

## THE DEVELOPMENT OF PSYCHO-ONCOLOGY WORLDWIDE AND IN SERBIA - FIRST STEPS AND FUTURE PLANS

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### Abstract

Psycho-oncology is a well-developed field in developed countries around the world and in Europe, both theoretically and practically. Psycho-oncology refers to the provision of psychological and/or psychotherapeutic assistance and support to persons with malignant diseases and their families. Twenty-two world congresses in psycho-oncology have been held. The existence of many published books, peer reviewed journal articles, numerous courses and specialization in this area attests to the importance of progress in this field. This paper serves to highlight the development of psycho-oncology in the world, with special emphasis on the current state of the discipline in Serbia. The number of publications and scientific research in the field are still limited and the number of engaged professionals is insufficient to effectively implement psycho-oncology in the Serbian health system. Nonetheless, there is reason for optimism. Pursuant to Article 38, paragraph 1. of the Law on the Planning System (Official Gazette of RS, No. 30/18), the Government of RS has adopted the *Program for the Advancement of Cancer Control in the Republic of Serbia* for the period between 2020 and 2022. The Action Plan for the Implementation of the *Program for the Advancement of Cancer Control* pays special attention to the development and implementation of psychosocial services and their integration into oncological treatment. The plan specifically envisions the establishment of 6 and 8 psycho-oncological services and counseling centers in health institutions in the secondary/tertiary level, in which cancer patients are treated, in 2021 and 2022 respectively. If the intended plan is realized, it will be a huge step forward and the beginning of the systematic, earnest development of psycho-oncology in Serbia.

**Key words:** cancer patients, psycho-oncology, psycho-social aspects of care, psycho-oncological services, counseling centers

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## РАЗВОЈ ПСИХООНКОЛОГИЈЕ У СВЕТУ И У СРБИЈИ – ПРВИ КОРАЦИ И БУДУЋИ ПЛАНОВИ

### Апстракт

Психонкологија је у развијеним земљама света и Европе развијена област, како у научно-истраживачким тако и у практичним, примењеним аспектима који се односе на пружање психолошке и/или психотерапијске помоћи и подршке особама оболелим од малигних болести и њиховим породицама. До сада је одржано 22 светска Конгреса из психонкологије. Много објављених књига, високо индексирани часописи, бројни курсеви и он лине курикулуми, специјализације и субспецијализације из ове области говоре о развијености области. Циљ овог рада је да укаже на развијеност психонкологије у свету уз посебан осврт на актуелни статус дисциплине у нашој земљи. Недовољан број ангажованих професионалаца у пракси, и мали број публикација, научно-истраживачких и стручних радова указују на недовољну имплементираност психонкологије у здравствени систем Србије. Разлога за оптимизам ипак има. На основу члана 38. став 1. Закона о планском систему („Службени гласник РС”, бр. 30/18) Влада РС је донела *Програм за унапређење контроле рака у Републици Србији за период од 2020-2022* године. Акционим планом за спровођење програма за унапређење контроле рака предвиђена је посебна мера која се односи на развој и спровођење психосоцијалних услуга и њихова интеграција у онколошко лечење што конкретно значи да се током 2021 године планира оснивање 6 а 2022 године 8 психонколошких служби или саветовалишта у здравственим установама секундарног/терцијарног нивоа у којима се лече онколошки пацијенти. Уколико се предвиђени план реализује то ће бити огроман корак и почетак системског, озбиљног развоја и примене психонкологије у Србији.

**Кључне речи:** онколошки пацијенти, психонкологија, психосоцијални аспекти лечења, психонколошки сервиси, саветодавни центри

### *THE DEVELOPMENT OF PSYCHO-ONCOLOGY<sup>1</sup>*

The successful development of psycho-oncology in the developed countries of the world and in Europe is reflected in the fact that 22 world congresses in the field have been held, with participants from over 40 countries of the world. The author of this report was invited to be a lecturer at the 19<sup>th</sup> World Psycho-Oncology Congress, which was held in Berlin. The title of the lecture was “Development of Psycho-Oncology in Serbia - first steps and future plans” and it was held as part of the symposium: Development of Psycho-Oncology in the Central-Eastern Europe. The symposium included representatives from our country, as well as col-

