Transforming research into action:

A European Parliament report on palliative care

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Summary: The authors of a European Parliament report on palliative care summarise the process of the five-month investigation, as well as the real and potential results of the study. Engaging a large number of national and international stakeholders, including ministries of health, national palliative care associations and the European Association for Palliative Care (EAPC), we were able to draw on a well of previous research and diverse experiences before formulating operative policy options for the EU and its Member States. While the report itself fomented some self-examination in the countries studied, its full exploitation by palliative care advocates is still pending.

Key words: palliative care, Europe, European Parliament, health systems, health policy and management

The European Parliament has recently published an external report, *Palliative Care in the European Union*.[1] As the main researchers in this endeavour, we examine the unique nature of the palliative care field, including the important role of multidisciplinary teams, psycho-social care, volunteers, palliative care training for general practitioners (GPs) and other specialists, and the challenges faced by patients with terminal illnesses. Delving into the individual palliative care structures among European countries, we found a pronounced heterogeneity in the way in which national health systems care for their dying, as well as the quality and access of the care provided, not only between countries, but also within them. The report concludes with a wide variety of policy options which are intended to present ideas, stir debate and stimulate creative proposals among decision-makers in their efforts to improve the care offered to patients at the end of their lives.

The study was, in part, conceived as a follow up to the *Recommendation Rec (2003) 24 of the Committee of Ministers to Member States on the organisation of palliative care*. That initiative, the most ambitious to date, made recommendations for palliative care development in the fifteen countries then making up the European Union. The next four years brought the expansion of the EU to its current twenty-seven countries, as well as advances in the palliative care field across the continent. These dynamic changes spurred the European Parliament Committee on Environment, Public Health and Food Safety to issue a closed invitation to tender in October 2007 for a new external study on palliative care in Europe, to be managed by the Economic and Scientific Policy Department.

The following December, one of us (Jose M Martin-Moreno, a medical doctor and public health specialist) was commissioned to lead the investigation. He assembled a multi-disciplinary team which included specialists in palliative medicine with extensive experience in comparative palliative care studies and an expert in health system economics. We also had the support and active participation of the European Association For Palliative Care (EAPC) through its president, Dr Lukas Radbruch, and other expert members. The EAPC proved to be a crucial partner in the initiative, as information was freely and collegially exchanged with the mutual objective of contributing at a policy level to the improvement of patient care.

Study objectives

The proposal to the European Parliament fitted closely to its stated wishes, with an increased focus on the elements characterising the palliative care field (see Box 1) and a brief description of the situation in the twenty-seven EU countries. A standard template was used in the country profiles to facilitate comparison, and an original and complex ranking system was formulated with information from the EAPC in order to measure the relative progress and vitality of each country's palliative care structures.

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Box 1. Areas of assessment

- Availability and access, including place of care, paediatric palliative care and availability of opioids
- Integrated health care networks
- Human resources, including GPs, nurses, palliative care and paediatric palliative care specialists, psychologists, social workers and volunteers
- Quality assurance
- Emotional and psychological support
- Legal and policy provisions
- Financial planning models
- Best practices

Methodology

Due to the short time frame for the study (five months), the limited space requested by the European Parliament (fifty pages) and the broad scope and impact of the study, conciseness and efficiency were as important as up-to-date accuracy. With this in mind, the research team took three steps that simultaneously maximised efficiency and enriched the final text.

First, a comprehensive search of scientific and grey literature was surveyed. Synthesising and analysing this information, we were able to depict a relatively accurate picture of the situation in European countries, as well as describing some of the key areas of assessment. A few of the principal sources used in this endeavour, especially for the country profiles, were the *EAPC Atlas of Palliative Care in Europe*,[2] *Helping People at the End of their Lives*[3] and *Transitions in End of Life Care*.[4] This research also helped identify national policies which have already been proven successful in improving quality of life for European patients; these positive national experiences are the backbone of the policy options at the end of the report.

In order to update the secondary data gathered, we directly contacted all ministries of health and palliative care organisations throughout the EU to obtain primary data on the organisation of palliative care in their countries. After two rounds of contact letters and emails, nearly forty responses were received from twenty-six European countries, allowing us to update our findings with current figures and developments. These reflected the vitality of the palliative care field and also highlighted the need for regular comparative studies to document the achievements. Although the EAPC Atlas was published with data from 2006, our contacts with national stakeholders showed that much progress and many changes had occurred in the following two years.

Interestingly, the responses received from health authorities in many countries with little palliative care development were quite candid, acknowledging that palliative care had received little attention in their health system but also recognising its importance. This circumstance suggests the pro-active effect that this type of report can stir, stimulating national policy-makers to consider bringing a palliative care agenda to the table. The involvement also provided the opportunity for health authorities to explain the strengths and weaknesses of their national model, as well as allowing for palliative care associations to express their ideas, frustrations and successes.

Finally, a number of European specialists were invited to make special contributions to the final text, detailing their area of expertise and the pending challenges to tackle. They included Franca Benini (paediatric palliative care), Marilène Filbert (GP training), Phillip Larkin (nurse training), Inmaculada Martín-Sierra (social work), Marina Martínez (psychologist training), David Oliviere (volunteers), Lukas Radbruch (quality assurance and best practices), Stein Kaasa (research) and Luzia Travado (psychological support). Channeling these contributions into a broader public health-based approach, we aimed to synergise solid research evidence with operational health system policies.

