

Bosnia-Herzegovina

In the spring of 1992, Bosnia and Herzegovina declared its independence. Soon after, war broke out among the Croat, Serb and Muslim (Bosniak) inhabitants of the former Yugoslav Republic. Over the course of the next four years an estimated 250,000 people lost their lives. In November 1995, in Dayton, Ohio, the parties approved a US-brokered peace deal that retained the country's external borders but divided it almost equally into $\frac{3}{4}$ a joint Muslim/Croat Federation and the Bosnian Serb Republika Srpska (RS). The Federation and RS entities oversee internal functions while the national government conducts foreign trade and monetary customs policy.¹



¹ Bosnia-Herzegovina Country Profile; United States Agency for International Development, http://www.usaid.gov/regions/europe_eurasia/countries/ba/index.html

1 Palliative care service provision

1.1 Current services (last updated: May 2002)

The following palliative care services are known to exist in Bosnia-Herzegovina:

		<i>Existing services (2002)</i>
Adult	Inpatient - Freestanding	0
	- Hospital unit	0
	- Hospital mobile team	0
	Nursing home	0
	Home care	1
	Day care	0
	Total	1
Paediatric	Inpatient	0
	Home care	0
	Day care	0
	Unspecified	0
	Total	0
Grand total		1

Current projects (last updated: May 2002)

The following palliative care projects are known to exist in Bosnia-Herzegovina; these are not yet operational services:

		<i>Known hospice/ palliative care projects (2002)</i>
Adult	Inpatient - Hospital	0
	- Hospice	1
	Home care	0
	Unspecified	0
	Total	1
Paediatric	Hospital	0
	Hospice	0
	Home care	0
	Unspecified	0
	Total	0
Grand total		1

In Bosnia-Herzegovina, the palliative care approach is adopted in within Sarajevo's oncology hospital: 'We provide palliative care as a part of total care for oncological patients during their stay at the Institute of Oncology and in their active treatment. We

receive patients for palliative care only exceptionally². A department of pain management was opened in Sarajevo General Hospital in 1998 and has had Open Society Foundation funding for 'Project Palliative Care in the Hospital Setting'. The home care service NJEGA is operational in the city; and the Sarajevo Hospice takes forward a number of educational initiatives as well as giving support to local individuals and groups, including a clinic for young people with amputations. There is no institutional form of paediatric palliative care and no signs of its development.³

NJEGA is a service that aims to provide quality care to terminally ill people dying of cancer in their own homes in the Canton of Sarajevo, and is seen as pilot project which might be replicated elsewhere. Based in a health care centre, NJEGA comprises 2 doctors (who work closely with the senior consultant in oncology at the hospital), 4 nurses and 1 part-time social worker. Team members care for the patients and give advice and support to family members; they are also able to provide some medical supplies and materials. The first year of NJEGA's activities have been described in a prize-winning poster.⁴ In the year beginning August 1999, 345 patients were cared for (174 male, 171 female) for an average period of 45 days, in a total of 4,606 home visits. The most frequent diagnoses were lung cancer (93), cancer of the digestive system (84), breast cancer (48), gynaecological cancers (30). The most frequent symptoms treated were: pain, asthenia, vomiting and constipation; and the vast majority of patients were experiencing socio-economic problems.

Sarajevo Hospice does not yet offer direct patient care services, but its work in public and professional education is significant. It engages closely with local academic and clinical groups and with the Ministry of Health in assessing the need for palliative care and planning the relevant approach in the context of limited resources. In 1999 it began an annual international seminar in palliative care, attracting contributors from several European countries. It has translated palliative care textbooks and other educational materials and identified key local leaders to develop a postgraduate module in palliative medicine to be taught at the Medical Faculty of the University of Sarajevo. It has also fostered the development of a palliative care education unit and

² Questionnaire data (EAPC East)

³ Questionnaire data (EAPC East)

drop in facility within the Faculty of Medicine, to open in 2002. It wishes to support research into war injury survivors with chronic pain. Sarajevo Hospice has been given land by the Canton for the establishment of a hospice building, but so far funds to progress this have not been forthcoming. Sarajevo Hospice also works closely with Hope 87, an international NGO project that cares for young people who have had limb amputations.

