

Editorial

Dear Readers,

Let me share with you, at the end of another year, a few thoughts about the issues of palliative care. The care of dying patients has been part of nursing practice since its beginning. Still, we are currently talking about palliative care and palliative medicine as about a new, rapidly evolving field. Changing the society's attitude to death and dying gradually changes the doctors' and other health workers' attitude to this topic. A dying patient should no longer be perceived as a "failure of medicine", but as a person who has their dignity, needs and rights, including the context of health care provision.

In the past twenty years, the definition of palliative care has been redefined. The definition by the WHO from 1990 is one of the most commonly cited, defining palliative care as a complex (symptomatological, psychosocial and spiritual) care for patients who do not respond to curative treatment, in order to achieve the best quality of life for patients and their families. At that time, palliative care was provided mainly to patients with an oncological disease with terminated curative treatment at the terminal stage of the disease. In 2002, a newer definition by the WHO was published. It put greater emphasis on the prevention of suffering and at the same time was seen in a wider concept for patients with life-threatening illness. The aim of palliative care is to promote, maintain, strengthen, and sometimes achieve a better quality of life in patients with life-threatening illness, including patients with chronic, progressive, non-cancer diseases.

The principles of palliative care, according to this definition, can be applied in the early stages of the disease and combined with curative treatment. Patients with non-cancer disease may also benefit significantly from specialized palliative care services. It has resulted in a debate about how to apply the principles of palliative care in patients who die of cardiovascular, neurodegenerative, or other non-cancer disease, and how to apply these principles in various care settings, such as in hospitals, long-term care homes, homes for the elderly or other social services facilities.

In April 2017, our department started the project AZV MZ ČR 17-29447A called "*Neuropalliative and Rehabilitation Approach to Preserve the Quality of Life in Patients with an Advanced Stage of Selected Neurological Diseases*". Patients with progressive neurological disease (e.g. patients with multiple sclerosis, Parkinson's disease, Huntington's disease or motor neuron disease) belong to a group of patients who do not die directly, but they do face life-threatening diseases and need high-quality symptom management, appropriate communication that would support and facilitate decision-making on further treatment and care and help in coordinating care provision in various settings before the onset of the terminal stage of the disease. However, palliative care services are not usually offered to these patients. Already in 2008, the European Association for Palliative Care and the European Academy of Neurology have begun to discuss the link between neurological and palliative care. As part of our project, we would like to open the question of applying the model of "neuropalliative and rehabilitation care" also in the Czech Republic. We believe that opening up a professional discussion on this topic will be also beneficial for the patients and their family members.

doc. PhDr. Radka Bužgová, Ph.D.
University of Ostrava, Faculty of Medicine,
Department of Nursing and Midwifery