

Scientific report on project implementation between January-December 2014

Project Title: Assessment of Psycho-Social and Communication needs in Oncology patients (APSCO)

Project Code: PN-II-RU-TE-2012-3-0011

Phase: Single

Single-phase objectives for 2014 were:

(1) Data collection, having the following subsumed activities: (1.1.) Completion of the quantitative research on specific samples of patients suffering from cancer and (1.2.) The introduction of empirical data.

The results which were to be delivered for the objectives and activities of this phase were: (1) completion of 700 questionnaires (initially 300 questionnaires) among patients suffering from cancer and (2) the establishment of the SPSS database corresponding to the quantitative empirical research.

(2) The analysis of empirical data, involving: (2.1.) Achievement of quantitative analysis with SPSS.

The results, which were to be delivered for the objectives and activities of this phase, were: (1) design of the activity report, research.

(3) Dissemination of results achieved by: (3.1.) Participation in international conferences and workshops, (3.2.) Editing publications, respectively (3.3.) Updating the project web page.

The results which were to be delivered for the objectives and activities of this phase were: (1) Oral communication and / or poster, with peer-reviewed abstract, (2) Publication of scientific papers (3 on the whole by the end of the project), and (3) Completion of the project site, <http://www.psychooncology.ro>, and updating it with activities performed in 2014.

(1) Achieving the first objective involved the completion of the quantitative research and the empirical data entry. (1.1) Thus, the first activity sub-summed to the first objective represented a completion of the quantitative research on samples specific to patients suffering from cancer.

We emphasize that initially, in accordance with the application filed and the related contract, the project implementation plan concerned a questionnaire survey on a sample of up to 300 patients diagnosed with various forms of cancer. Based on this goal, at the beginning of the year, we committed that we would apply 700 questionnaires. In reality, however, in the final database we have introduced a number of 800 valid questionnaires, which far exceeds the threshold originally proposed, reaching nearly a tripling of the number of patients surveyed reported to the number of respondents proposed at the start of the project.

In preparing and implementing the quantitative research study we used a non-probabilistic cross-sectional (comparative) design with repeated measurements (repeated cross-sectional design; Steel, 2008), and in the sampling process we used the proportional quota sampling (according to Sedgwick, 2012).

Therefore, we included in the study the most important four cancer centres in the country (Bucharest, Cluj, Iasi and Oradea), to which we added Sfantu Gheorghe County Hospital and Miercurea Ciuc County Hospital (Harghita and Covasna Counties). The choice of these locations has ensured the establishment of a nationally representative sample, where the proportions of gender and ethnicity were maintained.

In the quantitative research design and methodology we have complied with all the requirements of medical ethics and research ethics. Thus, we included in the study only patients who were at least 18 years at the time of survey; they have expressed their consent to participate in the study; they had an appropriate state of mental and physical health in order to properly complete the questionnaire; they were able to answer questions from the interview-based questionnaire. In the collection, evaluation and data processing process we have followed all steps necessary to preserve the confidentiality of the identity of the participants. At the institutional level, prior to research implementation, we obtained the approval of the Ethics Committees of each institution involved. In addition, all employees who participated in the evaluation of patients diagnosed with cancer have signed a confidentiality agreement, by which they undertook to remain anonymous in relation to the information obtained in connection with institutions and persons involved in the project and keep the ethical conduct on the protection of participants in the study. Moreover, team members and collaborators involved in field obtained in advance, the web training graduation certificate, called "Protecting Human Research Participants" provided by NIH Institute (The National Institutes of Health - NIH - Office of Extramural Research).

Based on the analysis and synthesis of the research literature on the most appropriate methodology for psycho-oncologic studies, we conducted the selection of different dimensions assessment tools regarding the oncology distress and well-being of patients with cancerous diseases. We list a series of questionnaires / scales resulting from this approach: (a) the Questionnaire including socio-demographic characteristics of the patients (age, gender, residence, ethnicity, education level, marital status, socio-economic and health status); (b) Beck Depression Inventory - BDI; (c) Emotion Thermometers - ET, which assess the patient's emotional state in the last seven days prior to the date of the survey; (d) Spielberger's State-Trait Anxiety Inventory - STAI-T); (e) The scale for measuring the patient's quality of life (FACT-G 4.0 - Functional Assessment of Cancer Therapy-General - Fourth version).

In addition to these questionnaires / scales, we considered important (f) conducting an exploratory analysis on the question: "Does the patient know his/her own medical oncologic diagnosis?" (with response options "yes" or "no"), since now in Romania some resistance from doctors is detected in relation to disclosing the patient the tumour diagnosis.

At the end of the section of the report devoted to the analysis of quantitative data obtained by applying the APSCO questionnaire among the 800 patients suffering from cancer, we present you another (g) Distress assessment tool namely the NCCN Distress Thermometer - DT.

In addition to the tools for assessing the psychosocial status of cancer patients that we shall describe below, we note that the structure of the questionnaire for patients contains questions and scales, which we mention, but the results of which are not detailed in this report: patient's knowledge about the disease; patient's readiness to talk about his/her illness; mental condition of the patient; other personal data (income, frequency of physical activity, alcohol, tobacco consumption); Hopelessness Scale; Vital Exhaustion Questionnaire; Life Events Rating Scale; Social and Emotional Loneliness Scale - SELSA; Health Locus of Control Scale - MHLCS; Illness Intrusiveness Rating Scale - IIRS; Coping Scale (WAYS);

Coherence Scale; General Self-Efficacy Scale, Dysfunctional Attitudes Scale, Scale Type-D - BI; collateral negative life events and social support received; general condition of the patient; respectively data obtained directly from the evaluators / collaborators.

Given that the fulfilment of the first objective **(1)** and of the second objective **(2)** are closely related, we will refer to the activities relating to (1.2) empirical data entry (2.1) the achievement of the quantitative analysis, where we shall present the most important results.