Bosnia-Herzegovina currently has an estimated 4 physicians (including 2 family doctors) and 4 nurses with some form of palliative care training, together with 1 social worker.⁵

Among our sources for Bosnia-Herzegovina we had a total of 12 completed questionnaires, sent to us by those involved in hospice, palliative care and oncological work.

One palliative care worker summed up the local problems in the following way:

‘We are a post-war country. It is obvious that we need palliative care, but we do not have recognised specialisation for doctors and we do not have resources like doctors in western countries. We do not have enough staff in our team or access to all the drugs we need. We need better co-operation with other hospitals and clinics developing palliative care.’⁶

Another senior figure observed:

‘There is a great interest in and need for palliative care in Bosnia and Herzegovina. Its development is in the beginning. There is only one special palliative care service in Sarajevo. There are no palliative care units or hospices. Opioids are not available in the whole country and personnel don’t have enough knowledge to handle the opioids. There is no support or understanding from politicians and health care authorities.’⁷

1.2 Reimbursement and funding for services

No information currently available.

⁴ Bezdrob L, Obralic N, Dizdarevic Z, Yokic M, Zvizdic F, Sarac A. Palliative care of the oncological patients in Sarajevo. Poster: *Seventh Congress of European Association of Palliative Care*, Palermo, Italy, 2001.

⁵ Questionnaire data (Observatory)

⁶ Questionnaire data (Observatory)

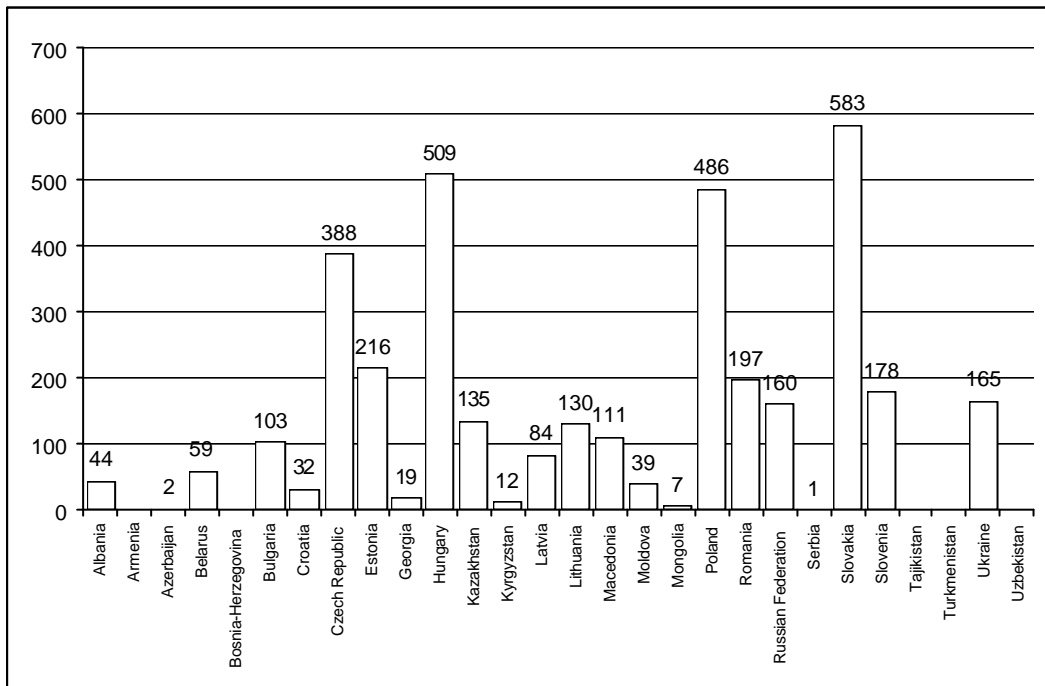
⁷ Questionnaire data (EAPC East)

1.3 Opioid availability and consumption

In Bosnia-Herzegovina each opioid must be prescribed on three prescriptions, approved by the hospital and registered in a special book for narcotics.