Findings

The wide participation in the formulation of this document ensured that the conclusions truly reflected the diversity, but also the inequalities, of the European reality. Palliative care structures vary widely, as different cultures deal with death in different ways. England is the cradle of the 'hospice', while France initially developed services in hospitals. Other countries, such as Ireland and Hungary, concentrate their resources on providing home-care teams, whereas Belgium and the Netherlands are increasingly investing in day centres and nursing homes. Grassroots movements have been responsible for palliative care development in Poland, while government intervention was the key in the Netherlands. Inequalities within countries vary as well; rural/urban divisions, regional socioeconomic status and decentralised governance seemed to be the most important factors, although economic resources should not be discounted.

The needs of patients with terminal illnesses, however, are strikingly similar: high quality multi-disciplinary care with clear pathways and lines of communication between the care team, the patients, their loved ones and other related professionals; treatment options which allow them to stay in their homes as much as possible, reducing suffering and respecting their wishes; and a social network which actively includes patients and their families in a supportive community.

Europe could play an important role in some of these key areas: currently, there are neither accepted standards nor evidence-based solutions to measure the quality of a programme. Official certification for professionals is not available in most countries. It would be ideal if palliative care were recognised on the same terms as other social and health care structures, thereby ensuring funding and investments in organisation. European support for these objectives would be welcome, both by patients and professionals in the young palliative care field. Furthermore, it is our hope that by directly engaging high-level stakeholders in the formulation of the report, we have opened a new door to the self-examination of palliative care services within the different national health systems.

Policy options

With this in mind, and knowing that the European Parliament was not looking for a prescriptive solution, but for a range of operational alternatives, we presented three policy options based on solid data and experience collected and documented during our investigation. The first was a conservative, horizontal approach, which in theory could be accomplished by simply acknowledging palliative care as a medical field. A second strategy was a recommendation to Member States on further actions to take; this has been an effective tool in the past to promote development in targeted areas while respecting national sovereignty. A third course of action was to intervene directly with European legislation. These tactics were detailed fully in the report and are summarised in Table 1.

Discussion

The proposals were presented to the European Parliament; however, many of the ideas are relevant for national policy-makers as well. We believe that the report itself constitutes a potentially effective tool for

Table 1. Policy options to advance palliative care in the European Union

Strategy	Course of action	Advantages	Disadvantages
Conservative and horizontal approach	• Ensure that palliative care is recognised as a medical field • Bolster general measures to improve health care delivery, such as reducing waiting times and declaring a Patient s Bill of Rights	Minimise bureaucracy and increase flexibility in innovation and treatment decisions	Given the lack of development in many countries, this approach may not be enough to guarantee quality or access.
Recommendations to Member States	Some possible recommendations: • Formulate national plan on palliative care • Increase investments in training and research • Improve accessibility and proper use of opioids • Promote integrated health care networks • Facilitate specialist accreditation • Identify and promulgate best practices • Forge partnerships within and between countries	This could be an excellent tool for advocacy in many Member States while respecting some countries wishes for no new legislation. It could also pave the way for recognised guidelines in Europe.	Because it is important to ensure some degree of harmonisation in such an important field, this plan may fall short.
New European legislation or directives	Possible areas of legislation: • Guarantee equal rights for all patients • Ensure availability of opioids • EU action plan and monitoring system • Declare palliative care to be a human right • Create a dialogue with Member States to discuss priorities and identify challenges • Establish a European platform to stimulate research • Establish an interface between research and policy • Create a European Reference Centre or European Institute of Palliative Care • Promote cross-border cooperation and patient mobility	Direct European Parliamentary involvement would work to make palliative care a priority on the European agenda and would bring about an enormous advance where palliative care is currently not very developed. Investments, especially in research and training, would provide welcome stimulus to the field.	Harmonisation efforts could be problematic for countries whose palliative care programmes are already developed. Additionally, European competence in national health systems has yet to be solidly established, which would make some of the proposals very difficult to achieve.

lobbying efforts, and we continue to support its dissemination. In May 2008, the results were presented at the 11th Congress of the European Association for Palliative Care in Vienna, where the team leader reiterated his encouragement for its use in the national and European context. For governments with limited experience in palliative care policy, section two of the report, detailing the basic elements of a successful programme, is a useful summary and builds the foundations of knowledge to begin debating on what policies would work best in their country context. Section three provides a concise quantitative and qualitative comparison on service provision in Member States. It provides an idea of what is possible within limited resources. Section four, covering best practices, has a benchmarking function and aims to both recognise merit and stimulate interest in successful initiatives. Finally, the conclusions and policy options set out a flexible and adaptable plan of action to move forward.

Unlike other issues which have received more rapid attention from the European Parliament following the publication of an independent report, palliative care has yet to be added to the agenda. Particularly now, as the world financial economy teeters and the EU and Member States struggle to find a coherent response, it will be challenging to return palliative care policy to the European and national stages. However, the ageing of the population means that this issue will gain relevance rather than lose it in the coming years. Local activism has been the principal engine of palliative care development in most European countries since its beginnings in the late 1960s in England, and it must continue to be so for the sake of patients and their loved ones. Real development in Europe will not be the fruit of this report, but rather the result of how it is utilised, in combination with other advocacy tools, to raise awareness, disseminate knowledge, and fight for lasting change.

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