



Palliative care in Serbia and Montenegro: Where are we now?

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ABSTRACT

Palliative care has not been recognized as a specific discipline by health care professionals and policy makers in Serbia and Montenegro. There is low awareness of palliative care among patients, their families, and the general public. There is no national policy, guidelines, or standards on the organization of palliative/hospice care. There is no legislative framework for palliative care. A disease-oriented instead of a holistic patient approach is still present. The patient's right to the best quality of life is still under-recognized. Provision of care is mainly focused on physical domain, while other aspects of support (social, psychological, emotional, spiritual) are less frequently provided. Much palliative care is delivered by practitioners who are not specialists in palliative care. Availability and accessibility of opioids for medical use is still low and inadequate. Immediate release morphine is not available. The National Task Force for Palliative Care is established under the auspices of the Ministry of Health as well as the first non-governmental organization devoted to palliative care. The first national Palliative Care Guidelines for the management of cancer pain, dyspnea and nausea are prepared and published.

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The World Health Organization (WHO) has defined palliative care as "an approach that improves the 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" (1). In the recommendation on the organization of palliative care, Council of Europe (CoE) uses a slightly revised version of WHO definition: "Palliative care is the active total care of patients with advanced progressive disease aiming at the control of pain and other symptoms and offering psychological, social and spiritual support" (2). In this article, we will refer to the CoE definition of palliative care. Shared by these two definitions, however, is that palliative care is the total care of the patient's body, mind and spirit, and also involves giving support for the family. Palliative care does not address a specific disease, age or gender category. Rather, it aims to help patients (man, women or children) of all ages having advanced progressive disease and their families, from the time of diagnosis of advanced progressive disease until the end of bereavement. The goal of palliative care is the achievement of the best possible quality of life for patients and their families (1-3). In contrast with disease-directed approaches in medicine, palliative care is completely patient- and family-centered care (4).

Setting the scene

According to recommendations given by CoE, palliative care is "an integral part of health care system and an inalienable element of the citizen's right to health care, and that therefore it is the responsibility of the government to guarantee that palliative care is available to all who need it" (2). How many cancer patients, for example, need palliative care? Serbia has 7.5 million inhabitants (Kosovo and Metohija excluded) (5) and Montenegro 620 145 (6). Cancer is the second cause of death in Serbia with recorded 29 549 new cancer patients in the course of the year 2002 (7). According to WHO, 80% of this number need

palliative care (8), thus it can be calculated that approximately 24 000 cancer patients in Serbia will need palliative care. There is no national cancer register in Montenegro, however since population, morbidity and mortality do not differ significantly from Serbia, the incidence can be estimated to be 2450 of new cancer patients per year. Therefore, around 2000 of cancer patients will need palliative care in Montenegro. Unfortunately, palliative care still has not received adequate recognition in our country (9). The awareness of health professionals, policy makers, patients / their families and the general public regarding palliative care, its mission and achievements, is still low. The approach to patient is still disease-oriented instead of being patient-oriented and holistic. The patient's right to the best possible quality of life throughout disease trajectory is still underrecognized. Preservation and improvement of quality of life for patients and their family should be viewed as an important goal of patient care and should be given equal priority with diagnosis and treatment of the disease (3). Disease-directed approaches and (a patient and family-directed) palliative care interventions should be placed alongside each other and tailored to the clinical circumstances of the patient (10). In Serbia and Montenegro, significant progress is made in palliative care for cancer patients and for elderly, while pediatric palliative care and palliative care for non-malignant diseases (AIDS, respiratory disease, heart disease, neurological disorders) is less developed.

Palliative care settings and services

There are a few palliative care services and they rely mainly on the interest of the individuals. The services are mostly nonspecialized, medical and nursing services. Specialized palliative care services, defined as "services with palliative care as their core specialty and which are provided by an interdisciplinary team, under direction of a suitable trained and experienced palliative care professional" (2,3) almost do not exist. Specialized palliative care services include: inpatients palliative care units, hospices, hospital palliative care

teams, home palliative care teams and day care centers (3). We completely lack any inpatient palliative care unit. There is no hospital beds exclusively allocated to palliative care. The Institute for Oncology and Radiology of Serbia (IORS) has one supportive unit with 4 beds where the patients are admitted for prevention and management of toxicities induced by anticancer treatment as well as for treatment of cancer associated symptoms / complications (11,12). At the moment, there are no hospices in our country. There is 1 palliative care team at the University Hospital Bežanijska Kosa (Belgrade) and 1 supportive care team at the Institute for Oncology and Radiology of Serbia (Belgrade).

