
CLINICAL PRACTICE GUIDE IN PSYCHO-ONCOLOGY

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ABSTRACT

In the Romanian public medical system, psychosocial assessment is not integrated into routine oncological treatment and care. According to APSCO research data, cancer distress is recorded in about half of the Romanian cancer inpatients, the maximum admissible level. In this context, creating a clinical practice guide in psycho-oncology is one of the first actions needed to be taken. This guide corroborates clinical experience from within the Romanian oncology system, psychosocial resources available to Romanian professionals in cancer care and best practice recommendations from psycho-oncology literature. The intervention scenarios presented here are consistent with care requirements implied by the oncology hospital system in Romania. The therapeutic act involves three structural stages (initial, intermediate, final) of psycho-oncological intervention, several therapeutic targets and cancer-specific intervention techniques being presented in detail for each stage. A number of best practices for doctor-patient communication and psycho-oncological intervention, as well as recommendations for a comprehensive caretaking into account the patients' needs in order to maintain continuity and quality of life during hospitalization and rehabilitation have resulted from this line of action.

KEYWORDS: *cancer, distress, guide, psycho-oncological intervention, psychosocial support, Romania*

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INTRODUCTION

Patient care in the oncological system undergoes a major paradigm shift from disease management to a patient-centered approach, increasingly more attention being paid to psychosocial issues such as cancer distress, quality of life, patients' rights and empowerment, co-morbidities and survival. Negative phenomena in the life of cancer patients amplify each other, generating overlapping effects with a strong psychosocial impact on the quality of life. The World Health Organization defines quality of life as the individuals' perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHOQOL, 1995). For cancer patients improving quality of life is as important as survival or the prolongation of life. Most psycho-oncology studies view quality of life as an independent prognostic factor of disease progression and survival odds (Di Maio & Perrone, 2003).

Psycho-oncological care is part of an integrative evidence-based approach addressing the psychosocial needs of the cancer patient. "Cancer care for the whole patient" is an interdisciplinary approach including psycho-oncological interventions that is being centered on elements of strict particularity for each single case. Such typology actually gives the measure of therapeutic effectiveness (Bultz & Carlson, 2005)

As part of interdisciplinary medicine, psycho-oncology demands communication and co-operation between medical and non-medical professionals, aiming to derive increased patient satisfaction by promoting patient empowerment and greater participation, responsibility indecision-making regarding the treatment and compliance to the therapeutic program.

There is growing evidence that a multidisciplinary approach improves the level of care provided to the oncology patient, exerting beneficial effects on the professionals of the multidisciplinary team as well. Among the benefits of a multidisciplinary approach to cancer patient care one can mention improvements made by development of a treatment plan in line with the patient's needs and implementation of evidence-based best practices, increased survival rate, better chances to receive care in line with clinical guidelines, including psychosocial support, increased access to information - particularly regarding psychosocial support, increased satisfaction regarding the level of care and, finally, professional development and improved emotional wellbeing on behalf of the professionals involved in the multidisciplinary team (Sainsbury, Haward, Round, Ricler, & Johnston, 1995; Gabel, Hilton, & Nathanson, 1997; Richardson, Thursfield, & Giles, 2000; Changet al., 2001; Hawardet al., 2003).

This guide is addressed to psychosocial specialists working with cancer patients. It aims to provide an easy to use guide in a simply to adopt form for every specialist.

At the moment there are a number of intervention protocols, particularly in the cognitive-behavioral paradigm, but one of the problems encountered in their implementation is due to their format (evaluation and psychological intervention meetings structured over a longer period of time) as such model is not readily appropriate in some medical interventions, more so in an oncological context (considering all the aspects implied by a crisis situation, i.e. preoperative or postoperative psycho-oncological intervention).

In designing and adapting this guide we considered the resources currently available in the Romanian medical system, recommendations of the psycho-oncology literature - psychosocial care standards recommended by the International Society of Psycho-Oncology (IPOS) in particular -, and our clinical experience in oncology.

We tried to conceive this guide in a manner designed to be useful for specialists with various levels of experience.