INCB lists no data on opioid consumption in Bosnia-Herzegovina between 1994 and 1998 or for the average daily consumption of defined daily doses of these drugs per million inhabitants.⁸

Average defined daily doses of morphine, Central and Eastern Europe (1994-1998)



Source: Clark D, Wright M (2002) *Transitions in End of Life Care: Hospice and Related Developments in Eastern Europe and Central Asia*. Buckingham: Open University Press

1.4 National and professional associations

In addition to its links with St Gemma’s Hospice in Leeds, England, NJEGA also has links with Calderdale NHS Trust, Huddersfield, England, with palliative care specialists in Cardiff, Wales and with ECEPT and EAPC. Sarajevo Hospice has international links with academic departments of palliative medicine at the

⁸ International Narcotics Control Board (2000) *Narcotic Drugs: Estimated World Requirements for 2000. Statistics for 1998*. New York: United Nations.

Universities of Bristol and Sheffield, England and with the UK charity, Help the Hospices.

There is no national association for palliative care, though this is seen as a priority in educating the workforce in palliative care.

There is a concern among palliative care workers in Sarajevo that recent developments will be difficult to sustain as and if international NGO support declines.

1.5 Palliative care 'coverage'

There is a service providing palliative care for every 2.00 million people in Bosnia-Herzegovina.

Ratio of hospice/palliative care services per million population, Central and Eastern Europe (2002)

	<i>Ratio 1:</i>
Estonia	1: 0.14m
Poland	1: 0.15m
Slovenia	1: 0.32m
Bulgaria	1: 0.36m
Hungary	1: 0.37m
Latvia	1: 0.48m
Lithuania	1: 0.62m
Czech Republic	1: 1.02m
Albania	1: 1.03m
Romania	1: 1.07m
Slovakia	1: 1.33m
Macedonia	1: 1.98m
Bosnia-Herzegovina	1: 2.00m
Croatia	1: 4.60m
Serbia	1: 10.50m

Source: Clark D, Wright M (2002) *Transitions in End of Life Care: Hospice and Related Developments in Eastern Europe and Central Asia*. Buckingham: Open University Press

1.6 Palliative care workforce capacity

Bosnia-Herzegovina currently has an estimated 4 physicians (including 2 family doctors) and 4 nurses with some form of palliative care training, together with 1 social worker.⁹

⁹ Questionnaire data (Observatory)

2 History and development of palliative care in Bosnia-Herzegovina

2.1 Narrative history of palliative care in Bosnia-Herzegovina

Before the war of 1992-5, there had been some evidence of an interest in palliative care among individual health professionals within Bosnia and some palliative care was delivered in the University Clinical Centre at Sarajevo. The war caused many deaths, thousands still unaccounted for, and brought about the widespread separation of family members; it also led to war injuries on a massive scale and created new epidemiological trends and patterns. In the fragile peace that followed, two NGOs began to address the possible contribution which palliative care services could make to the country's problems.

The Sisters of the Cross and Passion, based in the UK, sent some of its sisters to Bosnia to explore how their order might develop its mission there. They decided to focus on palliative care and were able to draw on the expertise of staff at St Gemma's Hospice in Leeds, England, which is owned and run by the sisters. Sister Anne Cunningham and Sister Rosaleen Murray developed discussion with the Canton of Sarajevo's Primary Health Care Sector with a view to providing a service to people dying of cancer, in their own homes. Collaboration also developed with oncologists at the University Clinical Centre. Integration with the health care system was a feature of the service from the outset, coupled with the provision of training for Bosnian staff at St Gemma's Hospice in England. The service, entitled NJEGA, began caring for patients on 1 August 1999.

