Transitions in End of Life Care

Hospice and related developments in Eastern Europe and Central Asia

David Clark and Michael Wright
University of Sheffield, United Kingdom

with
Jacek Łuczak

in association with
Carl Johan Fürst and Sylvia Sauter

A report prepared for the Open Society Institute

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David Clark and Michael Wright
University of Sheffield, UK

d.clark@sheffield.ac.uk
m.c.wright@sheffield.ac.uk

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Executive summary

We are witnessing a remarkable growth in concerted efforts to improve end of life care in many countries of the world. These efforts focus on the relief of suffering in the face of terminal disease; they address physical, social, psychological and spiritual issues; they are based on multi-disciplinary teamwork; they employ partnership strategies to bring together public health planners, clinicians, non-governmental organisations, business and academia; their efforts are supported increasingly by an evidence base grounded in rigorous research. The work of hospice and palliative care has indeed come a long way since the work of its early pioneers in the 1950s and 1960s, who first drew attention to the inadequate care of dying people in the modern world[1].

[1] Clark D (2002) Between hope and acceptance: the medicalisation of dying. *British Medical Journal* 324: 905-07.

In 2002 the World Health Organisation defines palliative care thus[2]:

> Palliative care is an approach which improves quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:
>
> - Provides relief from pain and other distressing symptoms;
> - Affirms life and regards dying as a normal process;
> - Intends neither to hasten or postpone death;
> - Integrates the psychological and spiritual aspects of patient care;
> - Offers a support system to help patients live as actively as possible until death;
> - Offers a support system to help the family cope during the patient's illness and in their own bereavement;
> - Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
> - Will enhance quality of life, and may also positively influence the course of illness;
> - Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

[2] Sepulveda, C Marlin, A Yoshida, T Ullrich, A (2002 forthcoming) Palliative care: WHO global perspective. *Journal of Pain and Symptom Management* 24(2).

Scope of the review

This review reports on the current state of development of hospice and palliative care in 28 countries of Eastern Europe and Central Asia. It covers matters of service development, current levels of provision, policy implications, education and training, opioid availability, local, national and international partnerships. Much of the report distinguishes between countries of Central and Eastern Europe (CEE) and the Commonwealth of Independent States (CIS), plus Mongolia.

Central and Eastern Europe (CEE)	Commonwealth of Independent States (CIS), plus Mongolia
Albania Bosnia and Herzegovina Bulgaria Croatia Czech Republic Estonia Hungary Latvia Lithuania Macedonia Poland Romania Serbia Slovakia Slovenia Total population: 127m	Armenia Azerbaijan Belarus Georgia Kazakhstan Kyrgyzstan Moldova Mongolia Russian Federation Tajikistan Turkmenistan Ukraine Uzbekistan Total population: 285m

Although some limited hospice developments did take place in this region before the collapse of communism, in Poland (from 1976) and in Russia (from 1985), in general the history of palliative care in the former communist countries of Eastern Europe and Central Asia is one which goes

back only to the early 1990s.

No detailed analysis has been conducted on the factors shaping palliative care development in these countries and there is a great need for comparative enquiry into achievements to date as well as problem areas still to be resolved.

The review made use of a wide variety of primary and secondary data including: public health sources of various kinds, more than 100 questionnaires returned by palliative care practitioners from the different countries, interviews with over 30 key individuals, unpublished policy papers and planning documents, correspondence, newsletters, professional and scientific journals and secondary publications.