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<sup>1</sup> Part of this article was presented at the 19<sup>th</sup> World Congress of Psychooncology and published in Abstracts of the 19<sup>th</sup> World Congress of Psycho-oncology. Asribabayan Y., Klikovac, T. (2017). Psycho-oncology capacity building in Armenia and Serbia: first steps and future plans. Abstracts of the 19<sup>th</sup> World Congress of Psycho-oncology. 26 (3):50-51.

leagues from Armenia, Hungary, Slovenia, Russia and Romania (Asribayyan & Klikovac, 2017). World congresses in psycho-oncology have been held annually with several hundred experts from all parts of the world presenting scientific papers and challenging cases from clinical practice. The field is supported by numerous textbooks, highly respected journals, an International Society of Psycho-Oncology, as well as numerous courses and on-line curricula. Most specialized fields of oncology and psychology recognize the importance of further development in this area.

The subspecialty of psycho-oncology began to develop formally in the mid-1970s and *The Journal of Psychosocial Oncology*, established in 1983, was the first journal dedicated to the dissemination of current research in the field. Dr. Jimmie Holland is recognized as the primary founder of the field of psycho-oncology. In 1977, Dr. Holland worked with two colleagues to establish a full-time psychiatric service at Memorial Sloan Kettering Cancer Center in New York, USA, a program which is currently headed by Dr. William Breitbart. Dr. Holland's program was one of the first of its kind in cancer treatment, and trained its psychologists to specialize in issues specific to people living with cancer.

A few years before her death, Dr. Holland (2015) wrote:

“I am one of the few living today who have seen the evolution of psycho-oncology from its birth, through its adolescence, and now into its full maturity. This gives me an unusually broad perspective on the challenges and successes. Psycho-oncology is almost 40 years old, and much progress has been made in that short time. The discipline has an accepted place in the oncologic, psychological, and psychiatric community, both in clinical care and in research. Worldwide implementation of what we now know could greatly improve the psychological well-being and quality of life of patients with cancer” (Holland, Breitbart & Jacobsen, p. 6).

The development of Psycho-Oncology has been intensifying since 1984 when the International Psycho-oncology Society (IPOS) was established in the USA with the primary goal of improving the “human” side of cancer care globally. Important goals of the IPOS are:

- To foster international communication
- To educate professionals in psychosocial care across countries
- To advocate for making psychosocial care an integral part of total cancer care
- To examine social and cultural factors that impact quality of life and care

According to Holland, Breitbart & Jacobsen (2015):

“Psycho-oncology is defined as a subspecialty of clinical oncology relating to two dimensions: 1) psychological reactions of cancer patients and their families in all stages of the disease and 2) the psychological, social and behavioral factors that impact on cancer risk and survival”(p. 34).

The field of psycho-oncology is interdisciplinary. Psychosocial support for cancer patients addresses the psychological, social, existential, spiritual and other needs of persons with cancer throughout the cancer trajectory, including the assessment of personal considerations concerning treatment, rehabilitation, survival and palliative episodes (Pop, Postolica, Lupău & Dégi, 2016).

Cancer diagnosis almost always creates a crisis requiring adaptation to catastrophic information. Shock, confusion, anger, denial, disbelief, distress, isolated reactions and conditions of anxiety and depression are frequently associated with the beginning of the treatment of malignancy and the duration of the complex oncological treatment (Grassi et al., 2004; Grassi & Riba, 2012). Cancer diagnosis is a shocking experience itself, while the complex oncological treatment represents a life crisis both for the affected person and for the members of their family. Patients and families report a type of “psychic numbing” during the time of the beginning of the cancer treatment. The previously mentioned emotions and reactions to the diagnosis of a malignant disease are understandable and normal, but they can interfere with the many important, life-altering decisions to be made about treatment. Adequate communication with oncology patients from the beginning of treatment, during all phases of treatment, and after treatment, in the period of regular monitoring and control, is extremely important because patients are subject to shock, distress and various reactions or more complex conditions (anxiety, depression, declining quality of life, existential and spiritual crisis).