At the same time an English public health consultant and aid worker, Stephanie Simmonds, who had represented WHO in Bosnia during the war and lived in Sarajevo throughout the siege which it endured, began in 1996 to consider the need for palliative care services locally. She went on to establish Sarajevo Hospice in November 1998 as a Bosnian NGO in Sarajevo Canton 'to help develop the concept of palliative care, and its practice in a hospice'.¹⁰ The group is concerned both with the care of people affected by cancer and of those with war injuries and trauma; and is particularly interested in where these two sets of problems interconnect. So far its

¹⁰ Sarajevo Hospice, Information Sheet Number 2, February 1999.

main achievements relate to public information and professional education in palliative care.

Almost all the key developments in palliative care in the country so far relate to individuals and organisations based in Sarajevo.

NJEGA has also produced a narrative account of its early activities, from which the following case history is taken.¹¹ The description is given by one of NJEGA's nurses, Emina Milsic:

One of our first patients was Admir, a forty year old man with stomach cancer. He suffered nausea and vomiting, lymphoedema and pain. Our first meeting made a big impression on me and his life story was very upsetting.

Before the war he lived in Visegrad and worked as a baker.

When the war started he had to leave everything he had worked for and journey into the unknown.

He and his family were walking through the woods for days trying to find a way into safe territory.

They came to Gorazde where they stayed for two years until his health problems began to show. The doctors then sent him to Sarajevo for urgent surgery. This was the second time in two years that he had to leave a home behind and look for help.

In the meantime his brother went missing in the war somewhere near Gorazde and Admir feared for his brother's life.

When the family came to Sarajevo they had no place to stay. They found a house destroyed by the shelling of the war and started to live there. Conditions were hard but it was the only home they had. After surgery Admir's health got worse and it was at this point that the family asked for our help.

When we met we grew to be friends and I was impressed by his strength and persistence. He tried to live a normal life, even though conditions were bad. He was full of zest for life and longed to walk through his old town again. He liked to talk about his problems, hopes and fears and his condition improved.

¹¹ *The Experience of Palliative Home Care in Sarajevo, 1999-2000*. NJEGA: Sarajevo, pp27.

Two months later he discovered that his brother was dead and he had to go and identify the body.

Once again he lost his will to live. Our conversations became longer and deeper but the look in his eyes was empty. He told me that he felt he had no reason to live any more but feared for his wife and children, that they would have no place to live and no one to take care of them.

Admir didn't actually know that he had cancer and was going to die, but he didn't have any will to live because of all that had happened to him. He died five months after my first visit.

When he spoke about his brother's death he often said that it might be better to be dead than to suffer as he was suffering. The day he died he thanked me for my help, kindness and friendship and asked me to help his family if something happened to him. He died that night.

His family, who already had such pain in their lives, were very upset. Everything seemed to be going wrong for them.

I tried to speak to his wife but found it very difficult to say something that would comfort her, and it was hard to see the sadness in her eyes. She was incredibly brave and said "What can we do? It was God's will and I can't do anything about it".

Admir's dream did not come true. He never saw his beloved town again and his family still live in that destroyed house.

In April 2001 NJEGA hosted the first palliative care conference for nurses in Bosnia and Herzegovina, with almost 300 participants. Also in 2001 one of the NJEGA doctors completed the Diploma in Palliative Medicine at Cardiff and another completed the Diploma in Palliative Nursing.

2.2 Hospice/beacon case studies

No information currently available.

2.3 Life/oral histories

No information currently available.

3. Public Health Context

3.1 Population

The 2001 estimate of the population of Bosnia-Herzegovina was 3,922,205.