Home palliative care is provided through three different approaches in health care system. First, at the primary healthcare level, physicians and nurses working in so called "Primary Health Centers" provide usual, mainly basic physical care, to the person with advanced progressive disease and their family at home as an integral part of routine practice. Health professionals working in these services may have received some palliative care education, but they are not suitably educated and trained. The care is provided through two different forms of service: a) service for home treatment and care and b) polyvalent patronage service. Second, the Institute for Gerontology, Home Treatment, and Care (IGHTC) provide non-specialized palliative care to elderly citizens at home at ten municipalities of Belgrade. Symptom control is mainly provided, but also some forms of psychological and social support. Third, the Centre for palliative care and palliative medicine: BELhospice (Belgrade) has recently established home care team with specialist palliative care service (13). At the moment this team consists of palliative care specialist, nurse, psychologist and 1 volunteer. There are 7 services for cancer pain management, all of them providing consultations for outpatients and 2/7 also for inpatients. There are no day care centers and bereavement care services in our country. Palliative care for children does not exist in our country. There are no specialist palliative care services and no beds allocated to children with palliative care needs. Social affairs services contribute to palliative care services through gerontology centers and homes for elderly. Palliative care services are funded by compulsory health insurance funds, governmental budget for social needs and by out of pocket payment for some categories.

Palliative care workforce capacity

Much of the professional support given to patients with palliative care needs is delivered by practitioners who are not specialist in palliative care and who are not suitably educated and trained. In general, somatization of medicine is present; the approach to patient is still disease-oriented and not holistic. Provision of care is mainly focused on physical domain, while other aspects of support (social, psychological, emotional, spiritual) are less frequently provided. There is 1 physician holding a diploma in palliative medicine (Dr. Nataša Milićević, medical oncologist) and 4 physicians educated and trained abroad in palliative / supportive care. Ten nurses and a small number of other relevant practitioners (3 social workers, 3 psychologists / psychiatrists, 2 physiotherapists / occupational therapist and 2 chaplains) have received some palliative care training, mainly through routine daily work with patients with advanced progressive diseases. We have not succeeded in recruiting volunteers to work in palliative care services; so far we have only 1 volunteer working in the BELhospice centre (13). Palliative care for children does not exist in our country. However, at the IORS, there is 1 pediatrician oncologist educated and trained abroad in palliative care and 1 psychologist providing psychological help and support to children / adolescents suffering from cancer and their families.

Policy and organization

Serbia and Montenegro has no national guidelines, recommendations, standards or policy concerning palliative care (9). At the moment there is no legislative framework for palliative care. Availability and accessibility of essential drugs for palliative care, especially of impor-

tant WHO recommended opioids, is still low and inadequate. Immediate release oral morphine is unavailable in our country.

Several important steps were, however, made. National Task Force for Palliative Care in Serbia was established in April 2005 under the auspices of the Ministry of Health (president: Dr. Nataša Milićević, vice president: Dr. Snežana Bošnjak) with the aim to: promote palliative care goals and achievements according to Recommendation of the Council of Europe (2), make palliative care an integral part of a country health care system, increase awareness and applicable knowledge among healthcare professionals / public in general of palliative care, and highlight the right of patients and their families facing life-threatening illness to have the best possible quality of life, as an ethical and clinical imperative. The Task Force has 15 members among them 2 representatives of the Ministry of Health (public health specialists), 1 representative of the Ministry of Labor, Employment and Social Policy, 1 specialist in neurology, 1 specialist in infectious diseases, 2 specialists in internal medicine (pulmology), 1 specialist in internal medicine (gerontology), 1 specialist in internal medicine (medical oncology), 1 general practitioner, 1 general practitioner (gerontology), 2 nurses, 1 psychologist and 1 chaplain. Also, first Centre for palliative care and palliative medicine BELhospice was established in Belgrade (2004, director: Dr. Nataša Milićević), as a non-governmental, non-profit organization with the goal to promote palliative care as a discipline, to provide good quality palliative care for patients and their families, to organize education in this field and to promote the idea and the philosophy of hospice / palliative care in the country (13). BELhospice is supported by Hospice of Hope from the UK as part of the "Beacon Project". One of its first tasks was to translate the *Recommendation to member states on the organization of palliative care issued by the Council of Europe* (2), and to establish a Palliative Care School.