The 800 questionnaires completed during the field survey were entered into a single database, using SPSS Program, version 20. Starting from this database, quantitative analyses regarding cancer patients participating in the research were performed.

We shall start with the description of the socio-demographic characteristics of the sample of cancer patients with respect to: age, gender, residence, ethnicity, education level, family status, socio-economic and health status. Thus, the average age of the sample is 56.38 years, the youngest respondent having 18 and the oldest 82 years. Among patients investigated, 42.3% are men and 57.7% women. Regarding the place of residence, 34.2% of respondents come from large cities, 28.2% reside in small towns, and most of them - 37.6% - live in villages and communes. In terms of ethnicity, 69.5% of patients belong to the ethnic majority, Romanian, 28.8% are Hungarian, 0.9% is Roma and 0.8% belongs to other ethnic groups.

In terms of educational level, most patients included in the survey - 26.3% - have graduated from a vocational school of arts and crafts. Otherwise, 8% of respondents have completed less than 8 grades, 14.3% have eight general school years, 13.8% obtained a baccalaureate degree from an industrial high school, 18.3% have completed a baccalaureate in a theoretical high school, and 19.3% have higher education. Regarding family status, almost three quarters of patients investigated are married (71%), followed by widowed (14.1%) and divorced (9.5%); the percentage of the unmarried is very small, only 5.4%. The socio-economic status was measured by means of the answer, affirmative or negative, on whether the income is so low that the respondent is unable to purchase the necessary items for daily living.

Thus, it appeared that almost one third of patients - 31.3% - live in a state of material uncertainty, while the other more than two thirds of the sample - 68.7% - do not face major financial difficulties materials. As for the subjective assessment of their health status, the results show that over half of respondents - 55.6% - perceive themselves as having average health status; 1 in 5 people with cancer think they have bad health status, and 17.7% report a good health; the remaining respondents are extremes, namely 5.8% consider their health as very bad and far fewer - 0.9% - consider their health as excellent.

Evaluation of the psycho-oncologic condition of patients using Emotion Thermometer Tool is another way of measuring cancer distress. This new visual scale (Mitchell, Baker-Glenn, Granger, & Symonds, 2010), with multi-domains applications was created in 2007 by PhD Prof. Alex Mitchell, in the UK. This innovative tool has the ability to accurately measure through five subscales, each represented by a thermometer: stress, anxiety, depression, anger and the need of help. The patient can assess the five fields by an 11-point Likert scale (0-10), in a period of about 55 seconds, even in the absence of medical knowledge (Vodermaier, Linden, & Siu 2009). In addition to the distress assessment tool in cancer patients by means of the five Emotion Thermometers, which we translated, adapted, validated in Romanian and Hungarian, within the APSCO Project we translated, applied and validated another new instrument for assessing psycho-oncologic status of patients with cancer originating in the United States, which is called simply NCCN Distress Thermometer - DT. In case of both

instruments, we have obtained copyright, which allows us their application in Romania for a period of two years, starting from March 2014. These tools can be viewed at <http://www.psychoncology.ro/resources/>, on the APSCO Project site. The distress assessment tool, Distress Thermometer (DT) (Dabrowski et al., 2007; Gil, Grassi, Travado, Tomamichel, & Gonzalez, 2005; Hoffman, Zevon, D'Arrigo, & Cecchini, 2004; Holland & Bultz 2007), developed by the National Comprehensive Cancer Network - NCCN, USA is a single scale with 11 points (the distress level increases from 0 to 10), with the shape of a thermometer that measures the levels and grades of distress. The issue list annexed to the scale asks respondents to answer 34 questions (items that relate to practical, family, emotional, spiritual / religious, physical issues). In the clinical practice, DT is a fast and modular control tool used in the detection and follow-up of oncologic psychosocial distress both in patients and in carers. We note, however, that the assessment of the psychosocial factors in older patients or coming from disadvantaged socio-economic categories can become a problem in terms of methodology, due to any shortcomings of the subjects regarding health literacy and functional illiteracy rate (Speros, 2005).

(3) The achievement of the third objective showed in the dissemination of the results obtained in this phase by (3.1) Participation in international conferences and workshops, through oral communications and / or poster, with peer-reviewed abstract (3.2) Editing publications or (3.3) Updating the project web page.

(3.1) Regarding the first set of sub-summed activities of the third objective of the project during 2014 we achieved within the APSCO Project 10 participations in international and national conferences, in which 17 papers were presented as oral presentations, posters, lectures or e-posters.

These results are absolutely remarkable in at least three ways: on the one hand, they indicate, among other events in the project, an average rate of participation in events destined to disseminate the newest results of the project of over an event per month; on the other hand, we are dealing with an average of almost two presentations for each event; thirdly, the diversity of the types of presentation and participation, which include almost all possible forms of dissemination, from the most classic, such as oral presentations to the latest, as e-poster presentations and from simple ones, such as the poster presentations, to the most complex, as in the organization and coordination of a symposium in the context of a larger conference is notable.

Besides this brief statistics on the frequency of conferences and presentations and brief overview of the diversity of types of communications made, we consider it very important to emphasize that in the record of activities focused on the dissemination of the project results, three participation, research and training missions are included, conducted by the Project Manager, Dr Dégi Laszlo-Csaba, during 2014 and about which we shall offer you more details further on.

In the detailed description of conferences, presentations, participations and internships we shall address a chronological perspective, thus showing the temporal sequence of events and content and not necessarily their importance for APSCO project. Also, in the presentation of each event we will follow the same structure, which includes, first of all, the mentioning of the topic, of the title of the event, of the organizing institution, of the place and period of deployment and of some general information about the event. Then, depending on the capacity in which the project team members were involved in each event, we shall briefly describe the role they played, the papers that they submitted and the network of professionals with which interactions and professional exchanges took place.

