

Palliative Care in the Czech Republic in 2013

The perspective of the Czech Society for Palliative Medicine, member of Czech Medical Association of J.E. Purkyne

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Basic epidemiologic data and the need for palliative care in the CR

How people die in the CR

With its population of 10,5 million inhabitants the Czech Republic belongs to the developed and relatively rich European countries. Every year 105 000 people die in the CR: 25% of malignant tumours, 50 % of circulatory system diseases (cardiovascular and cerebrovascular diseases), the remaining 25 percent being pulmonary, liver and kidney diseases, poisoning and accidents¹. Most of the people thus die of progression or complications of some chronic disease. The structure of death causes is similar to that in other developed East and West European countries. Based on the knowledge of the usual course of these most common diseases, it is possible to estimate that in the CR there are 60-70 000 chronic patients in advanced and terminal phases of incurable diseases, who need some kind of palliative care every year.

Where people die in the CR

In the CR, as in other European countries, the most frequent place of death is acute hospital (60%) and long-term care hospital (9%). About 20% of deaths occur at home. The last case however consists mainly of sudden unexpected deaths when the patients die before the arrival of the first aid and medical service team. According to qualified estimation only 5-10 % of home deaths are expected.

End-of-life care in the CR – the 2013 reality

In the last ten years it has been recommended, when analysing quality and accessibility of the palliative care in the public health system, to work with two levels of palliative care: general palliative care and specialised palliative care.

General palliative care in the CR

We describe as general palliative care the clinical care that health workers of different specialisations provide to terminally ill patients within their routine care. The quality indicators of this care (at the public health system level) are: palliative care education of health workers, quality of the health worker-patient communication, accessibility of essential drugs to control the symptoms and the willingness of doctors to prescribe these drugs, factual

¹ The data about the causes and places of death are from official Ministry of health statistics published in Zemřeli 2011. Praha.UZIS 2012. ISSN: 1210-9967. See: <http://www.uzis.cz/katalog/zdravotnicka-statistika/zemreli>

possibility to choose the place of care, hotel services quality in health care facilities, accessibility of psychological care etc.

Unfortunately there are no representative data either about the quality of end-of-life care or about the quality of life of advanced medically ill patients for the Czech Republic. Existing case studies, personal experiences and surveys and assessments however show that:

Primary care

- General practitioners (in general) are insufficiently trained in palliative care. They are neither able nor willing to conduct and coordinate the end-of-life care. Often, especially in towns, they are unwilling to visit patients at home. The GPs are also not very keen to prescribe the necessary symptomatic drugs (opioid analgesics, antiemetics, infusions – parenteral hydration for home use, bandages, and medical aids).

Out patients specialists

- Even in very advanced stages of diseases (in the last weeks and days of life) patients are followed and cared for in several specialised ambulatory centres (such as cardiology, diabetology...)
- Specialist doctors are often insufficiently educated in the palliative medicine and they do not try hard enough to relieve pain and other troublesome symptoms.
- A network of pain management clinics has been set up in the past ten years. Still the accessibility of their care is insufficient at present. Moreover these ambulances usually provide only pain management and not comprehensive palliative care.

Home care and long term care

- There is quite a dense net of home care agencies in the CR that provide nurse care upon indication of a GP or an ambulatory specialist. This service is covered by the public health insurance. Apart from the home health care, most of the country is covered by home assistance services that provide social care: help with shopping, cooking and washing and personal assistance.
- The general home care for the patient at the end of life does not have the character of a multidisciplinary team work. A doctor is not part of the team and it is not possible to count on his/her visits in the patient's home especially outside his/her working hours. Most of the home care agencies do not operate continuously (7/7, 24/24). The nurses are not specifically trained in palliative care.

Residential homes for elderly and nursing homes

- Medical care in residential homes (most commonly in nursing homes for seniors) is usually provided by general practitioners. The quality of medical and nursing care and of complex psychological and social care in the end-of-life phase is very varying and differs greatly according to individual establishments. The situation is similar to that of patients in the care of home care agencies described above.

Inpatient medical settings

- Most patients in the end-of-life phase (last weeks and days of life) are referred to hospitals to receive acute care because according to their doctors their care is “not manageable” in their home environment. This “unmanageability” however is very

often sign only of insufficient support and help provided to patients and their families by the health system.

- The end-of-life care for patients in inpatient establishment of acute, post-acute and long-term care is often inadequate. The most frequent deficiencies include: bad communication with family, insufficient treatment of pain and other symptoms, too many beds in rooms, small attention given to psychosocial and spiritual aspects of the disease. Exceptions exist of course.
- The opinion survey conducted in a representative sample of lay and professional public in 2011 by the agency STEM/MARK proved that citizens (potential patients) in the CR are worried about their end-of-life care. They fear that in hospitals and especially in nursing homes their pain will not be sufficiently treated and that not enough attention will be paid to their psychic, social and spiritual needs and difficulties.

Specialised palliative care in the CR

Inpatient hospices and palliative care units

The hospice and palliative care as a specific multiprofessional approach and model of care for the incurably ill has been developing in the CR only after 1989. Since the beginning the inpatient hospice care has been developing the most. Inpatient hospices in the CR are usually non-governmental health establishments that exist independently (not as part of other health institution such as hospitals). Apart from these there are two palliative care units that are part of other health institutions.

