

THE DEVELOPMENT OF PALLIATIVE CARE AND DEVELOPMENT PERSPECTIVES OF PALLIATIVE NEUROLOGY IN TUZLA

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INTRODUCTION

The term «palliative» has its origins in Latin, from the Latin word *pallium*, meaning robe, cover, veil or coat. And indeed, in the palliative care the symptoms are “hulled”, “covered” with different treatments in order to increase the patient’s comfort or to remove unease, just like a coat shields the body from rain or cold.

The word «hospice» is often used in the context of palliative care, and although it is used in several meanings (it sometimes refers to a building – «St. Christopher’s Hospice», sometimes to a group of people – «hospice team», and sometimes to a programme - «hospice service»), hospice is first and most the elaboration of a philosophy that can be summarized, according to the Hospice Association of Southern Australia, as follows:

«The hospice care accepts death as a normal process and understands it as the last life phase of the dying person, as a special time for integration and conciliation. It furthermore accepts the need of the dying to live a full, proud and comfortable life up to their death, it does not hasten nor defer death. And finally, it secures support to the grieving family and friends.»

The term hospice also originates from the Latin word expressing welcome, hospitality to a stranger, the warm feeling between the host and the guest. It is interesting that palliative care and hospice are mostly connected with malignant diseases (in the perception of the general public, of lay persons, of health care workers and also in technical and scientific literature), although many other (non-malignant) internal or neurological diseases can and must be treated with “palliative” and/or “hospice” methods.

According to a recent analysis of papers published in three important journals dealing with palliative care (from Great Britain, Canada and the USA), the most common primary interest of authors is the advanced malignant disease. Less than 5% of papers deal with non-cancerous states, mostly with respiratory, cardiac and renal diseases. The only neurological representative is the amyotrophic lateral sclerosis (ALS).

On the other hand, the texts and articles published in the neurology field mostly deal with diagnostic procedures and the active treatment of diseases, they rarely include states related to the care of the neurological patient at the end of his life, the effective treatment of symptoms in the advanced stage of the disease. This is a problem in itself in need of a different approach so that neurologists, but also other doctors (e.g. general prac-

titioners) could be more active in the promotion of palliative neurology, in a more intensive commitment to the identification of better (palliative) treatment of symptoms of numerous neurological states in the advanced stages of diseases.

DEVELOPMENT OF PALLIATIVE CARE IN TUZLA

The University clinical centre (UKC) Tuzla is today most certainly one of the better equipped high quality institution of this type in Bosnia and Herzegovina. But some fifteen or twenty years ago we were far from this goal. However, we have always had the wish, the enthusiasm and the will to learn and to improve. We did not want to just sit and wait for «orders», for «better times», we wanted to work with everybody that we could learn from, to use every possible opportunity for improvement. This is how we developed cardio surgery, transplantation and many other segments in the surgical and non surgical disciplines. And this is how we started the development of palliative care.

Under several favourable circumstances, in early 2003 a contact and then a cooperation was started with a nongovernmental humanitarian organisation «Sisters of the Cross and Passion» from the United Kingdom (Ireland). The sisters offered help, we accepted it and the result was the first stationary hospice opened on November 11, 2003 with 13 beds (some 500 square meters), after the reconstruction of the former hospital for pulmonary diseases (picture 1 and 2). We have concluded a contract with the regional health insurance institution according to which the hospice is to be financed like the clinics and wards within the UKC. The personnel were trained as the premises were reconstructed, mostly in the UK. The «sisters» were satisfied with



Picture 1 Clinic for pulmonary diseases before the reconstruction and the opening of the hospice



Picture 2 Hospital after the reconstruction

our work, so the cooperation continued. This resulted in the opening of an ambulatory hospice on October 20, 2005 for 12 patients a day, followed by a training centre with library on October 10, 2006. The «sisters» helped the formation of a team for palliative house calls by donating the necessary vehicles. And finally, we opened a children's hospice on May 19, 2009 (picture 4). And we are proud of it.