Finally, for each event we shall refer towards the link on the website of the APSCO project or on the sites of conferences of organizing institutions, where you can find all possible details about each event and about the papers presented by members of APSCO team and about the capacity in which they were involved in each case.

The first event for 2014 was the participation of the Project Manager, Dr Dégi Laszlo-Csaba at "The 1st EORTC Cancer Survivorship Summit" (First Summit of Survival in Cancer), held in Brussels in Belgium, during January 30- 31, 2014. This event was even more special as their Royal Highnesses Princess Astrid and Prince Lorenz of Belgium attended it.

This summit brought together, besides professionals in psycho-oncology, representatives of the pharmaceutical industry, of banks, of insurance companies, politicians, patients and patient advocacy groups to discuss the special needs of people who have survived a cancer disease. Starting from the premise that the diagnosis of cancer is not a death sentence and that more cancer patients continue their lives after this illness, summit participants advocated for the need to broaden the perspective of cancer survivors approach and move the focus from the solving of medical problems derived from the treatment of disease to new concerns derived from the social needs of the cancer survivors, related to labour relations, life insurance or relations with banks regarding the loans issue. All information on this meeting can be found on the following website of the event: <http://www.eortc.org/survivorship2014/>.

The professional level of the meeting was raised by the presence of leading figures in the field, among which we shall mention Dr Luzia Travado, new IPOS president, Manager of the Department of psycho-oncology in the Champalimaud Clinical Center, and Dr Anja Mehnert, a Professor at the University of Leipzig with which, the Project Manager discussed science topics related to the possibilities of exploitation and dissemination of quantitative data from APSCO research.

Following these interconnections and a prior preparedness, the Project Manager, Dr Dégi Laszlo-Csaba was invited and performed a study and research mission two weeks at the University of Leipzig, Germany, from January 28 to February 9, 2014, having as scientific coordinator Dr Anja Mehnert, professor and director of the Department of Medical Psychology and Medical Sociology. About the scientific coordinator and host institution more information can be found on the following web site: <http://www.psychooncology.ro/study-and-research-mission-at-leipzig-university/>.

The series of conferences at which APSCO team members participated started with "International Thanatological Conference" from Targu Mures, Romania, held from February 28 to March 2, 2014. During the event, the Project Manager, Dr Dégi Laszlo-Csaba, presented a paper in Hungarian, „Az onkológiai betegek pszicho-szociális szükségleteinek felmérése” (Assessment of psychosocial needs in oncology patients) and communicated on scientific issues with a professional network composed of: the President of the National Association for Palliative Care, Dr Daniela Moşoiu; Director of Hungarian Hospice Foundation, Dr Muszbek Katalin; PhD in cancer rehabilitation, Barabás Katalin, University of Szeged; and PhD Szabó Mónika from Saint Blaise Foundation. The oral presentation made at this conference can be accessed on the website of APSCO Project at: <http://www.psychooncology.ro/international-thanatological-conference/>

The second conference, „The Changing Prospects for Cancer: New models of aftercare for those living with and beyond cancer” (Prospects of Change in Cancer: New models of post-care for those who live or beat cancer), was held at the University of Salford in Manchester, UK, in April 1-4, 2014. At this conference, whose theme is closely related to the project, the Project Manager, Dr Dégi Laszlo-Csaba, presented as a poster, the paper "What are the key challenges for patients living with and beyond cancer in Romania?".

The poster can be viewed on the project website at the web address: <http://www.psychooncology.ro/the-changing-prospects-for-cancer/>.

The conference was held under the patronage of two agencies: Christie NHS Foundation Trust and the National Cancer Survivorship Initiative, and the network of professionals with whom professional exchanges took place centred on: Dr Ziv Amir, physician and PhD professor of the Cancer Rehabilitation Centre attached to Salford University; Karen Steadman, a researcher at The Work Foundation; and Huget Desiron with Master's degree in health sciences in the Department of Public Health, University of Leuven, Belgium.

May 2014 was a very eventful month full of occasions to disseminate results or training and research and intervention skills formation and development in the psycho-oncology field.

The series of events from APSCO Project where the Project Manager, Dr Dégi Laszlo-Csaba participated in 2014, is continued by "1st CANWON training school - Register based research within Europe regarding cancer and work", having as main theme the comparison of cohort studies on cancer and work in European countries („Comparing cohort studies within Europe regarding cancer and work”). Research internship took place in Solna Campus of Karolinska Institute in Sweden, during May 12-14, 2014.

An important goal of the training session was to promote collaboration and scientific exchanges between young researchers working in the field of psycho-oncology and encourage their participation in the next three formative schools organized by professional network "Cancer and Work Network "and which will address topics such as research based on data from surveys, analyses in economics or evidence-based intervention studies. More about this school can be found at the web address: <http://www.psychooncology.ro/register-based-research-within-europe-regarding-cancer-and-work/>.

Among teachers who trained and guided the students in this school and with whom the Project Manager has interacted specifically we shall mention: Kristina Alexanderson, a professor at the organizing body; Christoffer Johansen, a professor at the Institute of Cancer Epidemiology; and Ute Bultmann, from the University of Groningen.

The third conference of 2014 timeline was the "The XXIIIrd Annual Meeting of the Hungarian Psychological Association", held in Targu Mures, Romania, between May 15 -17, 2014. This conference was one of the most relevant from our point of view, since not only several papers of the team members were presented, but more than that, this event devoted to APSCO Project a separate symposium, in which they offered to the public five presentations on topics closely related to psychosocial research and care in psycho-oncology.

