

# VIEW FROM THE OBSERVATORY

## Palliative care policy development in Central and Eastern Europe and Central Asia: an Open Society Institute initiative

Michael Wright\*, Joseph Clark<sup>†</sup>, Anthony Greenwood\*, Mary Callaway<sup>‡</sup>, David Clark\*

\**Lancaster University, UK*

<sup>†</sup>*University of Nottingham, UK*

<sup>‡</sup>*Open Society Institute, New York, USA*

In October 2003, delegates from 12 Central/Eastern European and Central Asian countries were invited to participate in a palliative care policy development conference in Budapest, presented and sponsored by the Open Society Institute Network Public Health Program Palliative Care Initiative in collaboration with the Soros Foundation Hungary and the Open Society Fund – Lithuania. These countries were: Bulgaria, Croatia, Czech Republic, Georgia, Hungary, Lithuania, Moldova, Mongolia, Poland, Romania, Slovakia and Slovenia. Each country selected 5-member teams to represent cancer and AIDS control, palliative care, ministries of health, education, finance and insurance. The goals of the conference were:

- to describe and discuss model country examples of the integration of palliative care into national health care programmes
- to use the experiences of developing these programme policies, laws, regulations, health care systems, financing, standards and professional education to assist these 12 countries in their own development
- to facilitate debate by means of an international faculty drawn from Austria, Hungary, Ireland, Poland, Spain, the US and the UK.

### Address for correspondence:

The Revd Dr Michael Wright  
International Observatory on End of Life Care  
Institute for Health Research  
Lancaster University  
Lancaster LA1 4YW, UK  
E-mail: mc.wright@btinternet.com

In preparation for the conference, the Open Society Institute commissioned the International Observatory on End of Life Care (IOELC) to survey country representatives and collate information about palliative care needs and provision in these 12 countries.

Discussion was facilitated by the presentation of a range of country models, including: Catalonia, Spain (1), Poland (2), Austria (3), and the US (4). Other perspectives were presented from the World Health Organization (5), the Open Society Institute (6), the European Association of Palliative Care (7), the Council of Europe Committee of Experts (8), and the International Observatory on End of Life Care (9). Inputs also focused on issues around palliative care standards (10) and how to undertake a needs assessment (11).

### Previous research

The 2003 survey built on information already gathered during our previous review of palliative care services in 28 countries of Eastern Europe and Central Asia (12), now posted on the IOELC website (<[www.ioelc-observatory.net](http://www.ioelc-observatory.net)>). This review used a mixed-method design to gather epidemiological data from governmental, public health and NGO sources. Questionnaire surveys were conducted of palliative care services and educational programmes. Recorded interviews were undertaken with stakeholders ( $n = 37$ ) in countries throughout the region; and case studies were conducted of five outstanding services in Hungary, Poland, Romania, and Russia.

A defining feature of this region has been the collapse of communism and a process of transition as governments explore the democratic process, health systems decentralise, and insurance-based models of re-imburement gain ground. In this changing scenario, the philosophy underpinning hospice/palliative care services contrasts sharply with the Soviet ideology of health care that focused primarily on physical care and maintenance of the work force. Furthermore, these palliative care services have sought to address the cultural issues surrounding death and dying, cancer and its myths, spirituality and the place of truth-telling.

With the exception of Poland, palliative care services in all countries in the original study had been established since the demise of communism. Only two countries (Poland and Russia) had more than 50 services and 5 countries (Georgia, Kazakhstan, Tajikistan, Turkmenistan and Uzbekistan) had none; 13 countries had five services or less. In total, 222 home-care services were found in 17 countries;

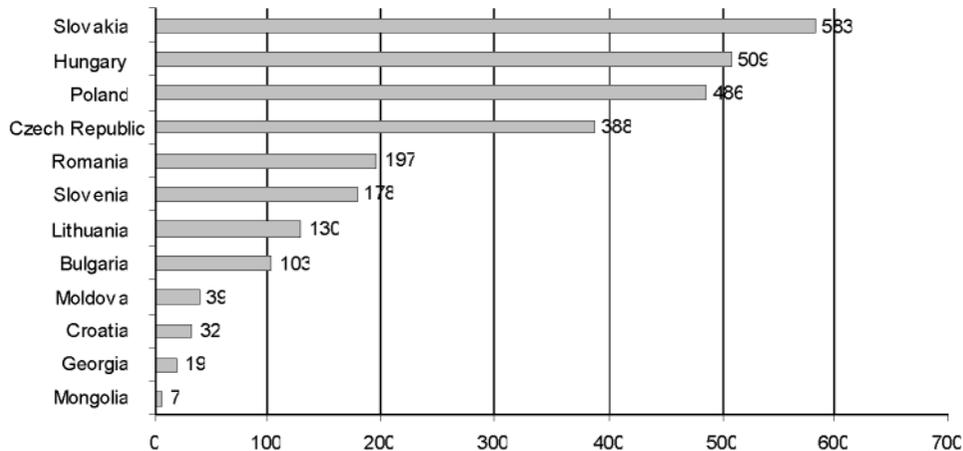


Figure 1. Average daily consumption of defined daily doses of morphine per million inhabitants, 1994–1998.

and 172 in-patient units were found in 13 countries. Paediatric provision was sparse: only 50 services were found in 9 of the 28 countries and 30 of these were in Poland.