3.2 Epidemiology

In Bosnia-Herzegovina life expectancy in 2001 was 69.04 years for males and 74.65 for females. In the same year infant mortality was 24.35 per 1,000 live births. In 2000, GDP per capita was US\$1,138 and inflation stood at 8%. In 1999 there were 16,108 deaths, of which 2,659 deaths were from cancer.¹²

Population and life expectancy, Central and Eastern Europe (2000)

	<i>Population</i>	<i>Life expectancy</i>	
	<i>Millions</i>	<i>Male</i>	<i>Female</i>
Albania	3.1	64.3	72.9
Bosnia- Herzegovina	3.9	68.7	74.4
Bulgaria	7.9	67.4	74.9
Croatia	4.6	69.8	77.7
Czech Republic	10.2	71.5	78.2
Estonia	1.3	65.4	76.5
Hungary	9.9	66.3	75.2
Latvia	2.4	64.2	75.5
Lithuania	3.7	66.9	77.2
Macedonia	2.0	70.2	74.8
Poland	38.6	69.2	77.7
Romania	22.4	66.2	73.5
Serbia	10.5		
Slovakia	5.3	69.2	77.5
Slovenia	1.9	71.9	79.4

Source: World Health Report 2001

¹² Bosnia-Herzegovina Country Profile; United States Agency for International Development, http://www.usaid.gov/regions/europe_eurasia/countries/ba/index.html :passim.

*WHO age standardised death rates per 100,000 population,
Central and Eastern Europe (1995-1998)*

	<i>Year</i>	<i>All causes</i>	<i>Cancer</i>
Albania			
Bosnia- Herzegovina			
Bulgaria	1998	958.9	123.3
Croatia	1997	836.0	174.2
Czech Republic	1998	706.6	182.9
Estonia	1998	907.7	157.8
Hungary	1998	917.8	219.4
Latvia	1998	955.2	152.1
Lithuania	1997	817.2	149.4
Macedonia	1997	809.1	126.6
Poland	1996	812.2	165.2
Romania	1998	933.9	130.6
Serbia			
Slovakia	1995	820.9	172.3
Slovenia	1997	666.1	167.5