Education and training

Palliative care is not included in medical undergraduate or postgraduate school curriculum, in nursing school curriculum or in school curriculum for other relevant practitioners working with patients with advanced progressive disease (i.e., social workers, psychologist, physiotherapists, chaplains) (9).

However, there have been several multiprofessional educational courses on palliative care organized in the last several years, for example: Palliative Care School on palliative care in general (October 2004: 35 participants; May 2005: 35 participants), an international Education Symposium on supportive care in cancer patients (October 2004: 158 participants) (14); two courses held on palliative care in patients with lung cancer (April, 2002:140 participants; December 2004: 200 participants) and two courses on palliative care in elderly patients (October 2003: 90 participants; March 2005: 128 participants).

Key international publications, such as WHO monographs on cancer pain relief (15) and symptom relief in terminal illness (16) have been translated as well as *Recommendations on the organization of palliative care from Council of Europe* (2). Useful local publications have also been produced such as "user friendly" handbook for physician and nurses on the pharmacotherapy of cancer pain (17), an educational flyer: "True and false about the use of oral morphine in cancer pain management", as well as a brochure on the proper use of transdermal fentanyl in the treatment of cancer pain. The Serbian Society for the Fight Against Cancer has published a paper: "Drugs for the management of cancer pain" for patient and family education (18).

Quality improvement and research

In accordance with the CoE recommendation that "all palliative care interventions should be supported to the greatest possible extent by relevant research data" (2), first evidence-based clinical practice guideline for palliative care in cancer patients was developed with recommendations for the management of pain, chronic nausea and dyspnea (19). Its dis-

semination and implementation took place during the year 2005. Also, according to the CoE recommendation that "collaborative research, but at national and international level should be encouraged" (2), several international (20,21) and national (22-26) research studies were conducted. Finally, professional links were made and active cooperation is ongoing with the most important international organizations such as: the International Association for Hospice and Palliative Care (IAHPC), the European Association of Palliative Care (EAPC-EAST), the International Observatory on End of Life Care, the European Society of Medical Oncology (ESMO - Task Force on Palliative Care), the Multinational Association of Supportive Care in Cancer (MASCC), the Open Society Institute, the Hungarian Hospice Foundation; with international hospices (St Christopher's Hospice - London, Hospice Palium - Poznan); with hospital palliative / supportive care teams (palliative care and treatment of pain: hospital Hotel Dieu, Paris; palliative care and treatment of pain: the Institute Gustave Roussy, Paris; the academic unit of supportive care: the Hallamshire Hospital, Sheffield); with international leaders in palliative care (S.H. Ahmedzai - UK, E. Bruera - USA; J. Luczak - Poland; J.M. Lassauniere - France; P. Poulain - France; N. Cherny - Israel; C. Ripamonti - Italy; D. Clark - UK, C.J. Furst - Sweden).

Support for the family

An education and support program "Learning to live with cancer" for cancer patients and their family members / significant ones is running at the IORS with the goal to improve the knowledge and understanding of cancer and modern anticancer approaches, to inform participants about possible reactions to a new state of crisis, to relieve emotional distress and to raise capability of person fighting with cancer to attain control over health and life (27). Several patients' associations, such as: "Living like before" (for women with breast cancer) or Association of parents of children diagnosed with cancer as well as Association of patients with colostomy provide support for patients with cancer and their families.

In conclusion, palliative care still has not received adequate recognition in Serbia and Montenegro. There are no national guidelines, recommendations, standards or policy concerning palliative care. Palliative care services are mostly nonspecialized while specialized palliative care services almost do not exist. There is no hospital beds exclusively allocated to palliative care. Provision of care is mainly focused on physical domain, while other aspects of support (social, psychological, emotional, spiritual) are less frequently provided. Much of the palliative care is delivered by practitioners who are not specialist in palliative care; however there is 1 physician holding a diploma in palliative medicine and 4 physicians educated and trained abroad. Availability and accessibility of essential drugs, especially of important WHO recommended opioids, is still low and inadequate. Immediate release oral morphine is unavailable. The first important steps towards better palliative care have been taken namely: the establishment of the National Task Force for Palliative Care in Serbia, the foundation the Centre for palliative care and palliative medicine (BELhospice, Belgrade) and the publication of the evidence-based clinical practice guideline for the management of cancer pain, chronic nausea and dyspnea. Nevertheless, there is a lot to be done.

Note

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