BULGARIAN LONG-TERM AND PALLIATIVE CARE SOCIETY

Prof. Dr. Lyubima Despotova-Toleva, PhD is the chairman of the Bulgarian Long-term and Palliative Care Society. She holds diplomas for acquired specialties in pediatrics, general medicine, health management, certificate of medical law, she has also completed a specialization in pediatric cardiology. She has specialized, conducted research and was a guest lecturer at leading universities in a number of European countries, England, USA, Japan, Iceland, etc. Prof. Lyubima Despotova-Toleva is the author of over 30 monographs, textbooks and manuals, over 130 scientific publications and about hundred quotes in Bulgarian and foreign specialized publications. She has been a scientific supervisor of successfully defended PhD students and others at a different stage of their doctoral studies. She teaches general medicine to medical students and specialist doctors, conducts postgraduate training courses aimed at a wide range of specialists, incl. in the field of pain management and palliative care. She speaks German, English, Russian, uses French. Prof. dr. Lyubima Despotova-Toleva is a permanent member of the World Organization of General Practitioners WONCA, a Board Member of EMA and EGPRN, a permanent member of the International Association of Hospice and Palliative Care /IAHPC/, World Hospice and Palliative Care Alliance /WHPCA/, National Association of General Practitioners in Bulgaria /NAGPB/, Bulgarian Medical Association and others. She is an organizer of international and national scientific congresses, conferences, seminars, etc. and the editor-in-chief of the Folia Palliatrica journal.

1. **How many and what patients need palliative care every year in our country and how many of them receive it?**

Prof. Lyubima Despotova-Toleva, MD, PhD :
The number of people in need of palliative care in our country cannot be exactly named. According to the WHO definition, palliative care aims to improve the quality of life of patients with life-threatening illnesses and their families by preventing and alleviating suffering by early identifying, accurately evaluating and treating pain, other symptoms and problems of physical, mental and spiritual nature (it is particularly important that the doctor and the clergyman cooperate in the interest of the patient). This naturally requires the use of a holistic approach, also called bio-psycho-social, which is fundamental and most important to work in general medical practice. It is high time our institutions to realize that palliative care should be given to all those in need, without being limited by diagnosis and prognosis. Statistically, on first place among diseases in which patients need palliative care, is cardiovascular disease - 38.47% of patients. Only after them are cancer, respiratory diseases, HIV / AIDS, diabetes mellitus, kidney, neurological, rheumatoid and other diseases. In other words, oncology patients are only one third of those in need of palliative care. In fact 78% of the adults in need of palliative care are in low or middle income countries to which Bulgaria belongs. This means that, unlike many European countries, there are many more patients in our country who need, but do not receive the necessary palliative care.

Not only adults but **children** need palliative care.
The distribution of these children by gender is the same as in adults, but there are significant differences in diseases leading to the need for palliative care. Overall global statistics show that children have the highest proportion (25%) of congenital abnormalities followed by various conditions in the neonate period (14%) followed by meningitis, HIV / AIDS, cardiovascular, endocrine, immune , cancers, neurological, renal and hepatic diseases in minimal percentages. Almost all children in the world who require palliative care (98%) at the end of their life are from low or low middle-income countries (or 35% and 48.5% respectively). In high income countries, only 2% of children have palliative care needs. It is good to say that along with the term palliative care there are other different terms - long-term care, supportive care that basically describe the same comprehensive approach to the needs of patients with life-threatening diseases and their families. In addition, it is necessary to clearly distinguish the palliative from the terminal care that is placed on the dying patient. One more concern should not be forgotten - the condolence care of the family and relatives after heavy loss. Overall global statistics show that about 6% of children under14 need palliative care, 25% aged 15-59 and 69% over 60. The gender breakdown shows that 52% of those in need of palliative care are men and 48% are women. Impressive is the fact that the smallest percentage of children in need of palliative care (only 3%) is in the European countries. Therefore, it is very difficult, even impossible, at this point, to find accurate data on what exactly patients in our country, according to the WHO definition, have a real need of palliative care.

2. How many public and private hospices are there in Bulgaria?

Prof. Lyubima Despotova-Toleva, MD, PhD :

Hospices in Bulgaria are very few and unevenly distributed. In November 2017, architect Nina Toleva-Nowak prepared and published an interesting map of hospices registered under the Hospitals Act, their location and distribution by district, based on Internet access data

from Regional Health Inspectorates (current to the summer of 2017). It is clear that from the 28 administrative districts in Bulgaria there is not even one hospice in 10 of them, and in 9 there is only one for an area. From the remaining nine districts, only two have more than three hospices - Sofia and Varna. The worst is the situation in Northern Bulgaria. The problem is that more and more registered hospices close doors without opening new ones on their place. Another issue is the emergence of "hospices" that are not actually registered under the legal order and mislead both patients and their relatives who are in a particularly vulnerable position.