The first part of the guide refers to the definition and rationale of psychosocial care in oncology, the second addresses the communication process engaged with the cancer patient, while part three covers screening, psychosocial assessment and practical psycho-oncological interventions during each step of the curative oncological treatment, while part four provides final recommendations on psychosocial care.

For practical effectiveness, the interventions included in this guide are presented in short and clear sequences. The proposed intervention modalities are consistent with hospital care requirements and resources available to Romanian psychosocial specialists in the field of oncology.

An important aspect would be that, when the effective implementation of the intervention is prevented by strong patient resistance induced by personality traits or other issues of palliative nature, adjustments in the clinical evaluation and greater adaptation of the intervention package to patient needs should be made in consultation with colleagues more experienced in the field of psycho-oncology.

Being a highly sensitive issue, duration of the psycho-oncological interventions was established based both on research data regarding the optimal length of the therapeutic contact and on the resources of time available considering hospitalization routines imposed to the cancer patient requesting the intervention. The duration of a meeting should be established based on how much the physical health of the patient is affected (differing for a patient hospitalized in an intensive care unit compared to a patient following radiation therapy treatment). Recommendations are a maximum of 30 minutes for a supportive intervention involving a patient on respiratory support in the intensive care unit, 50 to 90 minutes for a first meeting with a patient undergoing radiation therapy treatment

and a first or last meeting to provide psychological support to a certain patient, such as when he/she is an outpatient or is about to continue treatment in another oncology clinic.

We do not pretend that a cognitive behavioral intervention is the only effective approach (although its effect was most rigorously investigated), but we recommend using the principles of cognitive-behavioral therapy adapted to cancer patients in a synergic form based on a good therapeutic relationship.

In brief, we expect that the contents of this guide provide useful recommendations for psycho-oncological intervention on patients hospitalized for curative treatment of cancer. It helps when implemented with tact, care, clinical judgment and responsibility.

Defining the scope and rationale of psychosocial care in oncology

According to Holland et al. (2010, p. 10), "*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*".

Based on the APSCO quantitative research studies in 2006 and 2013/2014 involving Romanian cancer patients (N = 1220) and a mixed method (quantitative and qualitative) research in 2014 involving Romanian specialists in cancer care, we conclude that in present day in Romania cancer is still a significant source of vulnerability and an unresolved psychosocial burden for both patients and professionals who provide psychosocial support for this category of patients (Dégi, 2009; Dégi, 2011; Dégi, 2013; Dégi & Cîmpianu, 2014; Kállay & Dégi, 2015; Faludi & Dégi, 2016; Dégi, 2016a,b,c). Data concerning the non-disclosure of the cancer diagnosis to the patients themselves, as derived from the APSCO studies, show that cancer non-disclosure rates have halved during the 7 years following Romania's accession to the European Union, but the psychosocial distress remained high while the cancer patients' quality of life, although improving, remained at a level below internationally accepted values (Brucker, Yost, Cashy, Webster, & Cella, 2005). These results justify current efforts of Romanian professionals to promote psychosocial support for cancer patients on the health minister's priority agenda.

The results of those studies indicated that 1 in 5 (19.7%) Romanian cancer patients suffered from moderate depression, while 27.7% reported symptoms of severe depression. Also, 47.2% of the patients had accumulated severe anxiety symptoms and more than half (50.1%) admitted they needed significant help. Data revealed that a high percentage of cancer patients presented symptoms of significant psychosocial distress, highlighting some gender differences in this regard. Certain groups - women, elders, lower educated and single/divorced/widowed patients -

reported significantly higher distress levels and lower levels of psychosocial well-being. Inability to work, reported by 40% of the cancer patients, correlated with tiredness, problems faced in meeting their needs, a poor physical and sedentary (i.e., lying in bed) condition (Dégi, 2014a). Data also suggested that in Romania work and illness-related issues should also be addressed together since the moment of cancer diagnosis in order to comprehensively evaluate the impact of cancer on work ability. Regarding the psychosocial wellbeing and quality of life, no significant differences were found between patients undergoing cancer therapy and those in rehabilitation or palliative care. Regardless of the evolution stage, in Romania the cancer itself remains an important factor of vulnerability and continuous psychosocial burden for both patients and specialized oncology service providers.

