

Abstract

Assessment of Psycho-Social and Communication needs in Oncology patients (APSCO) in Romania

My name is Csaba L. Dégi PhD, MSW. I am Assistant Professor at the Babeş Bolyai University, Faculty of Sociology and Social Work in Cluj-Napoca, Romania. I have bachelor and master degrees in social work, and I am a licensed principal social work practitioner. The Babeş Bolyai University is the oldest academic institution in Romania, founded in 1581, and one of the first institutions in Romania committed to developing and evaluating psychosocial services for cancer patients, together with its partners. In 2010, I got my PhD in clinical psychology / psycho-oncology at the Semmelweis University, Institute of Behavioral Sciences in Budapest, Hungary. Based on my clinical and research experience in cancer care I have developed and coordinated several cancer-related research programs, diploma works and prevention activities. Since 2001 I have been working with cancer patients, cancer survivors, medical social workers, palliative care social workers, oncology nurses and hospital pastors from the Central-North-Western region of the country.

My activity was developed in the last decade both in Romania and abroad, starting with the six year research period at the Semmelweis University, Institute of Behavioral Sciences in Budapest, Hungary where I completed my doctoral studies under the supervision of Professors Dr Ferenc Túry and Dr Mária Kopp. Dr Katalin Hegedűs, member of board of directors of the EAPC - European Association for Palliative Care, was a reviewer of my doctoral thesis and also a PhD committee member. Being a constant and prolific promoter of research on psycho-social aspects of cancer I was awarded with five research scholarships by the Hungarian Academy of Sciences - Domus Hungarica Scientiarum et Artium Program and the Hungarian Ministry of Education and Culture - Hungarian Scholarship Board which supported my post-doctoral studies at the Semmelweis University, Institute of Behavioral Sciences, Budapest, Hungary.

One of the most important results of my activities in the last decade is my contribution to include Romania in the group of countries involved in psycho oncology research, supportive and palliative cancer care.

In 2008 I was personally involved in the Best Practices Exchange in Psychosocial Oncology Summit, organized by the National Association of Social Workers (NASW - the largest membership organization of professional social workers in the world) and Cancer Care from United States, held at the University of Debrecen, Hungary. The Summit funded by Bristol Myers Squibb Foundation was successful and I was invited to contribute to the NASW WebEd credited courses (<http://www.naswwebed.org/>). In 2009 our team developed and adapted the course “Understanding Cancer Caregiving: The Social Worker’s Role” which is still available and singular among international courses offered by NASW WebEd. Since then I have been working closely with Prof. Dr Ellen Csikai, editor of the Journal of Social Work in End-Of-Life & Palliative Care, affiliated with the Social Work in Hospice and Palliative Care Network in the USA. In 2013 I was invited to be editorial board member for this journal. She is also a co-author in one our peer-reviewed articles and next year I will assist her in an already approved project to be implemented in Alabama - USA, Hungary and Romania. Furthermore, in 2013, I significantly contributed to the Training Course on Psychosocial Oncology Care, held at Institute of Oncology in Cluj-Napoca and organized by EPAAC-WP7 – International Psycho-Oncology Society (IPOS) together with the Romanian Ministry of Health.

In the last 10 years I had publications in highly respected peer-reviewed ISI – Web of Science journals (e.g. Supportive Care in Cancer, Psycho-Oncology, Psychology & Health and Journal of Cognitive and Behavioural Psychotherapies), tens of articles in journals indexed in international and national databases (EBSCO, CEEOL, CNCSIS – e.g. Social Work Review, Psychiatria Hungarica, Journal of Mental Health and Psychosomatics and Transylvanian Journal of Psychology), and book chapters, three of them published internationally. For example in the Oxford Textbook of Palliative Social Work (2011), I wrote a full chapter (56: Palliative Social Work in Central-Eastern Europe: The Case of Romania) about our experiences, resources and challenges in palliative social work. This highly prestigious textbook is edited by Professors Dr Terry Altilio and Dr Shirley Otis-Green.

My scientific contributions have been widely recognized. I presented at numerous world and international conferences in Oxford, New York, Washington, Miami, Berlin, Lisbon, and Budapest, etc. I am active member in various scientific associations, the most important ones being: International Psycho-Oncology Society, USA (2012) - Romanian representative and European Co-Executive; Multinational Association of Supportive Care in Cancer, Denmark (2011); board member in the Central and Eastern European Society of Behavioral Medicine, part of the International Society of Behavioral Medicine, Hungary (2010); Social Work and Health Inequalities Network, UK (2011); senior in the Romanian National College of Social Workers, Romania (2011) and the Association of Schools of Social Work in Romania (2010).

