

VIEW FROM THE OBSERVATORY

The International Observatory on End of Life Care: A New Research and Development Initiative in Palliative Care

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Introduction

We describe here a major new initiative in palliative care research and development – the work of the International Observatory on End of Life Care. In subsequent issues we will provide ongoing commentary about this work through a regular update.

The global context

Around the world more than 1 million people die each week. It is estimated that 60% of these could benefit from some form of palliative care. Yet at the moment only a tiny minority of dying people ever receive the support of hospice and palliative care services and unrelieved suffering persists on a large scale. Palliative care is hugely underdeveloped in most resource-poor countries, and it is still significantly constrained even in many countries with otherwise ‘advanced’ healthcare systems. At the same time there is a significant shortage of political leaders and ‘product champions’ with an interest in palliative care and we lack national and international policies to promote its development. The creation of a trained multidisciplinary workforce to deliver clinical care, educational programmes to support them, and an evidence base to highlight both unmet need and the efficacy of existing provision are all additional challenges.

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Now more than ever, it is a time to be thinking globally, as well as acting locally.

A new research and development initiative for end of life care

With these issues in mind, plans are under way to establish a programme of activity focusing on comparative research-based information relating to hospice/palliative care around the world. The programme will seek to generate such data from original studies, collate material gathered elsewhere, and above all turn this into useful *intelligence* that can influence current policy and service development.

The International Observatory on End of Life Care: www.ioelc-observatory.net

From September 2003 the International Observatory on End of Life Care (IOELC) is to be established at Lancaster University, UK, within the Institute for Health Research. It will be led by David Clark, working with a team of collaborating researchers at the University and in partnership with colleagues and organisations in many parts of the world. In addition to the Observatory’s project-based research and development programme it will also house the digital and paper archives of the well-known ‘Hospice History Project’ and contain an extensive collection of current reference materials.

Aims of the Observatory

- To provide clear and accessible research-based information on hospice and palliative care provision in the international context, incorporating public health, demographic, epidemiological and healthcare systems analysis as well as ethnographic, historical and ethical perspectives.
- To disseminate this information through the Observatory website and through published articles, monographs, reports, CDs and other media, in ways that facilitate cross-national comparative analysis and stimulate practical development.
- To undertake primary research studies and reviews to generate such information.
- To develop a small grants programme to support academic work relating to the aims of the Observatory in resource-poor regions.
- To work in partnership with key organisations and individuals, nationally and internationally, in order to foster a sense of inclusion and participation in the work of the Observatory.

Features of the Observatory

The idea builds on other 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. Its starting point has been a major review of hospice and palliative care in some 28 former communist countries of Eastern Europe and Central Asia (1) and this in turn has built on another comparative study of palliative care development in Western Europe (2).

The Observatory website is located at: <http://www.eolc-observatory.net> (3). From the home page, information can be accessed on individual countries via an alphabetical list or a world map. For each country, information is organised into the following four main themes, each of which has its own sub-themes as indicated (4):

- Palliative Care service provision:
 - Current services.
 - Reimbursement and funding for services.
 - Opioid availability and consumption.
 - National and professional associations.
 - Palliative care 'coverage'.
 - Palliative care workforce capacity.
- History and development of palliative care services:
 - Narrative history of palliative care.
 - Hospice/beacon case studies.
 - Life/oral histories.

- Public health context:
 - Population.
 - Epidemiology.
 - Healthcare system.
 - Political economy.
- Ethics and ethnography:
 - Ethical issues.
 - Ethnographic studies.

All pages are fully referenced and lists of further reading are available.

Each country has a home page with a brief description of the geo-political situation and a map. Information on the sub-themes can be accessed via drop-down menus for each main theme on a menu bar. Figure 1 shows the home page for Hungary together with the drop-down menu highlighted for 'Opioid Availability and Consumption' within 'Palliative Care Service Provision'.

From any given sub-theme the user can cross-reference to the same information for another country by using the pop-up menu entitled 'Choose a country' located beneath the list of themes in the frames section (Figure 2).

In this way, the website can be explored 'vertically' (by country) and 'horizontally' (by theme or sub-theme).

