration with the national associations, who will be asked to indicate their level of agreement or disagreement with each suggested norm using a standardised consensus method (Delphi procedure). Using the feedback from the Delphi process, the EAPC will then prepare and endorse a set of widely accepted norms.

Support from European institutions

Through these various projects, the EAPC helps national associations in their advocacy work and healthcare professionals in their practice of palliative care. In addition, it needs to raise the support of the European institutions – the Council of Europe, the European Commission and the European Parliament. Their involvement is needed to support palliative care, empower patients and families, and develop palliative care (see Box 1).

Box 1. Areas where support is needed from the European institutions

Support palliative care

- Support the European Association for Palliative Care (EAPC)
- Support standards and norms of the EAPC
- Support Recommendation 24 of the Council of Europe[7]

Empower patients and families

- Provide access to palliative care for all those who need it
- Establish palliative care as a human right

Develop palliative care

- Include palliative care in a European research agenda
- Establish long-term research collaboratives
- Develop an ethical framework for palliative care

Support of palliative care should include support of existing networks, led on a European level by the EAPC. More specifically, norms and standards of the EAPC should be presented to the European institutions for implementation in their political work. Existing documents, such as Recommendation 24 of the Council of Europe,[7] should be acknowledged by all work groups within the European institutions.

Empowerment of patients and families includes, foremost, the access to palliative care for all those who need it. Palliative care should be available at different levels (palliative care approach, specialist palliative care) and in different settings (home care, inpatient units). An important step towards adequate access for all would be the acknowledgement of palliative care as a human right; 'Hospice and palliative care: a human right' is the theme of the next World Hospice and Palliative Care Day on the 11 October 2008 (www.worldday.org).

Developing palliative care in Europe requires the inclusion of palliative care in a European research agenda. Recently, several large research collaboratives have received grants from the 6th and 7th Framework Programmes for Research and Technological Development, and from the Public Health Executive Agency (PHEA). These collaboratives reach critical mass and will lead to a steep increase in the quality and amount of palliative care research in Europe. However, without long-term funding, they will not be able to continue, and experiences and collaborations that have been put in place will be lost once more.

An important step towards adequate access for all would be the acknowledgement of palliative care as a human right

Developing palliative care throughout Europe also requires an ethical framework supported by the European institutions, for example establishing a right for care leave, rejecting legalisation of euthanasia or providing clear guidance on treatment withdrawal.

These goals can be achieved with a strong commitment from decision-makers in the European institutions and other national or European stakeholders. To summarise it in the words of David Tasma, the first palliative care patient of Dame Cicely Saunders: 'I only want what is in your heart and in your brain'.

References

1. Radbruch L, Nauck F, Fuchs M *et al*. What is palliative care in Germany? Results from a representative survey. *J Pain Symptom Manage* 2002; **23:** 471–483.
2. Von Gunten CF. Humpty-Dumpty Syndrome. *Palliat Med* 2007; **21:** 461–462.
3. Centeno C. Latest report from the EAPC Task Force on the Development of Palliative Care in Europe. *European Journal of Palliative Care* 2006; **13:** 149–151.
4. Centeno C, Clark D, Lynch T *et al*. EAPC *Atlas of Palliative Care in Europe*. Houston: IAHPC Press, 2007.
5. Centeno C, Clark D, Lynch T *et al*. Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC Task Force. *Palliat Med* 2007; **21:** 463–471.
6. Radbruch L, Foley K, De Lima L, Praill D, Fürst CJ. The Budapest Commitments: setting the goals – a joint initiative by the European Association for Palliative Care, the International Association for Hospice and Palliative Care and Help the Hospices. *Palliat Med* 2007; **21:** 269–271.
7. Council of Europe. Recommendation Rec(2003)24 of the Committee of Ministers to member states on the organisation of palliative care. Adopted by the Committee of Ministers on 12 November 2003 at the 860th meeting of the Ministers' Deputies. http://www.coe.int/t/dg3/health/recommendations_en.asp (last accessed 19/06/08)

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