Failure to timely apply appropriate supportive psychosocial measures results in a substantial worsening in the quality of life (Parker, Baile, Moor, & Cohen, 2003), increased pain intensity (Spiegel, Sands, & Koopman, 1994), reduced survival odds (Watson, Haviland, Greer, Davidson, & Bliss, 1999), and increased suicidal risk (Hem, Loge, Haldorsen, & Ekeberg, 2004). Conceiving that they become a burden to their family (Pitceathly & Maguire, 2003), patients begin to give up treatment (DiMatteo, Lepper, & Croghan, 2000), thus chemotherapy loses its effectiveness (Walker et al., 1999) and hospitalization time increases (Prieto et al., 2002) entailing higher costs and hindering psychosocial rehabilitation. Quality care in cancer have to integrate patients' psychosocial needs in the routine treatment. Stigma is not a specific problem of the Romanian oncology system, but it remains a significant barrier against integrating psychosocial support in the internationally applied scheme of cancer treatment (Holland, Kelly, & Weinberger, 2010).

Psychosocial support for cancer patients addresses the psychological, social, existential, spiritual and other needs facing cancer-affected persons throughout the cancer trajectory, including the assessment of personal experiences concerning treatment, rehabilitation, survival and palliative episodes.

The APSCO research project in 2014 assessed from the perspective of oncology professionals the situation concerning unmet psychosocial needs of Romanian cancer patients during treatment. It indicated that the most pressing problem was the absence of standardized assessment tools and evaluation protocols regarding distress among Romanian cancer patients. Adequate supervision at work, instruments and training courses for delivering psychosocial support to cancer patient and their families were found to be professional priorities.

Psycho-oncology is currently in a phase of exploring its possibilities in an attempt to surface the Romanian medical system. Psychosocial assessment of cancer patients is not part of routine oncologic treatment and so there is no possibility to detect mental health problems and treat psychosocial crises faced by cancer patients. It is estimated, that only about 5% of the patients actually receive some kind of professional psychosocial support (Dégi, 2016a).

Given that presently Romania cannot develop specialized human resources (i.e., psychosocial professionals such as psycho-oncologists and/or oncology social workers), this clinical practice guide in psycho-oncology aims to assist professionals in their clinical decisions and improve services they provide in the healthcare system.

Communication with cancer patients

The Romanian bill on patients' rights (Law no.46/2003, chapter II, art. 4-12.) states that any patient has the right to be informed, to decide whether and the extent to which he/she wants to be informed and whether relatives and/or friends of the patient should be informed about developments in the medical investigation, diagnosis and treatment. Although there is an ethical, moral and legal right of the patient to be truthfully informed, a study conducted within the Oncology Department of the Tg. Mureş University of Medicine on a group of physicians from various specialties concluded that in the current medical practice communication of the diagnosis and prognosis regarding a cancer patient is most frequently directed towards the patient's family members (Lupşa & Gagyi, 2003). Failure to inform the patient about his/her diagnosis and prognosis might bear consequences in the compliance to treatment or communication with the medical team and could raise certain ethical problems considering that the patient seeking treatment has to à priori sign a consent form implying knowledge of the diagnosis and prognosis. Also, the patient's psychological preparation in view of discussing diagnosis and treatment options is part of the early doctor-patient interaction. This psychological preparation and education includes an analysis of individual, family and social resources available to the patient, identification of the psychosocial factors that may interfere with decisions regarding the medical process, as well as the patient's own perception regarding his/her health state.

Good communication between the cancer patient, family members and the interdisciplinary team helps improving the wellbeing and quality of life of the patient. Communication on the patient's concerns and decision making is equally important in all therapy and supportive stages. When important decisions need to be taken (i.e., learning about one's diagnosis, decisions about new treatment and/or care options) communication plays a crucial role, being instrumental in achieving the medical and psychosocial objectives.