PALLIATIVE NEUROLOGY

Numerous subspecialisations in neurology exist providing a very high level of knowledge in certain neurological fields, but they do not (or at least very superficially) focus on the palliative approach, but instead on modern etiology, diagnostics and the

active treatment in the early stages of the disease.

To give an example, it has been seriously considered recently in the USA to introduce a special neurological specialization for the brain-vascular field, mostly due to the increasing number of brain-vascular diseases, but not, as far as I know, (not only in the USA), to introduce palliative neurology. It is of course not necessary to formalize knowledge and have the approach through specializations or sub-specializations in order to change things, but is most certainly necessary to do something about the training of "everybody involved".

In practical neurology many degenerative diseases are incurable causing major difficulties to the patient himself and to his family. Some of them are quickly progressive, like ALS with a fast development of difficulties in speech, swallowing and breathing, some are slower like the Duchenne muscular dystrophy with a progressive development of respiratory insufficiency. Both diseases, that are fortunately not very common, require a certain degree of knowledge of palliative neurology and the application of the palliative approach, but not many countries and not many communities offer them to the patients and their families.

There are furthermore numerous neurological diseases (dementia, brain vascular disorders, Parkinson's disease, multiple sclerosis, painful neurological syndromes) leading the patient and his family to a very difficult state throughout the years. These patients normally do not get held in large clinics («this is a thing for the lower health care levels»), in cases where the service exist, they are not easily accessible (lack of personnel, appointments, distance). On the «lower levels» on the other hands, there is not enough knowledge, and even less understanding or financial support.

PERSPECTIVES FOR THE DEVELOPMENT OF PALLIATIVE NEUROLOGY IN TUZLA

The neurology clinic in Tuzla is a relatively small ward situated within the University clinical centre with 50 beds, providing neurological services for approximately 500 000 inhabitants of the Tuzla region. In the last years the Clinic provides highly differentiated diagnostic and therapeutical services for patients from several regions of Bosnia and Herzegovina (the Federation of Bosnia and Herzegovina, the Brčko district, partly the Serbian Republic), counting more than 2 million inhabitants. The clinic has 14 specialists, four residents and 42 nurses. It is a teaching unit for the Medical, Pharmaceutical, Educational and rehabilitation school and the High school for health care of the University in Tuzla.

The clinic has a relatively good development trend, it has been based on certain principles for several years (permanent education, uniform development of all subunits/neurological fields, chances for creative individuals, educational contacts with others, own initiative for improvements). We always try at the Clinic to put the patient in the centre of our work, the holistic approach in the daily clinical practice is nurtured, and all employees are continuously trained.

And what about palliative neurology (care)? Can the undergraduate study give students basic knowledge of palliative / hospice care? Is this possible in the postgraduate studies? Is



Picture 3 Hospice interior



Picture 4 The children's hospice

it possible to have a neurological hospice alongside the existing hospice (hospital and ambulatory), functioning within the UKC and the regular health care system and soon a children's hospice?

Is it possible to have palliative outpatient clinics/services within the Clinic for the control of different symptoms in chronic neurological patients? Is it possible to function in multidisciplinary teams in this context?

The answer to all these questions is – yes! We must only persist in the idea and in the mentioned principles for the introduction of palliative neurology into practice. Just like we introduced speech pathologists and teams for early rehabilitation, like we encouraged anaesthesiologists/intensive care specialists to work together on myasthenia crises, the epileptic status, respiratory insufficiencies in Guillain-Barre syndrome (GBS), like

we motivated nephrologists to apply plasapheresis in the treatment of myasthenia gravis together. Like we formed the brain stroke unit and introduced thrombolysis in the treatment of the acute ischemia insult, like we started the treatment of blepharospasm and focal dystonia by botulinum toxin, like we introduced neuropsychology in the everyday clinical practice...

CONCLUSION

In order to realize some of the abovementioned questions (goals) we do not need money (training), we do not need „directives from above“, we do not need „better times“, there is a motive, it must still be „polished“, and the money question is certainly not the decisive one. Palliative neurology is definitely on the agenda in Tuzla.