Three papers were presented in Hungarian, two of which have had as sole author Dr Dégi Laszlo-Csaba, being entitled "A hatodik életjel műhely" (The sixth vital sign workshop) and „Igények és lehetőségek az erdélyi szociomedikális segítők körében - első helyzetkép" (Needs and opportunities for psychosocial oncology helpers in Transylvania - the first snapshot), and the third was conceived by Andrea Varga, whose presentation was entitled „Diakónia Keresztény Alapítvány" (Diakonia Christian Foundation). The symposium included two presentations in English, the first being on "Reducing distress in a sample of Romanian female cancer patients with expressive writing", having as authors two members of APSCO project, namely the Project Manager, Dr Dégi Laszlo-Csaba, and researcher Dr Éva Kállay. The second paper, entitled "Eclectic methodological approach to psychological intervention in cancer" was presented by clinical psychologist Florina Pop.

In addition to the work of the symposium dedicated to APSCO Project, the Project Manager, Dr Dégi Laszlo-Csaba, has offered to the broader audience of the conference a thematic plenary presentation in Hungarian, entitled "Pszichoonkológia Erdélyben: szükségletek és távlatok" (Psycho-Oncology in Transylvania: needs and perspectives). We conclude by stating that by the multiplicity and diversity of the team members' involvement in this international event, the project not only demonstrated its usefulness in promoting practices based on evidence from empirical research, but has also broadened the vision beyond national borders. References to the contents of the six presentations that had been offered to the public at this conference can be found on the APSCO project web page at the link:

<http://www.psychooncology.ro/xxiiird-annual-meeting-of-the-hungarian-psychological-association/>. Discussions on science topics were held during the conference with Bányai Éva, a Professor at Eötvös Loránd University.

The fourth conference attended by the Project Manager, Dr Dégi Laszlo-Csaba was "The 4th International Conference on Sociology and Social Work", which was held at USC School of Social Work in Los Angeles, USA, during May 19-20, 2014. This event was very important for our project, in at least two respects: first, the mission it proposed is relevant for the current challenges of oncologic psychosocial care in our society and, secondly, our effective participation in this conference allowed the transmission of the message about professional challenges in the field of psycho-oncology in Romania even beyond the European area, in that the audience included participants from around the world. In this fourth edition of the International Conference of Sociology and Social Work, organizers suggested participants a reflection on the current social challenges in social work, such as fragmented health and mental health care systems, social stigma problem and the need for reform in the child protection. They also appreciated the contributions that supported the efforts to promote interdisciplinary interaction between sociology and social work, which could contribute to the creation of a better world. From this perspective, oral presentation of Dr Dégi Laszlo-Csaba, "Psychosocial oncology care in Romania: building professional capacities" ranged abundantly in the proposed theme, as he demonstrated by the results of a questionnaire survey conducted among professionals in Romania, the essential role that social workers of the Association of Oncology Social Workers in Romania would play in promoting quality psychosocial services of care for patients with cancer diseases, adapted to the Romanian cultural context. Full presentation of this paper can be accessed on our project website at the web address: <http://www.psychooncology.ro/4th-international-conference-on-sociology-and-social-work/>. We should add that, in the event, the professional network with which the Project Manager talked on scientific topics was made up of two Professors from the host institution, the Dean Haluk Soydan and Professor John Brekke, and a Professor at University of Chester, Carey Malcolm.

The fifth conference we attended was held throughout the United States and had been particularly important by the theme addressed by the fact that two papers in the project were presented and that they were so well received by organizers and the public, that the Project Manager already received at the end of the conference, the invitation to attend the next year edition, which will be held in Denmark. So, here we are talking about "International Symposium on Supportive Care in Cancer - Care Possible", held in Miami, Florida, from June 26-28, 2014.

The first work, having Dr Dégi Laszlo-Csaba as sole author was a poster presentation, entitled „Work-related challenges for cancer patients during treatment in Romania”. The aim of the study was to investigate the correlations that exist between the ability to work at the workplace and at home and work satisfaction in cancer patients who are under treatment.

The results obtained support the idea that the co-approach of issues related to work and cancer in the diagnosis stage can help planning the care after overcoming the disease and determining the full impact that cancer has on the work performed by cancer patients in Romania.

The second paper, entitled „Making the case for psychosocial oncology actions in Romania: evidence from repeated cross-sectional data”, had five co-authors, of whom the first four are members of the APSCO Project Team: Dégi Laszlo-Csaba, Éva Kállay, Ignac Gy. Lukacs, Mihaela E. Cîmpianu, the fifth author, Cristina Burz, being an oncologist in the chemotherapy department of "PhD Prof. Ion Chiricuță" Oncologic Institute in Cluj-Napoca. This paper stood out because it was presented as an e-poster discussion, therefore the first author, as a representative of the group of authors presented the essential information of the poster to an audience directly interested in the subject of the paper. This second study investigated the prevalence of cancer diagnosis non-disclosure in relation to psychosocial distress and life quality of cancer patients, from the perspective of data resulting from a repeated cross-sectional research - APSCO - initiated in 2006 and repeated seven years after Romania's entry into European Union. The results of the comparative analysis of empirical data showed that although the prevalence of non-disclosure of cancer diagnosis halved, however, psychosocial distress, especially depression and anxiety, remain high, and the quality of life of patients with cancer, although recorded slight improvement remains at a level below normative values of original research in the field. The paper concludes that these trends observed among patients with cancer justify the current efforts to include psychosocial care of cancer patients on the agenda of priorities of the health system in Romania. The abstracts of the two presentations can be studied using the link <http://www.psychooncology.ro/international-symposium-on-supportive-care-in-cancer-care-possible/>, while posters can be viewed at section APSCO Project resources, at <http://www.psychooncology.ro/resources/>.

And on this occasion, the Project Manager discussed with Petra Feyer, Professor at Klinikfur Strahlentherapie, Radioonkolgoie, Nuklearmedizin Vivantes - Klinikum Neukolln in Berlin, Germany, and with Anne Young, Development Manager and Study Group Coordinator within MASCC organization (Multinational Association of Supportive Care in Cancer) on scientific topics.