Figure 1. Home page for Hungary on the IOELC demonstrating the drop-down menu facility

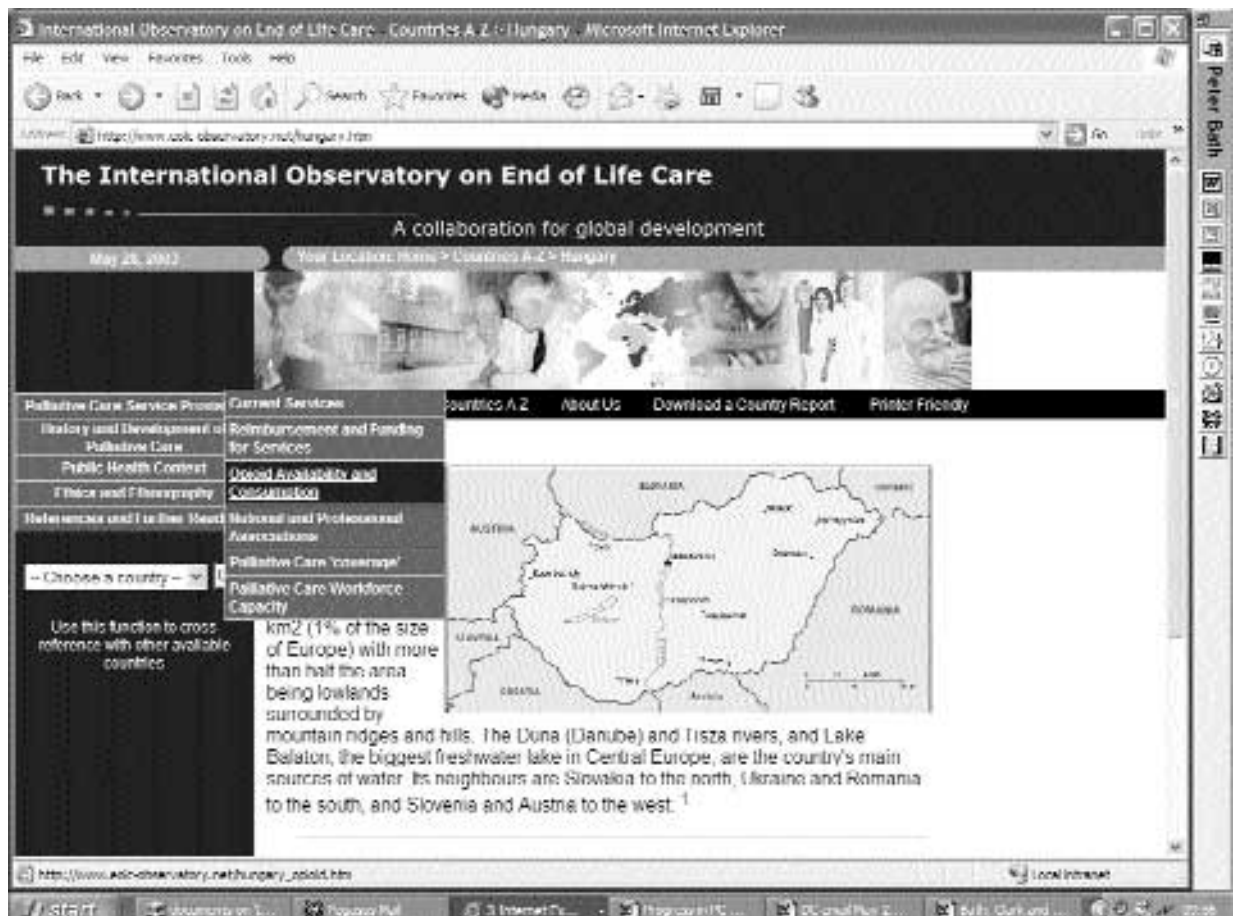
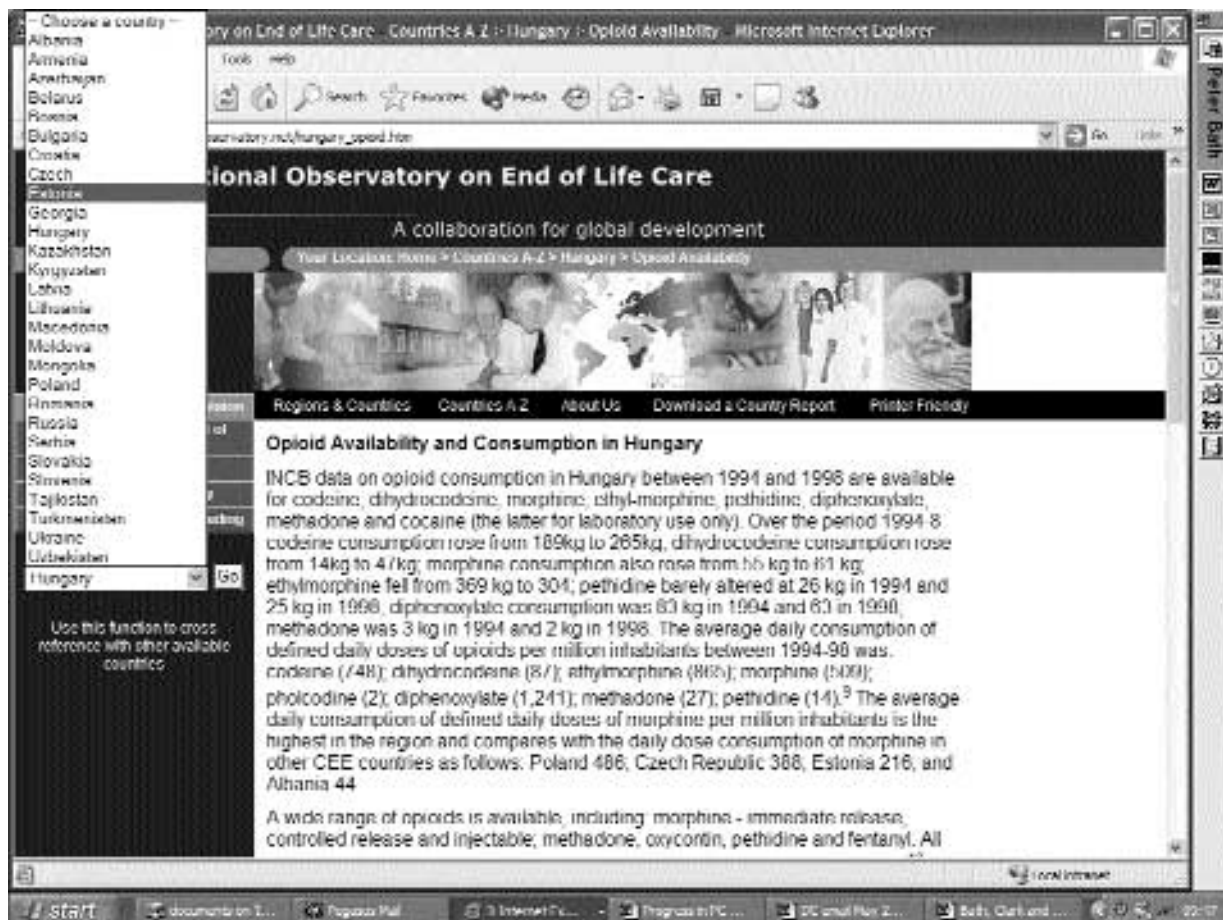