This information provides a base-line for reviewing subsequent hospice/palliative care developments throughout the region.

### The delegate countries for the Budapest meeting

Turning to the current survey, the 12 delegate countries fall within the geographic regions of the Balkans, the Baltic States, Central Europe, Eastern Europe, Caucasia and Central Asia, and together encompass a population of around 117 million. As a group, the countries display a broad disparity of provision and resources.

The largest country is Poland (38.58 million); Slovenia (1.98 million) is the smallest. Life expectancy is greatest for both men (72.1 years) and women (79.5 years) in Slovenia; it is lowest for men (61.2 years) and women (68.3 years) in Mongolia.

Adult mortality per 1000 population is highest for men (308) in Moldova and for women (160) in Mongolia. It is lowest for both men (164) and women (73) in Slovenia. Diseases of the circulatory system are the highest cause of death in all 12 countries, followed by malignant neoplasms: 265.58 per 100,000 in Hungary (highest); 85.86 per 100,000 in Georgia (lowest).

The highest per capita gross domestic product (GDP) is found in Slovenia (Intl \$16,927), the lowest in Moldova (Intl \$ 1,802) – shown here in International dollars (13). Total per capita health expenditure is highest in Slovenia (Intl \$1,462) and lowest in Mongolia (Intl \$120). Two countries, Slovenia and the Czech Republic, spend over 1000 dollars whereas four countries – Georgia, Bulgaria, Romania and Mongolia – spend less than 200.

Alongside education and governmental policy, drug availability is regarded as a foundation measure of cost-effective palliative care. Opioids feature prominently in this

respect, particularly morphine. Figure 1 shows the average defined daily dose (14) consumption of morphine per million inhabitants for the years 1993–1998 (15). In two countries, Slovakia and Hungary, the average daily consumption was over 500 doses; in four countries (Moldova, Croatia, Georgia and Mongolia) the average daily consumption was less than 50 doses.

### The survey

A cross-sectional descriptive survey was undertaken by means of a self-completion E-mail questionnaire administered to a conference delegate nominated by the Open Society Institute in each of the 12 countries.

The questionnaire was constructed during July 2003 based on a series of questions supplied by the Open Society Institute. They were subject to careful scrutiny and underwent a rigorous process of development and revision. Completed questionnaires were returned from all countries.

Despite these efforts, some inaccuracies could still occur, due largely to a misunderstanding of the language of the questionnaire (English) or to a respondent's incomplete knowledge of national palliative care developments. To minimise these inaccuracies, the data were verified with the 5-member country teams at the meeting.

### Findings

The survey found that:

- with the exception of 2 countries (Georgia and Moldova), all 12 countries have a national hospice/palliative care association
- six countries (Croatia, Georgia, Hungary, Mongolia, Poland, Romania) have some form of certification programme for doctors; 4 countries (Bulgaria, Croatia, Hungary, Poland) for nurses. Only Hungary has programmes for doctors, nurses and other professionals

- Hungary, Poland and Romania are the only countries with standards in place for in-patient, home-care and 'other' palliative care programmes. Both in-patient and home-care standards are being developed in Lithuania, Slovakia and Slovenia; in-patient standards are being developed in Bulgaria and Georgia, and home-care standards in Croatia and Moldova
- all countries except Romania have national guidelines for the management of acute pain and chronic cancer pain
- national guidelines for symptom management (Georgia, Hungary, Mongolia), end-of-life care (Georgia, Hungary, Mongolia, Poland), home-care (Hungary, Poland) and in-patient care (Bulgaria, Hungary, Mongolia Poland) are found infrequently. Only Hungary has guidelines in place across all these categories
- nine countries (Bulgaria, Georgia, Hungary, Lithuania, Moldova, Mongolia, Poland, Romania, Slovakia) have a national cancer control policy, of which 5 (Bulgaria, Lithuania, Moldova, Poland, Slovakia) include palliative care
- Nine countries (Bulgaria, Georgia, Hungary, Lithuania, Moldova, Mongolia, Poland, Romania, Slovenia) have a national AIDS policy, of which 3 (Moldova, Poland, Slovenia) include palliative care
- the health care system makes a financial contribution to home-based palliative care in 3 countries (Poland Romania, Slovenia) and in-patient palliative care in 5 countries (Bulgaria, Czech Republic, Poland, Romania, Slovakia)
- six countries (Bulgaria, Georgia, Hungary, Lithuania, Poland, Slovakia) have legislated for palliative care to be delivered in the four settings of: hospital; in-patient hospice; out-patient setting; and the home-care systems
- five countries (Bulgaria, Georgia, Mongolia, Poland, Slovakia) have undertaken a palliative care needs assessment
- among 52 paediatric services, 42 are found in 2 countries – Poland (32) and Romania (10). Home-care features most prominently, especially in Poland; 5 countries (Bulgaria, Croatia, Georgia, Lithuania, Mongolia) make no palliative care provision for children; only 4 countries (Moldova, Poland, Romania, Slovenia) have more than 1 paediatric palliative care service

Among adult services, home-care features most prominently, with 209 services identified in 10 countries. Poland has the broadest range and greatest number of palliative care services overall (Table 1).