At the sixth conference on "Care and cure, an integrated approach to psychosomatic medicine" held in Sibiu, Romania, between June 25-28, 2014, representing the Annual Meeting of the European Association of Psychosomatic Medicine, the project team, represented by Dr Dégi Laszlo-Csaba and Mihaela E. Cîmpianu, was invited to present the poster entitled "Opportunities for psychosocial oncology care in Romania - professional perspectives" which can be found on the APSCO Project Resource page: <http://www.psychooncology.ro/resources/>. A very valuable result of the participation in this medical conference is that the work of both authors was published in book Proceedings ISI of EAPM Conference in 2014 and can be found at pages 82-85 of this publication. To view the work, you can access the link <http://eapm2014.medical-congresses.ro/>.

The seventh conference, where Éva Kállay and Dégi Laszlo-Csaba were accepted with a common paper was the 35th Conference of STAR - "Stress and Anxiety Research Society Conference", conducted in Cluj-Napoca, Romania, between July 2-4, 2014 and was attended by Professor Colin MacLeod from the University of Western Australia, one of the keynote speaker of STAR Conference, who received, in this framework, the title of Doctor Honoris Causa from "Babes-Bolyai" University (UBB) for the merits to have made pioneering discoveries concerning the cognitive mechanisms of emotional distress and for his

decisive contributions to the development of psychology in the BBU. On July 4, in section D on "Health behaviours, coping with illness, healthy living", Éva Kállay presented the paper entitled "Trends in depression and well-being in Hungarian cancer patients. A longitudinal study". The conference program can be found by following the link: <http://star2014.ro/index.php/program>.

The eighth conference was the "13th International Congress of Behavioural Medicine - Innovation in Behavioural Medicine", organized by the Department of Health Sciences of the University of Groningen, the Netherlands, during August 20-23, 2014. From the APSCO Project team, researcher PhD. Éva Kállay participated with two co-authored papers. Both papers were presented as a poster and had the same three authors in the following order: Dégi Laszlo-Csaba, Éva Kállay ("Babes-Bolyai" University, Cluj-Napoca) and Maria Kopp (Semmelweis University, Budapest, Hungary). The titles of works were "Trends in depression and well-being in Hungarian cancer patients - a longitudinal study" and „Depression and its correlates in Hungarian cancer patients" and both were based on the longitudinal study Hungarostudy Epidemiological Panel, applied in three successive waves in 2002, 2006 and 2013 and which was replicated in Romania, but with a cross-sectional design in 2006 and 2013 by APSCO Project Manager, Dr Csaba L. Dégi. The participation in this conference with the two works is the result of a close collaboration of the Project Manager with researchers in Hungary on the psycho-oncology topic and shows that his concerns in this area are old and that the research of this topic in Romania was one built on a rigorous basis and already validated in other countries with a tradition of research in psycho-oncology. The link on the project website where the two presentations can be found is as follows: <http://www.psychooncology.ro/international-congress-of-behavioral-medicine/>.

The ninth conference where the results of the APSCO Project were made known, was the "The 16th World Congress of Psycho-Oncology Psychosocial Academy" of IPOS (International Psycho-Oncology Society), held in Lisbon, Portugal, between October 20 -24, 2014. At this event, the Project Manager, Dr Dégi Laszlo-Csaba, held both an oral lecture, entitled "Psychosocial oncology care in Romania: need for action" and a poster presentation, entitled „Screening Romanian cancer patients with the Emotion Thermometers (ET) tool: a validation study". Both works have shown the importance and usefulness of assessing the level of psychosocial distress of patients with cancer by tools validated in previous reference studies and the need for professionals working in the field of psycho-oncology to be trained and equipped to know and use such instruments, such as the Emotion Thermometers through involvement in future programs of training and supervision activities based on evidence-based practice. APSCO Project has proven through its scientific and research activity that it can provide a model of good practice in the assessment of psychosocial distress of cancer patients and advocates for a joint action of all stakeholders to improve the quality of life of patients ill with cancer, in accordance with the cultural particularities in Romania.

Both papers can be found on the project website at the link: <http://www.psychooncology.ro/16th-world-congress-of-psycho-oncology-and-psychosocial-academy/>.

Another important aspect of the conference was the fact that the project has interacted with a broader network of professionals, which lists some personalities with whom Dr Dégi Laszlo-Csaba has already developed strong professional ties such as Dr Luzia Travado and Dr Anja Menhert, this time the discussion in the professional network being focused on issues related to the development of the International Psycho-Oncology Society (IPOS).

Along with the two managers of the IPOS board, the Project Manager has also held discussions on the same topic with Prof. Richard Fielding (also in the board of managers of IPOS), Prof. Andreas Hinz (University Hospital Leipzig), Elisabeth Andritsch (Medical University of Graz), Natalia Rivkina (Head of Department in the European Psychiatric Medical Centre), Dr Rohánszky Magda (Tűzmadár Alapítvány) and Justyna Pronobis-Szczylik. On the same site indicated in case of papers this professional network and links refer to each of the eight specialists with whom discussions took place on the topic of development of professional body in psycho-oncology in Romania.

Last but not least, the tenth conference of the APSCO Project, „II. Test-lélek Konferencia” (II. Body and Soul Conference), was held at the National Institute of Oncology, Budapest, Hungary, on October 31, 2014. During this event, the Project Manager, Dr Csaba L. Dégi, lectured on „Az onkopszichológiai rehabilitáció lehetőségei Romániában” (Opportunities for psycho-oncologic rehabilitation in Romania). The program is on the conference web page: http://testlelekkonferencia.hu/?page_id=5.

We do not end point 3.1 regarding the dissemination of results before mentioning two new important collaborations ended in the year 2014 on the one hand with the American Association of Oncology Social Workers (AOSW) and secondly with the Romanian Cancer Society (SRC). The logos of the two partner organizations can be found on the APSCO Project collaboration: <http://www.psychooncology.ro/collaboration/>.