In 2009, the IPOS ([www.ipos-society.org](http://www.ipos-society.org)) proposed a new standard in quality cancer care (Holland, Watson, & Dunn, 2011) which states that distress should be measured as the 6<sup>th</sup> vital sign after temperature, blood pressure, heart rate, respiratory rate and pain.

The National Cancer Council Network (NCCN) defines distress as “a multifactorial, unpleasant experience of a psychologic (cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Early evaluation and screening for distress leads to early and timely management of psychologic distress, which in turn improves medical management. The panel for the Distress Management Guidelines recently added a new principles section including guidance on implementation of standards of psychosocial care for patients with cancer” (NCCN; 2021, p.1).

Among the rare research studies in the field of psycho-oncology in Serbia, there is one study conducted on a sample of 80 cancer patients<sup>2</sup>. The study showed that the great majority of patients experienced denial and depressive reactions such as disappointment, fears, and feelings of hopelessness and emptiness as significant distress signs at the beginning of cancer treatment. A large percentage of patients expressed that they felt sadness, despair, anger and anxiety about the future. A significant percentage of patients who participated in the study expressed that they had suicidal thoughts (40%) (Klikovac & Đurđević, 2010).

The assessment of distress on a sample of 40 oncology patients a year and a half after the end of their treatment showed that emotional problems (concern, anxiety, various fears, sadness and irritability and tension) in a significant percentage of patients were more pronounced compared to other problems in the post-treatment period (Klikovac, 2019; p.351).

Understanding the psychological, social, spiritual, and practical aspects of cancer and its treatment has therefore become a necessary part of multidisciplinary and complete cancer care. Recognizing different psychological reactions of cancer patients can be helpful for organizing adequate psycho-educational and psychosocial support, including psychotherapy for cancer patients and their families. Acknowledging the patients' psychological needs and organizing adequate psychological support are very important steps in integrating psycho-oncology into holistic anticancer treatments (Goerling & Mehnert, 2018).

Different topics, subject of both research and practical work, that indicate the development of the field of Psycho-oncology are: (1) psychological support for children, adolescents, young adults, adults and the elderly with cancer and psychological problems, (2) various psychological and psychotherapeutic interventions with patients with different tumor localizations (women - breast cancer, gynecological cancers; men - urological cancers, lung cancers, CNS tumors and late neuropsychological consequences, skin tumors, head and neck tumors and problems, etc.), (3) the evaluation of the different psychotherapeutic modalities in working with people with cancer, (4) QoL and patient well-being, (5) the importance of communication in oncology, (6) professional stress, burn-out and self care of medical staff, (7) the use of modern technologies (applications) in informing and providing support to patients, (8) palliative care – end of

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<sup>2</sup> This investigation was conducted at the Institute for Oncology and Radiology of Serbia, Belgrade, during the implementation of the European Educational Program (EEP) "Learning to live with cancer". At the beginning of the lectures, the patients were asked to fill in the self-describing questionnaire with 4 open questions: "Describe your common thoughts, feelings, behavior, and body reactions in the first 6 weeks of facing the fact that you were affected by cancer".

life care, (9) psychological aspects, survival and support after treatment, (10) evidence-based clinical research in Psycho-oncology, (11) Cancer care in low resource settings and (12) development of psychosocial services. There is great interest in utilizing modern technologies (e.g. websites and social networks and useful applications for smartphones) to prevent malignancies and promote healthy lifestyles, smoking cessation and diet control. Organizing forums and online support groups for the empowerment of patients is particularly interesting. Various programs and applications for practicing anti-stress breathing techniques, awareness of people who have been treated for malignancy, empowering young people facing cancer through a program to overcome the fear of relapse, sleep control applications to combat insomnia, applications to disseminate accurate information and knowledge about malignancies, and support programs for women with breast cancer and gynecological cancers represent some of the topics presented at the 21<sup>st</sup> World Congress of Psycho-oncology (Journal of Psychosocial Oncology Research and Practice, 2019).