Financing of inpatient hospice care is multi-source. 40-60% of total costs. Funding of specialised palliative care from public health insurance) is covered by the public health insurance. About 20% of costs are covered by the health care subsidies and social care allowances. The hospices have to raise 20-40% of their necessary income from donations and collections. The patients pay a fee of CZK 200-500 per day. At present there are 16 hospices in the CR and two palliative care units with the total capacity of 460 beds (i.e. 4,5 beds per 100 000 citizens), with the average time of hospitalisation of 30 days, mortality of 80-95%. In 2011 3,5% of all deaths in the CR happened in inpatient hospices. Most inpatient hospices are associated in the Association of Hospice Palliative Care Providers².

Out-patient palliative care, home hospice care and mobile specialised palliative care

There are 90 pain management clinics (PMC) in the CR. They are led by doctors with specialised licence in Palliative Medicine and Pain Management. The PMCs care mostly for non-oncologic patients with chronic pain and do not provide comprehensive palliative care. There are two oncology centres with a dedicated palliative oncology clinic led by palliative medicine specialists who provide ambulatory palliative care to oncologic patients.

Since 2001 the Hospice Association Cesta domů³ (the Homecoming) has been developing a multiprofessional specialised palliative care model (a mobile hospice) in Prague. Cesta domů has produced Palliative Care Standards and for many years it has initiated negotiations about

² Official webpage: <http://www.asociacehospicu.cz/>

³ Official webpage: www.cestadomu.cz

the appropriate form of funding of this care with the Civil Service and with the VZP ČR (General Health Insurance of the CR). Besides the Prague mobile hospice there are only three other home hospice organisations of similar scope and complexity in the CR.

Education in general palliative care

The improvement in the end-of-life care requires improvement in the palliative care knowledge and skill both specialised and general. The development of palliative care education in undergraduate teaching in medical schools and universities is part of this endeavour. A number of palliative care topics are already part of undergraduate curricula. Palliative care is also taught as an independent subject in nurse study programs on several medical schools. The contents and extent of the training in these schools differ greatly. An integrating subject that would focus on end-of-life care is missing completely in the curriculum of future doctors. In 2013 palliative care is taught as an independent subject (facultative) only at the faculty of medicine in Brno. The palliative care topics are purposely taught only within the specialisation preparation for the programs General Medicine and Oncology.

Palliative medicine as a medical specialty

Since 2004 there exists in the CR the medical specialty Palliative Medicine and Pain Management (PM-LB)⁴. This education program covers the areas of algesiology and palliative medicine. Most applicants come from the anaesthesiology field. With the gained expertise they established a good network of ambulances and pain management centres. Since 2004 125 doctors received licence in this specialisation and most of them work in pain management ambulances. Only 15 doctors work solely in palliative care. In 2010 the PM-LB course has been divided into two independent extended courses (certified courses): Palliative medicine (PM) and Algesiology (ALG). In 2012 16 doctors received the PM license and another 10 are preparing for the specialisation.

Legislative position of palliative care in the CR

The Czech health policy creators do not view the palliative care area as an autonomous field providing health and social care that demands a conceptual approach. Negotiating and adopting the National Plan for Palliative Care Development in the CR by the Czech government stagnates for different reasons a (see below).

The Czech Society for Palliative Medicine JEP CMA (ČSPM ČLS JEP)

The Czech Society for Palliative Medicine (ČSPM) was founded in 2009. It is one of the professional societies of the Czech Medical Association of J.E. Purkyně⁵. At present it has 130 regular members. The main goal and mission of the ČSPM is the development and support of education and good clinical practice in the area of general and specialised palliative care for patients in the final phase of their life. The publication of 2013 Standards of Palliative Care has been an important step towards this goal. The document was developed with the support of the Czech Ministry of Health. The ČSPM guarantees and organises specialised (licensed) preparation for the Palliative Medicine Program. In cooperation with the Post

⁴ Law 95/2004 Sb., o podmínkách získávání a uznávání odborné způsobilosti a specializované způsobilosti k výkonu zdravotnického povolání lékaře, zubního lékaře a farmaceuta

⁵ Official website of ČSPM: www.paliativnimedcina.cz

gradual Education Institute the ČSPM organises a number of courses within the frame of specialisation and lifelong education for doctors. The ČSPM is a collective member of the European Association of Palliative Care (EAPC). It is actively preparing the 13. EAPC World Congress that will take place 30.5.- 2.6. 2013 in Prague. The main motto of the Prague congress is "Access to palliative care the right way forward". ČSPM organises the annual Czech-Slovak Conference of Palliative Medicine. In 2013 it will take place 19.9.-20.9. at the ombudsman's seat in Brno. The ČSPM has participated in creating the Strategy for Palliative Care in the CR: conception documents produced on the demand of the Human Rights Committee of the Government Council for Human Rights in 2011. The text of the strategy has been submitted for signature to the Czech government in July 2012. Unfortunately the Strategy has not been passed or adopted yet.

The ČSPM perspectives and objectives in 2013

- to support the National strategy of Palliative Care Development (see above)
- to enforce the inclusion of further medical procedures of palliative specialists into the List of medical procedures as a necessary condition for the development of ambulatory specialised palliative medicine
- to support the development of mobile specialised palliative care in its different forms (in home or substitute social environment)
- to continue the support and development of education in the Palliative Medicine Program
- to integrate in a greater part the palliative care topics in the undergraduate and post graduate preparation for all specialisations which work with patients at the end of their lives
- to create an accredited educational program in palliative care for nurses
- to participate actively in preparing the 2013 EAPC Congress in Prague and to prepare the V. Czech-Slovak Conference of Palliative Medicine
- to establish cooperation with other disciplines and professional medical societies and start collective projects

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