Figure 2. Information on ‘Opioid Availability and Consumption’ for Hungary in the IOELC, showing the pop-up menu to access the equivalent information for other countries



Additionally, there is a facility to download and print off PDF files of entire country reports from a central point and with only a limited number of mouse clicks. There are also links to other important websites. Our vision is that in time the Observatory website will be further enhanced by the incorporation of primary data gathered in original studies – such as interview summaries, PDF files of key documents and bibliographies – and that multimedia will be used to include audio, and image, as well as textual data. In particular we hope to expand the number of country entries to give a truly global picture of palliative care. The website will also contain: the current set of Hospice History Project web pages (www.hospice-history.org); those of Mortal Press (www.mortalpress.com) which is the Observatory’s in-house non-profit publishing arm; and details of other related end of life care studies.

Personnel and Partnerships

The International Observatory on End of Life Care is seeking active and sustainable partnerships with organisations and individuals committed to the global development of palliative care. It has a growing network of collaborators across several countries and continents and has key links in India and South America, as well as Eastern Europe, Central Asia and Africa. The Observatory enjoys the support of the following organisations: Help the Hospices; International Association

for Hospice and Palliative Care; Open Society Institute Public Health Network Program, Palliative Care Initiative; Oxford University Press; The Project on Death in America. A review of palliative care and related developments in Africa has been commissioned by the Diana, Princess of Wales Memorial Fund will begin in September 2003. We welcome further enquiries and offers of involvement, via the Observatory website.

References

1. Clark D, Wright M. *Transitions in End of Life Care: Hospice and related developments in Eastern Europe and Central Asia*. Buckingham: Open University Press, 2002.
2. Ten Have H, Clark D. *Palliative Care Ethics. European Perspectives*. Buckingham: Open University Press, 2002.
3. The website has been designed by Stephen Williams, a former student of the University of Sheffield, with additional support from Anthony Greenwood, Philippa Hughes and Margaret Jane. We are particularly grateful to Help the Hospices for financial support with the initial website development.
4. Bath PA, Clark D, Wright M. The International Observatory on End of Life Care (IOELC): an information resource for palliative care. Proceedings of the Eighth International Symposium in Health Information Management Research. In press, 2003.