Current levels of hospice and palliative care provision

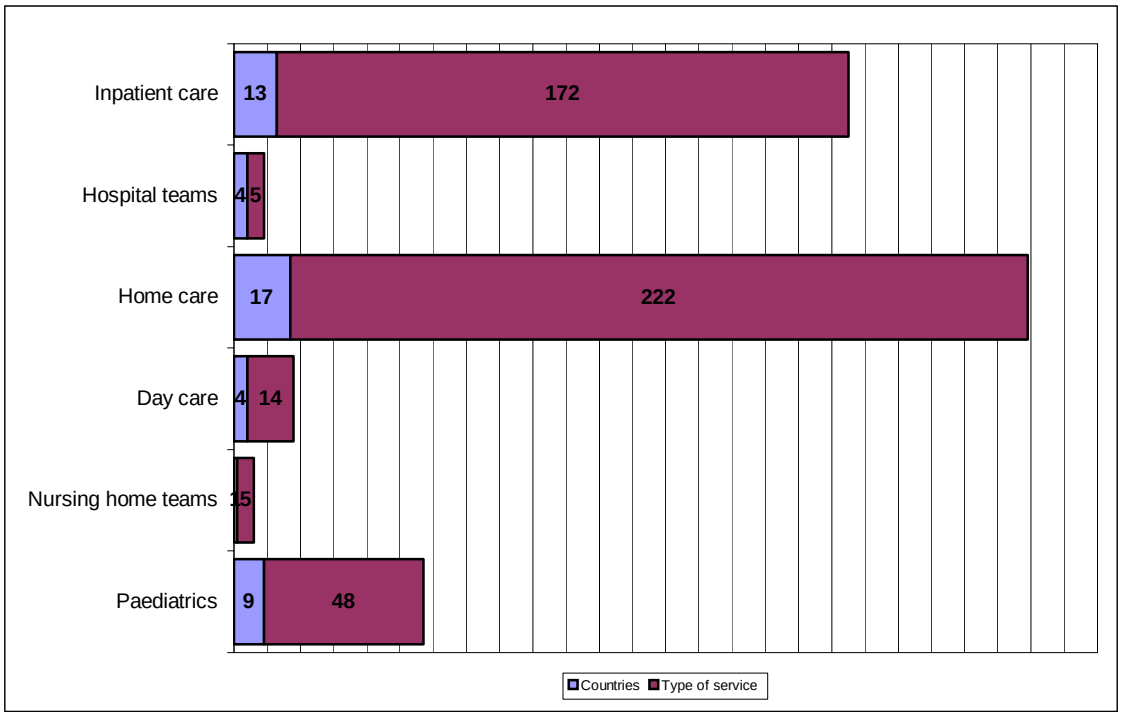
The distribution of services is extremely patchy. Only Poland and Russia have more than 50 palliative care services within the country; 5 countries have no identified palliative care services.

Current levels of hospice/palliative care service provision in Eastern Europe and Central Asia

Total services in the country	Number of countries	
0	5	Georgia Kazakhstan, Tajikistan, Turkmenistan, Uzbekistan
1 – 5	13	Albania, Armenia, Azerbaijan, Belarus, Bosnia-Herzegovina, Croatia, Kyrgyzstan, Latvia, Macedonia, Moldova, Mongolia, Slovakia, Yugoslavia
6 – 10	5	Czech Republic, Estonia, Lithuania, Slovenia, Ukraine
11 – 50	3	Bulgaria, Hungary, Romania
51 +	2	Poland, Russia

Various types of service delivery model are in evidence. Home care is the form of service most commonly found, followed by inpatient provision. There is a great absence of hospital mobile teams, services in nursing homes and day care provision. Only 48 paediatric palliative care services exist, covering just 9 of the 28 countries.

Volume of hospice/palliative care services available, by type, in Eastern Europe and Central Asia



Evidence was also gathered on palliative care services still at the planning stage and not yet operational. Whilst substantial plans exist in Poland and Russia, there was no evidence of new projects (adult or paediatric) in 16 countries.

Palliative care ‘beacons’

More encouragingly, there were examples of outstanding success in specific locations and these were designated palliative care ‘beacons’. Five beacons were identified, in 4 countries. In each of these examples there is evidence of the historical significance of the service within the national scheme of development in hospice and palliative care; there is involvement of personnel of national/international repute; there is a centre for education and training; and evidence of impacts upon national health policy. The ‘beacons’ provide good models for service innovation, partnership approaches and successful use of international mechanisms of support.

Brasov, Romania

Based in Brasov, Romania, Hospice ‘Casa Sperantei’ (‘Home of Hope’) came into being in 1992 as a Romanian/English charity, supported by the Ellenor Foundation, Dartford, UK; initially providing a home care service. It established a major educational initiative in 1997, housing the national palliative care resource centre and providing training in accordance with the national palliative care curriculum. It opened a purpose built facility in 2002, thus completing a full programme of adult and paediatric inpatient, home care and day care services, palliative care support for local hospitals and a telephone help-line.

Budapest, Hungary

The Hungarian Hospice Foundation was founded in 1991 at St Margit's Hospital, Budapest and focused initially on public awareness and education. The hospice now provides home care, day care and inpatient services for 11 of the 23 districts of Budapest, serving a population of around 1 million people. In 2001, the Hungarian Jewish Social Support Foundation established a mobile hospice team based in the Charity Hospital of 'Mazsihisz'. Budapest has become a centre for palliative care education, policy development and a range of courses, research activities and academic work based on the Semmelweis University of Medicine.