We emphasize that we took, translated and adapted the standards for professionals in psycho-oncology, from the American Association of Oncology Social Workers (AOSW), obtaining the copyright to use them in Romania. These standards can be found translated in Romanian, on the project website at the link dedicated to resources, namely: <http://www.psychooncology.ro/resources/>.

The foundation of this new collaboration with key organizations in the field of psycho-oncology at international and national level was represented by absolutely outstanding results obtained in the course of 2014 by APSCO Project team members under the continuous coordination and guidance of the Project Manager, Dr Dégi Laszlo-Csaba.

(3.2) In respect of the second set of sub-summed activities of the projects’ third objective, the project commitment included a publication for 2014, namely three publications during the three years of funding.

In relation to this proposal, this year publications, totalling no more than 9 (nine) scientific works, exceed by four times the threshold of three publications originally proposed in APSCO Project. Not only the large number of publications is absolutely impressive, but also the amount and diversity of publications.

Thus, by making an inventory of the number and type of publications in APSCO Project for 2014, we obtained the following ranking of papers published: 7 publications in ISI recognized journals and 4 papers published in BDI indexed journals. To these we can add 4 peer-review activities conducted by the Project Manager, Dr Csaba L. Dégi for 4 different journals. We conclude by pointing out that the publication activities for 2014 amount to a remarkable number of almost 100 pages.

Next, we shall present at first, every publication, then we shall refer to the four articles reviewed for national and international journals, and we shall conclude with other activities of the Project Manager, such as the ones of representation in the area of scientific and public involvement in the organization committees of certain conferences.

A). Articles published in ISI recognized journals

The first two publications in this category are more valuable than other papers published in journals and books during 2014, having as authors, members or collaborators of the APSCO Project team, as they appeared in a prestigious publication, having a very high Impact Factor, located currently at the rate of 4.044. Therefore, the two publications below can be found in the third supplement corresponding to the 23rd volume of *Psycho-Oncology Journal*, including the abstracts presented at symposiums in the 16th World Congress of IPOS (International Psycho-Oncology Society) held in Lisbon from 20 to 24 October 2014.

1. Dégi Laszlo-Csaba (2014). Screening Romanian Cancer Patients With the Emotion Thermometers (ET) Tool: A Validation Study. *Psycho-Oncology*, 23 (Suppl. 3), 255-307; 321, DOI: 10.1111/j.1099-1611.2014.3696.

This study aims to obtain the adaptation and validation for Romania of an original instrument for assessing oncologic distress, created by PhD Dr Prof Alex Mitchell and known as Emotion Thermometers Tool. The study results showed that thermometers corresponding to distress, depression and anxiety provide a quick and efficient evaluation of tumour distress in cancer patients treated in Romania, as a first step in the procedure for identifying patients with psychosocial care needs. In the field of research, attention is drawn to the sensitivity that this tool could have in relation to the cultural and ethnical context of patients. However, in clinical practice, Emotion Thermometers Tool proved to be a feasible method (short, rapid and visual) within the clinical evaluation procedure of cancer distress in various institutions of tumour treatment.

2. Dégi Laszlo-Csaba (2014). Psychosocial Oncology Care in Romania: Need for Action. *Psycho-Oncology*, 23 (Suppl. 3), 11-64; 59, DOI: 10.1111/j.1099-1611.2014.3693.

Based on a repeated cross-sectional quantitative research performed on cancer patients in Romania in 2006 and 2013 as well as on mixed-method design research - quantitative and qualitative - on psycho-oncology professionals in 2014, the author finds that, at present, in Romania, cancer is still a significant source of vulnerability and an unresolved psychosocial burden both for patients and for professionals who intend to provide psychosocial care to this category of patients. Therefore, the study calls for strengthening the collective voice of actors directly involved in the field, who with the support of the International Psycho-Oncology Society (IPOS), as a professional leader organization in promoting psycho-oncology at international level, to produce progress in providing psychosocial oncology care in Romania. The study findings outline the idea that, in psycho-oncology research one needs to take into account in assessing the psychosocial needs of cancer patients the Romanian multicultural context (including Romanian, Hungarian, Roma people and other ethnic groups) and in clinical practice, the adequate psychosocial care will be provided when cancer distress will come to be rated as the 6th vital sign, in compliance with IPOS standards of quality psycho-oncology care.

The following two publications are also valuable because they were published in the first supplement corresponding to volume of the Official Journal of MASCC/ISOO - the Multinational Association of Supportive Care in Cancer / International Society of Oral Oncology, occasioned by the conference this year organized by the two organizations in Miami in Florida, USA. Very important is the fact that this journal has a high Impact Factor, located for 2014 at a rating of 2.495.

3. Dégi Laszlo-Csaba (2014). Work-related challenges for cancer patients during treatment in Romania. *Supportive Care in Cancer*, 22 (Suppl 1), S1_S238; S207, Springer Link.

The study is a novelty in literature, because so far in Eastern Europe, work and cancer have not been investigated together. This paper aims to study how to correlate job skills and job satisfaction during cancer treatment, based on the sample of 784 patients with neoplastic diseases investigated in APSCO research. Inability to work, reported by 40% of respondents correlates with fatigue, problems in meeting one's needs, a poor physical condition and stay in bed. Satisfaction with work, including housework, reported by 57% of respondents, correlates with the ability to work, the ability to enjoy life and what makes them feel good. The author suggests that, in Romania, work and illness issues should be dealt with jointly from the moment of diagnosis, in order to fully determine the impact of cancer on work capacity.

4. Dégi Laszlo-Csaba, Kállay Éva, Cîmpianu Mihaela Elvira, Lukacs Gyula Ignac, Burz Cristina (2014). Making the case for psychosocial oncology actions in Romania: evidence from repeated cross-sectional data. *Supportive Care in Cancer*, 22 (Suppl 1), S1_S238; S174, Springer Link.