The number of publications in top journals from the last period, the invitation to be reviewer for international and national journals in the field, the active professional memberships are all due in a great extent to approaching a highly relevant topic in Romania, the psycho-social screening and care of cancer patients.

The APSCO - Assessment of Psycho-Social and Communication needs in Oncology - study initiated in 2001 follows the repeated cross-sectional design, while the proportional quota sampling method was applied in the four most important Romanian cancer centers to produce a nationally representative pool of oncology patients in terms of gender and ethnic affiliation. A mixed and various sample (N=1220) of 800 oncology patients was screened in 2014, and 420 in 2007. Seven years after acceding to the European Union and endorsement of several cancer control agendas (e.g. including EPAAC) the Romanian National Cancer Program, as there is not an integrated plan yet, does not include or cover psychosocial cancer care. In this situation we aimed to analyze prevalence of diagnosis non-disclosure, cancer distress and quality of life in Romanian cancer patients prior and post EU accession. The main objective of this study was to report on trends of cancer diagnosis non-disclosure in Romania, from 2007 to 2014, and to identify groups vulnerable to this risk. Study was supported by CNCS – UEFISCDI grant PN-II-RUTE-2012-3-0011 and by UBB grant no. GTC 34020/2013.

Our previous results from 2007 showed that 16.9% of cancer patients in Romania were not aware of their cancer diagnosis. New data indicate that prevalence of cancer diagnosis non-disclosure halved (8.0%) in Romania from 2007 to 2014. Even if cancer diagnosis non-disclosure percentages have lowered in the last years in the Romanian cancer population, certain groups of cancer patients experience significantly higher levels of risk for non-disclosure. Patients who are not told about their cancer diagnosis tend to be older (65 years or above), with a mandatory or vocational education, living in rural communities, diagnosed with lung cancer, and not receiving chemotherapy, both in 2007 and 2014. Also, male gender, advanced stage of the disease and lack of cancer experience in family increase risk of cancer diagnosis non-disclosure in Romania. New data show that prevalence of cancer diagnosis non-disclosure halved in Romania in this period. However, psychosocial distress is highly elevated and symptoms are relatively unchanged, especially depression (47.5% vs. 42.2%) and anxiety (46.7% vs. 47.2%). All aspects of quality of life (Ms = 63.37 vs. 70.63) - including physical, social, emotional and functional well-being - show clinically meaningful shifts but still under normative levels.

In the Romanian health care system cancer distress is not assessed and treated as the 6th vital sign, as recommended by IPOS. Levels of neglected psychosocial needs in cancer patients reach an alarming level in Romania. A necessary first step was the adaptation and validation of an effective cancer distress screening instrument. In this study we explored accuracy and performance of the adapted Romanian version of the Emotion Thermometers (ET) tool in cancer patients under active oncological treatment. The Distress Thermometer (DT), Depression Thermometer (DepT), and Anxiety Thermometer (AnxT) provided means for rapidly and effectively screening cancer distress in Romanian cancer patients.

This present research project is also a first assessment of the present situation regarding the unattended and unconsidered psychosocial necessities and needs within the oncological treatment in Romania, from the perspective of involved specialists. Our results show that over half of the oncology professionals in Romania do not use standardized psychosocial assessment instruments or protocols in their work, and only 15 % of the respondents receive supervision at work. These professionals working with cancer patients have given an average score of 4.04 to the degree of satisfaction (maximum 10) with care of cancer patients in Romania.

APSCO will significantly improve the knowledge base necessary for the elaboration of health and social policies in the field. Social work can be one of the comprehensive support sources by providing psychosocial and practical support to cancer patients, particularly for those of low socio-economic status, living in rural areas and for ethnic minority groups – like Hungarians, Roma. Achieving the proposed objectives, the APSCO research will encourage implementation of new perspectives, practical and policy ideas in this very important field of psycho-oncology and oncology social work in Romania. Based on this research, we will advocate for the development of new patient-focused psychosocial services in oncology in Romania. We will advocate for standard psychosocial screening in all cancer care settings: in active treatment, rehabilitation and palliative care. I am positive that the APSCO research and advocacy project will be appreciated by undergraduate and M.A. students and this project will be carried out, continued together with PhD students from the Babeş-Bolyai University, being asked to supervise more dissertations and theses in the future.

In Chapter I highlights about my activities and outcomes in the last decade are presented, especially about my professional career after PhD thesis, which was finalized in 2010. Chapter II presents all important details of our results, mainly trends of cancer distress screened in the APSCO research program. The last chapter, Chapter III uncovers teaching, supervision and research perspectives as well as the pivotal plan to develop oncology social work in Romania.