Effective communication during treatment and care stages leads to positive results as patients are more satisfied with the quality of care they are benefiting from. Feeling that by being better informed they exert greater control over the disease and treatment options, they clearly are more compliant to treatment (NCI, 2016).

However, in Romania there is no valid protocol regarding communication of the cancer diagnosis. In this context, the APSCO questionnaire-based research in

2013/2014 (N = 800) found out that 92% of the respondents actually knew their diagnosis, while 8% of the respondents were not aware of being diagnosed with cancer. Cancer patients not informed about their diagnosis were mainly elderly male rural residents with lower education levels in advanced stages of the disease. Not only were patients unaware of their cancer diagnosis more depressed, more stressed and anxious than informed patients, but they also acutely felt they needed help (Dégi, 2010; Kállay, Pinteá, & Dégi, 2016). These data confirm in a unified and consistent manner the psycho-social vulnerability of cancer patients uninformed about their diagnosis.

There is no universally-applicable way to communicate full medical truth to cancer patients. Several methods have been tested, sometimes used in combination, such as the terminology method, the oblique method, the statistical method or the preferable patient-centered method. Communication in this last one is customized taking into account patient's personality, coping mechanisms employed when faced with a problem, psychosocial and family resources, specific details that the psycho-oncologist can provide to the medical team in charge of the patient. Accurate information concerning the disease and life expectancy helps the patient to form a realistic rather than pessimistic or catastrophic picture of his/her situation providing that the information is adapted to the patient's level of understanding. Communication should be focused as much as possible on the present, on "what can be done now", today, tomorrow, in the near future, such an approach being useful both to the medical team in charge of the patient, which manage well the "now" situations, and to the patient, who will be thus helped out of the multilayer chaos induced by the cancer diagnosis (Holland & Zittoun, 2012). Orientating communication on the "what happens now", shifting from the "tell the truth" to "make the truth" paradigm, is a new perspective of patient-multidisciplinary team communication that can positively influence both the patient-medical staff relation and the perceptions, attitudes, education and information levels of the general public on cancer (Surbone, Zwitter, & Stiefel, 2012).

Screening and evaluation of psychosocial distress in cancer patients

The National Comprehensive Cancer Network in the United States (NCCN) defines distress as an unpleasant emotional experience of psychological, social and/or spiritual nature extending from normal feelings of vulnerability, sadness and fearful concerns to serious problems, disorders such as depression, anxiety, panic, social isolation and spiritual crisis (Holland & Weiss, 2010; Kállay & Dégi, 2014a,b).

Appropriate psychosocial support for cancer patients can be provided only when cancer distress will come to be rated as the 6th vital sign in accordance with the International Psycho-Oncology Society (IPOS) standards on quality psycho-oncological care. Distress, emotional and social suffering felt by the patient (depression, anxiety, adjustment disorders and stigma) are the 6th sign besides body

temperature, blood pressure, pulse, breathing and pain (Bultz & Carlson, 2005; Holland & Bultz, 2007). The assumption and application of this international standard in Romania presents challenges and emerging opportunities to oncology specialists (i.e., physicians, nurses, psycho-oncologists, oncology social workers, priests etc.), which generally are not well enough trained in their core curricula in regard to psychosocial and communication aspects of cancer.

Romanian specialists currently recommend that cancer distress should be assessed and monitored at least in patients who request or are recommended for psychosocial support.

Beyond the semi-structured clinical interview, assessment of the emotional state is indicated to be conducted with screening instruments for emotional distress such as the Distress Thermometer (DT) (Dabrowskiet al., 2007; Gil, Grassi, Travado, Tomamichel, & Gonzalez, 2005; Hoffman, Zevon, D'Arrigo, & Cecchini, 2004; Holland & Bultz, 2007) and the Emotional Thermometers (ET) tool (Mitchell, 2010; Mitchell, Baker-Glenn, Granger, & Symonds, 2010).

If the patient engaging the process of psychological intervention is facing a surgical intervention (usually implying up to 8 days of hospitalization) or chemotherapy (one to five days of hospitalization), then we know that time resources at our disposal are limited. In these conditions screening tools and the semi-structured clinical interview may be sufficient to create an overview and start psycho-oncological intervention.