Source: World Health Organisation: World Health Statistics 1997-1999

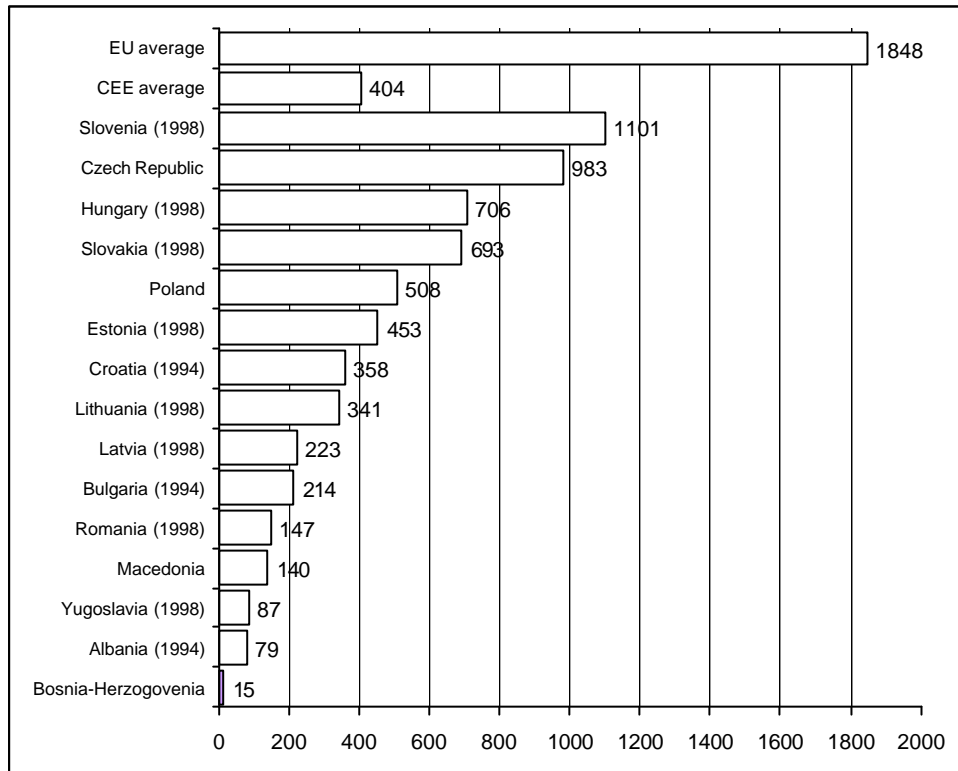
3.3 Health care system

Respondents commented upon the post-war situation in Bosnia-Herzegovina, and its effect on service development.

One commented, perhaps more optimistically than most:

‘We are at an exciting stage. Having started with a clean slate we have been able from the beginning to do: public health assessments of need before developing services; develop options for the type and mix of services needed in Sarajevo and the rational planning of services; support the independence of NGOs while ensuring that any of their palliative care services are part of the mainstream health services; have parallel, complementary strategies for developing formal education, services and research; ensure close collaboration and co-ordination; encourage a mix of players including the Ministry of Health, academia, NGOs and the local business community. But all of this is not without its problems and risks, most notably the highly complex post war political, economic, legal, social and cultural environment.’¹³

¹³ Questionnaire data (EAPC East)

*Health care expenditure (US\$) per capita, Central and Eastern Europe***Health care expenditure (US\$) per capita, CEE and the CIS**

Source: WHO Regional Office for European Health for All database and HiTs

3.4 Political economy

Bosnia-Herzegovina is in the centre of the Balkans, with Croatia to the west and north and south, and Serbia to the east. The aftermath of war in Bosnia brought new levels of disease, disability, social isolation and poverty. Over time it also saw large numbers of refugees returning to the country. The economy of the Bosnia-Herzegovina is still heavily reliant upon donor contributions however, and this situation is becoming increasingly serious as such donors withdraw and foreign debt continues to rise.

One respondent commented:

‘There are more than 2500 war injury survivors in Sarajevo, 50-80% have some form of chronic pain. There are about 1000 cancer deaths per year in Sarajevo, more than 800 have experienced pain. We suspect that these numbers are much larger for Bosnia-Herzegovina, but exact values are

unknown. These numbers show that we need to establish palliative care and pain therapy networks ...¹⁴

¹⁴ Questionnaire data (EAPC East)

4 Ethics and ethnography

4.1 Ethical issues

No information currently available.

4.2 Ethnographic studies

No information currently available.

5 References and further reading

5.1 References

1: Bosnia-Herzegovina Country Profile; United States Agency for International Development, http://www.usaid.gov/regions/europe_eurasia/countries/ba/index.html

2: Questionnaire data (EAPC East)

3: Questionnaire data (EAPC East)

4: Bezdrob L, Obralic N, Dizdarevic Z, Yokic M, Zvizdic F, Sarac A. Palliative care of the oncological patients in Sarajevo. Poster: *Seventh Congress of European Association of Palliative Care*, Palermo, Italy, 2001.

5: Questionnaire data (Observatory)

6: Questionnaire data (Observatory)

7: Questionnaire data (EAPC East)

8 : International Narcotics Control Board (2000) *Narcotic Drugs: Estimated World Requirements for 2000. Statistics for 1998*. New York: United Nations.

9: Questionnaire data (Observatory)

10: Sarajevo Hospice, Information Sheet Number 2, February 1999.

11: *The Experience of Palliative Home Care in Sarajevo, 1999-2000*. NJEGA: Sarajevo, pp27.

12: Bosnia-Herzegovina Country Profile; United States Agency for International Development, http://www.usaid.gov/regions/europe_eurasia/countries/ba/index.html :passim.

13: Questionnaire data (EAPC East)

14: Questionnaire data (EAPC East)