3. Why do so few people get palliative care?

Prof. Lyubima Despotova-Toleva, MD, PhD :

The reasons for this are many: there is a lack of understanding about the problems of palliative medicine; there is no reasoned adequate legal basis; lack of trained staff, lack of motivation in health care facilities, along with other problems to solve those of the palliative patients and their families; lack of adequate funding, etc. In practice, we do not apply the WHO definition of palliative care to allow a wide range of needy and their families to receive high-quality care and improved quality of life. Normatively, there is only one clinical palliative care pathway, targeting only cancer patients in the last stage of the disease, thus violating the rights of all other groups of palliative patients. We have recently published analytical material on the legal aspects of palliative care. Health policy makers should make it clear that the deprivation of many patients who do not fall within the quoted clinical path means a violation of their rights.

4. What should we change?

Prof. Lyubima Despotova-Toleva, MD, PhD :

First of all, thinking and understanding the issues.

Then we should carefully examine the real situation in Bulgaria regarding the need of palliative care and determine:

- The groups of patients who need palliative care

- The distribution by region

- The possibility qualified medical professionals by additional training to acquire knowledge and skills to work with such patients and their families.

It is necessary to create a relevant legal basis for the training of highly qualified doctors, nurses and other medical and non-medical specialists, as well as a national standard which guarantees high-quality specialized care for the palliative patients and their families. It is important to initiate training of medical specialists at all levels - doctors, nurses, rehabilitators, etc., and in its curriculum palliative medicine / care to be introduced as a mandatory subject in the Uniform State Requirements; to accredit the specialty as graduate doctors specialize shorter or longer depending on their qualifications – e.g. 3-4 years for basic medicine in palliative medicine and 1

year for doctors who have acquired another medical specialty (e.g. internal diseases, pediatrics, anesthesia and resuscitation, surgery, oncology, cardiology, etc.). Naturally, it should be accredited as a scientific specialty, which will guarantee a high scientific level of research, will allow the training of researchers and the development of dissertations in this field. It is also important to train non-medical staff to cope with the spiritual, legal, moral-ethical issues and dilemmas that often arise in the process of long-term palliative care. .

5. **Oncological hospitals claim that the money that the National Health Insurance Fund pays on the path of palliative care is too low. Is this true?**

Prof. Lyubima Despotova-Toleva, MD, PhD :

As I have already said, it is necessary to understand that not only oncological patients need palliative care. Considering that palliative care can be found in the home, in general practice, in hospices, in daytime hospices and in hospital departments of different levels, the issue is not relevant from the point of view of qualified palliative care. Oncological hospitals are not and cannot be the only places to provide such help. It is not possible to prescribe only one clinical pathway, thus depriving many more patients of the opportunity to receive the qualified help they need. And yes, financing on this single path is not enough.

6. Should oncological hospitals be obliged to provide such services? For example, for a chemotherapy contract they must have their own palliative care beds?

Prof. Lyubima Despotova-Toleva, MD, PhD :

Again the problem is displaced. I do not know why in Bulgaria the focus is on oncology and oncology patients only, since it is clear that they are only a third of those who need palliative care. Not only oncological hospitals, but other hospitals: university, multiprofile, etc. should have wards or beds in clinics designated for palliative patients.

7. How are these issues solved in Europe?

Prof. Dr. Lyubima Despotova-Toleva, PhD :

In short, they are solved on all levels, regardless the difficulties, because there are difficulties everywhere. Societies are committed to these problems. Needs are dynamically assessed, there are training and further training programs. Different types of medical care facilities aimed at providing palliative care are available, such as hospital departments (e.g. Sir Michael Sobel House at Churchill Hospital in Oxford), hospices, day-care hospices / hospitals, in the context of general practice. Palliative teams that provide home help are also very helpful.

There are different models of palliative care. Good examples can be found in England, Austria, Germany. Iceland is a good example of high-quality, long-term and palliative care adapted to the

community and the family. From our point of view, Icelandic solutions would be applicable and useful for Bulgaria. Interesting and also good is the Canadian model from Edmonton, where a regional palliative care program has been successfully implemented. Maybe it will sound exotic, but India is also working very actively and has successful models. Volunteers, non-governmental organizations, etc. are actively involved.

At the end of our conversation I would like to repeat that palliative care has both medical and non-medical aspects and they cannot be separated. The Bulgarian Long-term and Palliative Care Society has set itself the main goal to assist in the development and validation of long-term care and palliative medicine, health and medical science in the interest of patients, their families and relatives and society. It unites specialists, highly motivated to change attitudes in our society, to influence health policies, and to contribute patients, their loved ones and society as a whole, to receive optimal modern treatment and care.

Идеята ми е материалът да се оформи като интервю. Според отговорите Ви може да се наложи да пратя и уточняващи въпроси.
Естествено, ще Ви пратя материала за одобрение в окончателния му вид. При интервю е нужно да се публикават и снимка - ако е удобно да пратите Ваша, но не портретна като за паспорт, а например сендала зад бюро, все едно говорите с мен:), и визитка - основни данни за образование и професионална реализация