In this paper, the authors, starting from the idea that in the National Cancer Control Programme there is no integrated plan to cover the psychosocial care of cancer patients, they set out to investigate the prevalence of cancer diagnosis non-disclosure and of cancer distress and the life quality of cancer patients, from the perspective of a comparative cross-sectional study, conducted by the Project Manager in 2006 and repeated by APSCO team in 2013. The data showed that, when compared to the moment of pre-accession of Romania to the European Union (EU), seven years after this event, the non-disclosure of cancer diagnosis rate halved, but psychosocial distress remained at high levels, and the life quality of patients with cancer was improved though still remains at a level below internationally acceptable normative values. These results justify the current efforts of professionals in Romania to promote on the agenda of health priorities the psychosocial care of cancer patients.

The following two publications have appeared in the International Journal of Behavioural Medicine, ISI recognized and listed with an Impact Factor of 2.210 for the year 2013. Specifically speaking, it is the first supplement, corresponding to the 21st volume of this journal, which included the abstracts of papers presented at the "13th International Congress of Behavioural Medicine - Innovation in Behavioural Medicine", organized by the Department of Health Sciences, University of Groningen, The Netherlands, between August 20-23, 2014.

5. Dégi Laszlo-Csaba, Kállay Éva, Kopp Maria (2014). Trends in depression and well-being in Hungarian cancer patients - a longitudinal study. *International Journal of Behavioral Medicine*, 21(S1) S1-S216; P 26, S13, P.13-13.

Considering that Hungary has the highest rate of cancer deaths in Europe, the study aims to investigate the major trends in the rate of cancer, the trends regarding the depression and well-being of cancer disease patients in Hungary, based on the data obtained from the longitudinal study Hungarostudy Epidemiological Panel applied in three successive waves in 2002, 2006 and 2013 and totalling 2,000 participants. The results showed that the high death rates significantly influence the psychosocial burden caused by cancer. In time depression causes adverse health effects, but cancer patients could offset these effects through an adaptive process able to produce favourable changes on subjective well-being. The practical value of the results lies beyond the delimitation of trends regarding the rate of cancers and the level of depression in the identification of specific groups, which may be more vulnerable to changing trends in oncologic distress.

6. Dégi Laszlo-Csaba, Kállay Éva, Kopp Maria (2014). Depression and its correlates in Hungarian cancer patients. *International Journal of Behavioral Medicine*, 21(S1) S1-S216; P 28, S13, P.13-13.

The paper is based on the 2013 data of Hungarostudy Epidemiological Panel survey, applied to a representative sample and pursuing the assessment of the functional health of the population in Hungary. Of the 2000 participants, 49 were suffering from various forms of cancer. By using non-parametric tests demographic variables, depression, subjective well-being, sense of coherence, self-efficacy and anomia were assessed.

The results showed that cancer patients were significantly more depressed and reported levels of well-being and self-efficacy lower than the general population. Within the group of patients with cancer, we found strong positive correlations between depression and anomia and strong negative correlation between depression on the one hand and well-being, sense of coherence and self-efficacy, on the other hand. After controlling for age and gender variables, regression analysis indicated that anomia, the sense of coherence, self-efficacy and subjective well-being explained 51% of the variance of depression in cancer patients group. The study concludes that depression in cancer disease has a significant impact on disease progression and on the quality of life. The practical value of the results lies in the fact that it recommends to identify those areas of functionality in which psychosocial intervention may produce positive effects.

7. Dégi Laszlo-Csaba, Cîmpianu Mihaela Elvira (2014). Opportunities for psychosocial oncology care in Romania - professional perspectives. *Proceedings of EAPM Conference 2014*, Medimond Conference Proceedings, 82-85.

The paper is based on the first research project, which assesses the current situation in Romania regarding unmet psychosocial needs and the unmet needs during oncology treatment in terms of the experts in the field. The most pressing issues in healthcare signalled by were the lack of standardized instruments or protocols for assessing distress among oncology patients, the possibility of adequate supervision in the

workplace and training courses in assisting patients with cancer and their families from a psychosocial perspective. Quantitative and qualitative data obtained from professionals working in the field of psycho-oncology have shown that most of them are uninformed on the issues of (non) regulations of the National Cancer Control Plan. A positive result is that almost all interviewees want to participate in training programs in order to provide a holistic psychosocial care to patients with neoplastic diseases.

B). Articles published in BDI indexed journals

1. O'Malley Denalee, Dégi Laszlo-Csaba, Gilbert L. Brittany, Munch Shari. (2014). Addressing the Cancer Burden in Romania: A Critical Role for Social Work Practice. *Revista de Asistență Socială / Social Work Review*, Volume XIII, 2/2014, 1-18, www.swreview.ro.

In this article, the authors argue for an increased involvement of social workers in all phases of cancer control, from prevention, diagnosis and treatment, to rehabilitation and palliative care. Social workers following a specialization in medical care and acquire the necessary expertise in the assessment and psychosocial intervention in the health field, who acquire a micro- and macro-social vision and a tendency towards cultural diversity of patients, can become extremely valuable resources capable of to meet unmet needs of cancer patients and increase the overall cancer control efforts efficiency in Romania.

2. Kállay Éva, Dégi Laszlo-Csaba (2014). Distress in cancer patients. *Cognition, Brain, Behaviour. An Interdisciplinary Journal*, ISSN: 1224-8398, Vol. XVIII(1), 17-32.

Starting from the fact that advances in medicine allow the aging and even the cure of patients diagnosed with cancer, this article focuses on the impact of cancer distress on the quality of life and well-being of cancer patients. The authors did not only assess the prevalence of risk factors and their implications on depression, anxiety and suicide, but also offered some effective methods of psychosocial care to cancer patients, which can improve dysfunctions at the level of mental health specific to this category of patients.