### Palliative care barriers and opportunities

Respondents identified the main barriers to palliative care development as: (i) insufficient funding; (ii) low social and professional awareness of palliative care; (iii) poor pain control; (iv) the lack of trained staff; and (v) the absence of legislation.

Palliative care opportunities include: (i) the development of education programmes; (ii) ministerial support; (iii) the development of national standards; (iv) the increase in palliative care services/personnel; and (v) better pain relief.

A comment from Mongolia, one of the lower ranking countries in terms of GDP and health care expenditure, is indicative of the gains which can be made with the support of the international community:

**Table 1.** Adult hospice/palliative care services in 12 countries by type

Country	Inpatient units	Home-care services	Day-care units	Nursing home services	Hospital support teams	Total
Bulgaria	10	20				30
Croatia		1				1
Czech Republic	7	2				9
Georgia	1					1
Hungary	3	13	2	5	4	27
Lithuania	2	1			2	5
Moldova		7				7
Mongolia	1	2				3
Poland	100	155	12			267
Romania	6	6	1			13
Slovakia	3					3
Slovenia		2				2
Total services	133	209	15	5	6	368
Total countries	9	10	3	1	2	12

Other: Poland – 126 palliative care clinics (usually connected to home-care services); 9 lymphoedema clinics; a few hospital support teams.

**Table 2.** Policy development goals identified by country teams in Budapest, 2003

Country	Goal 1	Goal 2	Goal 3
Bulgaria	Present national palliative care standards to Ministry of Health	Change opioid laws and regulations	Re-imburse home based palliative care
Croatia	Prepare standards for Ministry of Health (Oct 2003)	Publish standards in medical/national press	Increased professional education
Czech Republic	Improve social awareness	Integrate palliative care into long-term care facilities	Effective client-focused financing
Georgia	Integration of palliative care into national health policy	Establish resource and training centre	Palliative care needs assessment
Hungary	Articulate minimum standards	Integrate palliative care into public health programme	Change system of re-imbursement
Lithuania	Verbal report to Minister of Health	Analyse legislation and identify changes required	Identify standards and give to Minister of Health
Moldova	Develop palliative care strategy with Ministry of Health and NGOs	Revise the legislation	Integrate palliative care into education programmes
Mongolia	Establish home care in the provinces	Review drug availability and financial resources	Develop standards and education programmes
Poland	National and local awareness raising	Improve palliative care for non-cancer patients	Introduce education programmes to all medical universities
Romania	Task force commissioned by Ministry of Health	Obtain Ministry of Health order for palliative care	National conference with international experts
Slovak Republic	Establish home-care provision	Establish palliative care in existing healthcare institutions	Develop national standards
Slovenia	Recruit and motivate health care professionals	Undertake a pilot study	Develop education

*The Mongolian Palliative Care Society was established in 1999 and: organised basic palliative care education for doctors, nurses, teachers of the Medical University and Colleges; translated and published the main WHO guidelines on palliative care; wrote and published handbooks for basic and advanced palliative care education; organised leadership conferences on palliative care; distributed materials to members of parliament and the ministry of health; undertook advocacy by TV and radio with the financial support of the Soros Foundation. Now, all Medical Universities and Colleges include a palliative care programme; a palliative care department was established in 2000. Two home hospices were established in 2002–2003 in Ulaanbaatar and Zuunhaara by members of the palliative care association (5).*

**Strategic planning for policy development**

The main thrust of the Budapest conference was to give country delegates time to debate the issues surrounding palliative care policy development and to identify three

realistic goals achievable within a finite time-scale. Four questions predominated:

- (i) What steps are necessary to integrate palliative care into the national health care programme?
- (ii) What policies, laws or standards are needed?
- (iii) What changes in financing are needed to include palliative care?
- (iv) What are the educational needs of health care professionals?

The gains for the country teams came from relating these questions to the practical needs of palliative care policy-making in individual countries. Time for delegates to debate the issues and devise action plans was invaluable. Each action plan contained three overriding goals for delegates to take home and implement. Awareness raising, national standards, legislation and education all figured prominently (Table 2).

**Conclusions**

Across the region, the patchwork of services has tended to develop in a piecemeal way with little co-ordination or

strategic planning. While individual services may flourish, it is essential that palliative care eventually becomes integrated into national health care systems to achieve maximum coverage. In this context, the Budapest conference was a far-sighted initiative that brought together personnel who were capable of influencing the policy-making agenda throughout the region. Both the process and the outcomes were encouraging.

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