#### *THE DEVELOPMENT OF PSYCHO-ONCOLOGY IN SERBIA*

Several years ago, Serbian media extensively discussed the prevention of malignancies, and the importance of regular screening. However, despite the recent increase in the number of advocacy groups for patients with various malignancies and their activism in our country, support programs remain inadequate. Patients' needs for expert information, psychological and social support are not sufficiently aligned with, nor have they been effectively integrated into, our country's healthcare system in accordance with world and European standards. Epidemiological data indicates that approximately 40,000 people in Serbia suffer from some form of malignancy annually, and approximately 23,000 people, including 300 children, die of various malignant diseases<sup>3</sup> each year. The current dilemma in contemporary Serbian media and the Serbian academic community is: Did the bombing of Serbia with depleted uranium in 1999 influence the increasing number of new cases of malignant diseases?

There are four clinical oncology centers in Serbia and approximately 30 oncology wards around the country (6 of them are hemato-oncological wards for children and teens). In public hospitals, there are only 10 psychologists working specifically in oncology wards (4 for adults and 6 for children). The total number of psychologists is far from enough to respond to the increasing needs of adult oncology patients. The

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<sup>3</sup> Data presented according to publications of the Institute of Public Health »Dr. Milan Jovanović Batut«, Incidence and mortality rate from cancer in central Serbia (2009, 2015). Institute of Public Health »Dr. Milan Jovanovic Batut«, Center for Prevention and Control of non-communicable Diseases, Belgrade

development of psycho-oncology, and especially pediatric psycho-oncology, in Serbia began in 2000 when the first psychologist was employed at the Department of Pediatric Psycho-Oncology of the Institute of Oncology and Radiology of Serbia. Between 2000 and 2010, psychologists joined medical teams in all 6 pediatric health care institutions in our country that had hemato-oncological and oncological wards treating children and adolescents suffering from various malignancies. The period from 2010 onwards has also been marked by the involvement of psychologists in the non-government sector, or more precisely, in various associations of parents of children suffering from malignant diseases. In our country, psycho-oncology and pediatric psycho-oncology developed primarily through practical work related to providing psychological support to adult patients, children, adolescents, and their parents during and after the completion of oncological treatments. These areas still lack comprehensive national research, monitoring studies and evaluations of the effectiveness of psychological practice, which are essential for the implementation of suitable theoretical and practical standards and models based on internationally accepted criteria of good practice. For Serbia, it is also important for psycho-oncology to further develop according to our specific socio-cultural features and the needs of ill children, and their families, in our care. In 2007, the Serbian Association for Psycho-Oncology (SAPO) was established in order to educate medical staff working with adult and pediatric oncology patients. At that time, the main focus were the occupational stress of medical staff, preventing burn-out, providing empathy and promoting successful communication skills. This effort included the first national project in collaboration with the Ministry of Health "SOS help-line for free psychological counseling and support for cancer patients and their families". During this project (October 2010 up to April 2011), a total of 2,748 patients and their families used the SOS help-line service (Klikovac, 2015; 726). Recently, new courses related to the fields of psycho-oncology and pediatric psycho-oncology have been introduced at the Faculty of Philosophy, University of Belgrade, for doctoral students at the Department of Psychology. Since October 2017, specific courses on Psycho-Oncology, Pediatric Psycho-oncology and Palliative care have been available to graduate students in psychology (Klikovac, 2018).

The *Republic Expert Commission for Support of Patients* was formed at the Ministry of Health of the Republic of Serbia in 2014/2015, with the task of highlighting the importance of adequate communication with patients and providing psychosocial assistance and support to persons suffering from the most severe diseases. One of the tasks of the Committee has been to write guidelines and standards of good practice similar to those in more developed healthcare systems, but adapted to Serbia's unique conditions (Klikovac, 2018; Šarić et al., 2018).

The *National Oncology Patients' Association* (e.g. NALOR) was founded with the main goal of lobbying for the rights of oncology patients (the right to psycho-social support, the right to adequate communication, right to innovative drugs in treatment, etc.)