Poznan, Poland

The first palliative care service in Poland to be organized within the National Health Service structure was created in Poznan in 1987. This home care service was supported by the Aleksander Lewinski and Antonina Mazur Society for the Alleviation of Suffering of Cancer Patients (the Polish Association for Palliative Care from 1991). In Addition a hospital ward opened in 1990, a bereavement service was founded in 1991, a hospital-based palliative care team in 1992 and an on-call team in 1993. The Hospice Pallium complex (opened 2001) consists of a 14-bedded ward, a day care centre, a palliative medicine clinic with home care and on-call teams, a chronic pain clinic, lymphoedema clinic and bereavement service; it also houses the palliative care resource and training centre. Poznan is the first academic centre for palliative care in Poland, based at the Karol

Marcinkowski University of Medical Sciences and has strong links with Sir Michael Sobell House, Oxford, thereby facilitating the organization of annual palliative care courses at nearby Puszczykowo.

St Petersburg, Russian Federation

The first hospice in Russia was opened in 1990 at Lakhta, St Petersburg, and its impact persuaded the mayor of the city to become committed to hospice care. In 2002 St Petersburg has 6 inpatient hospices and 17 home care services providing palliative care in 12 of the 19 districts of the city. As hospice care has become a part of the cancer care programme, 2 further hospices are planned, including a 50-bed free-standing hospice currently under construction. International links have been established with external non-governmental organisations and between Anglia Polytechnic University and Pavlov Medical Institute designed to introduce Russian-led palliative care courses for doctors and nurses.

Warsaw, Poland

The Warsaw Hospice for Children (a home care service) was established in 1994. New premises were purchased in 1998, equipped for additional use as an anaesthetic dental surgery, thereby providing supplementary funds for hospice activities. Around 80% of income derives from private donations. The hospice has become a centre for education and research. International conferences have attracted delegates from 19 European countries and 4 non-European countries. The hospice has close links with Poland's National Research Institute for Mother and Child.

Key themes and issues

Within the review, several issues and problems were found recurrently and these are affecting most countries to varying degrees.

Policy recognition, reimbursement and sustainability

Substantial policy recognition and integration into the structures of the national health care system has only occurred in Poland, Hungary and to a lesser extent Romania and Russia. Even here, this does not translate into agreed funding mechanisms at an adequate level. Elsewhere, the issue is only at an early stage of formulation or has not been addressed at all. In such circumstances, even in the most successful centres, there are major concerns about sustainability, not least in those cases where there is dependency on high levels of out of country financial support.

Opioid availability

This has already been a major focus of attention upon the part of expert groups and international agencies of various kinds. Three problems can be identified: the *quantity* of available drugs; the *types and formulations* in which they can be obtained; and the *restrictions and regulations* that control their use for purposes of pain relief. In Poland and Hungary, each of these has been addressed to good effect, though some outstanding issues remain. Elsewhere, practitioners report significant problems in all three aspects and emphasise that the situation away from tertiary and urban centres is in general comparatively worse.

Workforce development, education and training

There is an extensive mixture of palliative care training programmes, locally, nationally and to some extent internationally. In some countries there has been formal accreditation of programmes and providers. Nevertheless, the first generation of palliative care practitioners in Eastern Europe and Central Asia has mainly been trained outside the region and there is an issue about how the workforce can now be recruited, trained and sustained in a strategic manner.

Medical aids, equipment and materials

Within health care systems that are generally impoverished and suffer from limited reform and lack of appropriate investment, the dearth of medical supplies is an all-pervasive issue. We found many examples of hospice and palliative care services that were under-resourced and where some *concerted* help from international donors would be beneficial.

External partnerships

The most successful hospice and palliative care services in the region, and particularly the 'beacons', have made highly imaginative use of partnership models, locally, nationally and internationally. Sometimes, this is done by formal 'twinning' between a local service and another outside the region. There were several examples of this, with the United Kingdom appearing to be the major source of such partners.

Research

Audit, evaluation and more fundamental research have not so far been high priorities for many hospice and palliative care services in the region. Nevertheless, there were encouraging signs, in Poland, Hungary, Russia and Romania of new developments in this area. As academic and research interest expands, there will be great scope for partnerships with established academic centres in palliative and end of life care in Western countries.