3. Dégi Laszlo-Csaba (2014). Pszicho-onkológia/ Psychooncology, *Orvosképzés*, LXXXIX, volume, 3. number, 374-380.

This article, presenting an overview of psycho-oncology, is extremely valuable, as it appeared in "Orvosképzés" (Medical Training) journal, which is a Hungarian publication with a very old tradition, the first issue being released in 1911. Moreover this journal is the only one in Hungary, which addresses doctors, both to those with a gradual training and to those with post-gradual training. The message of this article is all the more important as it familiarizes the medical staff familiar with the significance and role of psycho-oncology and highlights the need of integration of psychosocial care in the health care system of psycho-oncology in order to improve the quality of life of cancer patients.

4. Kállay Éva, Dégi Laszlo-Csaba (2014). How does distress and well-being depend on demographic variables in a nationally representative Romanian sample of cancer patients. *Cognition, Brain, Behaviour. An Interdisciplinary Journal*, ISSN: 1224-8398, Vol. XVIII (4), 243-259.

The major aim of this work was to identify major areas where emotional functionality is affected, namely to investigate how the distress caused by cancer depends on demographic variables in a sample of 800 cancer patients, nationally representative. The results showed that a high percentage of patients with neoplasm manifest significant symptoms of psychosocial distress, as there are some gender differences in this regard. Moreover, certain groups of patients with cancerous diseases - women, elderly patients, those with a lower education level and the single / divorced / widowed - reported significantly higher levels of distress and lower levels of welfare. The authors concluded that these realities must be taken into account in relation to the development of effective psychosocial interventions.

As mentioned earlier, in addition to the intense publishing activity of the APSCO Project team members, the Project Manager, Dr Dégi Laszlo-Csaba, performed a multitude of other activities, either related to the writing of publications or of the type of collaboration and creation of professional networking relevant to the project implementation, which contributed to the increase of the visibility of project results and which could link the APSCO project to the international circuit of conferences, events and organizations with an interest in the development of psycho-oncology at national, European and global level.

Thus, in 2014, the Project Manager, Dr Dégi Laszlo-Csaba responded to the request of being a reviewer for four editorial teams, of which two international and two national. Taking them at a time, we note that the first work, having a size of 22 pages, was sent for reviewing by the prestigious journal BREAST, which currently has an Impact Factor of 2.581. Then, the Journal of Social Work in End-of-Life and Palliative Care asked the review of three scientific articles, totalling a total number of 85 pages. Nationally, Dr Dégi Laszlo-Csaba has been involved in reviewing a paper submitted for publication to the *Revista de Asistență Socială / Social Work Review*, which has a number of 19 pages, and he was also a referent in the editorial team of the journal *Cognition, Brain, Behaviour. An Interdisciplinary Journal*, B+ category in CNCSIS ranking, reviewing an 18-page article.

In terms of representations in the scientific community and the public area, the Project Manager, Dr Dégi Laszlo-Csaba had five academic representations and four in the public sphere. Thus, the five international academic representations, as a full member, took place in the following organizations: Society for Social Work Leadership in Health Care; European Social Work Research Association; Grounded Theory Institute; Hungarian Society of Oncology – Onco-psychology and Rehabilitation Section; and European Network for Mental Health Promotion. Also in 2014, Dr Dégi Laszlo-Csaba was a member of the Planning Committee of International Palliative Care Network Conference, organized by the Palliative Care Network in the United States.

In the international public area Dr Dégi Laszlo-Csaba was involved in organizing the symposium occasioned by the 23rd Annual Meeting of the Association of Psychologists of Hungary „A hatodik életjel műhely” (The sixth vital sign workshop).

As part of the 35th edition of the International Conference of STAR - Stress and Anxiety Research Society - Dr Dégi Laszlo-Csaba was invited as chairman of one of the thematic sections. At the event organized by the International Psycho-Oncology Society (IPOS), in Portugal, The 16th World Congress of Psycho-Oncology Psychosocial Academy, Dr Dégi Laszlo-Csaba was part of the International Scientific Committee and was nominated for one of the highest positions, European Co-Executive of IPOS federation. The Project Manager, Dégi Laszlo-Csaba had a prestigious national representation in UEFISCDI being invited as an expert in developing the National Research Strategy for 2014-2020, published in Official Gazette no. 785 of October 28, 2014.

(3.3) In respect of the third sub-summed activities of the third objective of the project, namely the project web page updating, we shall emphasize that all activities carried out during 2014 by and under the coordination of the Project Manager, Dr Dégi Laszlo-Csaba, are, in a form-to-date on the APSCO Project site, www.psychooncology.ro.

New information were placed in the appropriate site menus so that, in the Activities section one can see details about all conferences which took place this year, in the Report section one can find all scientific reports on project implementation (2012, 2013), and presentations from all dissemination events attended this year, in the Publications section one can find the full papers and references to the publications in which they were published, and in the Collaboration section one can see the new contacts that the Project Manager has set this year with professional associations relevant to the psycho-oncology field in Romania. We have detailed all these aspects in this report. They appear, however, on the site, in English, so that the area of APSCO Project visibility can be spread beyond national borders, and the psycho-oncology situation in Romania can be analysed and compared to what happens in this field at European and even global level.

We emphasize that by using the Google Analytics application, we obtained the information according to which the APSCO Project web page has been accessed by 5033 people, of which the new visitors share reached 80.1%, the other 19.9% representing users who have revisited the project web page. In addition, about 30% of visitors browse the project website regularly each week. The majority of them, 72.70% are visitors from Romania, but there visitors from the United States, Brazil, France, Germany, Belgium, Hungary, the UK and Italy as well. Most visited pages are: Home (35.39%), followed by Activities and Team pages visited in a proportion of about 11% in each case. But the most remarkable fact linked to our website is that if we write on the Google search engine the keywords "psychooncology" and "Romania" APSCO Project website appears among the top three results, which ensures it a high degree of visibility and accessibility among online users of scientific information in the expertise field of APSCO Project.

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