### CONCLUSION

A significant step in the systemic development of psycho-oncology in Serbia is the current *Program for Improvement of Cancer Control in the Republic of Serbia* for the period 2020-2022, with an action plan for the implementation of a program for improving cancer control as well as the establishment of psycho-oncological services and counseling centers in secondary/tertiary level healthcare institutions for the treatment of oncological patients.

For the future development of Psycho-Oncology in Serbia, more research in the field of psycho-social oncology, more opportunities for specialized education, enhanced international cooperation and realistic national funding for the general development of psycho-oncology are needed. It is particularly important that SAPO expands its activities and joins its colleagues from other countries that make up the IPOS Federation group. While there is still much to do to bring Serbia's care of patients with cancer up to the level of more developed countries, there is reason for great optimism as our healthcare Ministry has begun to recognize the importance of these services in all areas of cancer treatments.

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## РАЗВОЈ ПСИХООНКОЛОГИЈЕ У СВЕТУ И У СРБИЈИ – ПРВИ КОРАЦИ И БУДУЋИ ПЛАНОВИ

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### Резиме

Психоонкологија почиње да се развија као независна научна дисциплина од 50-их година прошлог века, како на нивоу базичних истраживања тако и на нивоу практичних интервенција везаних за пружање психолошке подршке и психотерапијске помоћи особама оболелим од различитих малигних болести и њиховим породицама. Предмет проучавања психо-онкологије, у најширем смислу, односи се на сагледавање утицаја психичких фактора у оквиру мултидимензионалног разумевања различитих малигних болести и укључује дијагностичке, терапијске, едукативне и истраживачке активности психијатара и психолога у онколошким институцијама и онколошким тимовима. Конкретније, психоонкологија се бави проучавањем психолошких, социјалних, бихејвиоралних, духовних и етичких проблема особа оболелих од различитих малигних болести. Последњих деценија у свету (САД, Канада, Аустралија) и у развијеним земљама Европе, дошло је до наглог развоја психоонкологије (у неким земљама психоонкологија је субспецијализација онкологије или субспецијализација из лиссон психијатрије и психо-соматске медицине или здравствене психологије), са покушајем разумевања мултиплих утицаја психо-социјалних фактора на онколошке пацијенте с циљем проналажења најбољих могућих психо-терапијских приступа и интервенција у свим фазама онколошког лечења. У процесу активног лечења пацијената са малигном болешћу али и након лечења, у периоду ремисије, не-

опходни су мултидисциплинаран приступ, активна партиципација пацијента и чланова породице као и стална комуникација са свим члановима медицинског тима. Развој и имплементирање психоонкологије као примењене и хуманистичке области савремене здравствене психологије у нашој земљи у прошлости се није одвијало и актуелно се не одвија континуирано и на системски осмишљен начин као што је то случај у развијенијим земљама Европе и света. Разлози су многобројни. Први разлог је спор процес мењања доминације старе парадигме био-медицинског модела ка новом био-психо-социјалном моделу који представља базу модернизовања сваког здравственог система. Разлике између био-медицинског и био-психо-социјалног модела су и концептуалне, теоријске, али се манифестују на практичном нивоу од опхођења према пацијенту, уважавања различитих потреба, поштовања права пацијената до разлика у сагледавању утицаја различитих психо-социјалних фактора у настанку и лечењу болести. Други разлог спорог развоја је свакако недостатак одговарајућих курсева и специјализација и субспецијализација из области психоонкологије у Србији. У том правцу је учињен један искорак и на Универзитету у Београду, на Филозофском факултету, на Катедри за Психологију у оквиру обавезног курса из Здравствене психологије на мастер студијама клиничког модула уведена су предавања о психоонкологији и педијатријској психоонкологији, а на докторским студијама је први пут од 2017. године уведен посебан изборни курс „Психоонкологија и палијативно збрињавање (психолошки аспекти)“, који је програмски уједначен са садржајима сличних курсева страних универзитета. Недостатак стручних истраживачких радова у области такође успорава имплементирање стандарда и модела добре праксе. Посебан проблем представља и незапошљавање довољног броја психолога у институције здравственог система у којима се онколошки пацијенти лече.