The culture of care

In all countries of the region there are complex and pervasive beliefs and values relating both to how the health care system operates and within it, the specific issue of caring for those with cancer and those who are dying. 'Soviet medicine' did not encourage a dynamic and holistic view of health care delivery. Similarly, cancer disease and the care of dying patients are still surrounded by powerful negative stereotypes. The palliative care practitioners of the region are actively promoting reform in these areas, but underlying cultural values are of great significance and it would be unwise to seek to import wholesale and uncritically as a package, all of those values which have come to represent the palliative care mainstream in the West. The emphasis which hospice and palliative care organisations in the region place upon public education in these issues is to be commended.

Ten recommendations

1. Power to the 'beacons'

Suitably supported, those centres of excellence identified in the review should be encouraged to take on a stronger role in sub- or pan- regional development, as follows:

- Warsaw Hospice for Children should be considered for a pan-regional role in supporting the development of paediatric palliative care services.
- Poznan and St Petersburg are best placed to support developments in Northern and Eastern parts of the region, covering Belarus, Poland, Russia and Ukraine.
- Brasov should further develop its regional role in the Balkans, supporting Albania, Bosnia-Herzegovina, Bulgaria, Romania, Macedonia, Moldova and Serbia.
- Budapest has a clear role in the Central European countries of Croatia, Czech Republic, Hungary, Slovakia and Slovenia.

'Directors of Development' should be appointed to further this work in each of the 5 beacons identified.

2. Lighting up more 'beacons'

Some sub-regions identified in this review have been less successful in their efforts so far to promote palliative care development. Strategic support is needed here to help establish at least 3 more 'beacons' by 2007. These should be located in the following sub-regions.

- The Baltics (Estonia, Latvia, Lithuania): the candidate location here should be Kaunus, in Lithuania.

- Trans-Caucasia (Armenia, Azerbaijan, Georgia): the candidate location here is much more difficult to recommend in an area with very little palliative care development and leadership.
- Central Asia (Kazakhstan, Kyrgyzstan, Mongolia, Tajikistan, Turkmenistan, Uzbekistan; plus Mongolia, though it is not in the WHO European region): the candidate location here should be Bishkek, in Kyrgyzstan.

3. Setting standards and measuring outcomes

Where they exist, standards of hospice and palliative care are usually local, sometimes national and almost never international. It is recommended that a core set of European minimum standards is developed, to facilitate providers' negotiations with ministries of health, health authorities, houses of insurance and sickness funds.

4. A better deal for dying children

Across the region as a whole, there has been insufficient development of hospice and palliative care services for children. There is an urgent requirement for a regional epidemiological needs assessment for paediatric palliative care, with an accompanying proposal for service development.

5. Building the palliative care workforce

None of the countries has made a concerted attempt to calculate the size and makeup of the required palliative care workforce. This should be based on simple epidemiological models coupled to the agreed minimum standards for services. Such a calculation would greatly assist national and international resource planning, allocation and lobbying.

6. Towards a common palliative care curriculum

Curricula for palliative care education and training vary considerably between and within countries. There is a strong case to be made for developing a core European curriculum at pre- and post- qualification levels, for each of the relevant professions involved in palliative care.

7. Producing a shared textbook

Translations of palliative care textbooks proliferate. Only one country in the region has its own, locally-written comprehensive text. A European expert group should prepare a common textbook, with the explicit intention from the outset that it will be used in a variety of countries and will require translation into many languages.

8. Dismantling the barriers to opioid availability

Much excellent work has already been carried out on this issue, but many problems still remain. Relevant organisations should focus on sub-regional groupings and in particular give priority to those countries where the problems are greatest. There is an important role for the 'beacons' and their Directors of Development in this.

9. An International Observatory on End of Life Care

A point has now been reached where an International Observatory on End of Life Care could do much to further collaboration and development in the region covered by this review and elsewhere. The outcomes of this review might form the basis of a web-based pilot for the Observatory.

10. A hospice "summit" for Eastern Europe and Central Asia

All of the relevant agencies and partners that feature so prominently in this review should be encouraged to come together for a "summit" meeting to discuss how the review and its recommendations can best be taken forward at a strategic level, making the best possible use of international partnerships and collaboration.

In conducting our review and in making these recommendations, we have been mindful of the major supportive role played by the Open Society Institute and its national Foundations in the strategic development of hospice and palliative care in Eastern Europe and Central Asia in recent years. This has indeed been an enormous commitment. The continued involvement of OSI in this work appears therefore absolutely vital if progress is to be maintained against some of the major challenges that remain outstanding.

David Clark and Michael Wright
University of Sheffield, UK
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