If the patient is hospitalized for radio-therapeutic treatment (3-8 weeks of hospitalization) then several other psychological evaluation instruments can be added to the screening tools used for emotional distress (DT and ET), including the Beck Depression Inventory BDI-II (Beck, Steer, Ball, & Ranieri, 1996; Beck, Steer, & Brown, 1996), rating scales for anxiety and depression such as the Generalized Anxiety Disorder Assessment (GAD-7) (Spitzer, Kroenke, Williams, & Löwe, 2006) and the Patient Health Questionnaire (PHQ-9) (Kroenke & Spitzer, 2002), the Endler scales for the multidimensional assessment of anxiety (Endler, Edwards & Vitelli, 1991), the Brief B-COPE Questionnaire (Carver, Scheier, & Weintraub, 1989), the revised Impact of Events Scale (IES-R) (Weiss & Marmar, 1997), the Functional Assessment of Cancer Therapy (FACT) modules (Cella et al., 1993) used to assess the quality of life, the General Attitude and Belief Scale (GABS) (Lindner, Kirkby, Wertheim, & Birch, 1999) for assessing irrational beliefs any other personality assessment tests or instruments required to effectively institute and direct the psycho-oncological intervention.

One can also set up a psychosocial assessment package by consulting the Psychosocial Evaluation of Cancer Patients module which can be accessed (text and audio format) in Romanian within the IPOS Curricula.¹

¹ http://docs.ipos-society.org/education/core_curriculum/ro/KochMehnert_assess/story.html

In Romania, where the annual rate of newly diagnosed cancer cases is relatively high and the number of psychosocial professionals is very low, an extremely useful existing resource for patients and their families, caregivers and health professionals is the APSCO application². This is a computerized evidence-based screening tool allowing the automated quantification of distress. It serves for self-guided emotional screening, monitoring and finding resources.

Not only is the tool extremely useful for screening and monitoring the distress level, it can also be used for monitoring the whole process of psycho-oncological intervention. The patient who has this application installed can monitor his/her distress since the beginning of the first meeting. This activity can be continued in the intervals between hospitalization or treatment sessions (e.g., between appointments for psychological evaluation or chemotherapy sessions). Monitoring distress using the APSCO application provides systematic feedback on the status and needs of the oncology patients, facilitating the effectiveness of the entire process of psycho-oncological evaluation and intervention.

Afterwards, the International Psycho-Oncology Society (IPOS) proposes endorsement of following statements on standards and clinical practice in cancer care³:

1. Psychosocial cancer care should be recognized as a human rights issue.
2. Quality cancer care must integrate the psychosocial domain into routine care.
3. Distress should be measured as the 6th vital sign after temperature, blood pressure, pulse, respiratory rate and pain (Travado et al., 2016).

Psycho-oncological interventions recommended in every stage of curative cancer treatment

Psychotherapy and psychosocial intervention with a cancer patient is once and again a unique challenge. The purpose of a clinical practice guide in oncology is to improve the quality of services offered by psychosocial specialists in Romania. This guide was conceptualized based on an analysis of the literature data, including similar guidelines made available by the International Psycho-Oncology Society (IPOS), and taking into consideration the currently existing local resources, including the professional experience of the Romanian psycho-oncologists.

The main aspects highlighted in literature that have proven their use in clinical practice relate to: a) providing a therapeutic environment where the patient can safely expose his/her concerns; b) building (of) a therapeutic relationship that should bring a sense of security and stability in the patient's life, c) centering on a flexible theoretical paradigm to facilitate adaptation to changes that may occur in a hospital environment (Holland et al., 2010).

² <http://www.psychooncology.ro/aplicatia-apsco/>

³ http://www.wpanet.org/detail.php?section_id=7&content_id=1087

The types of psycho-oncological interventions can be customized to address: 1) persons recently diagnosed with cancer; 2) patients in the active phase of treatment, 3) patients in total/partial remission; 4) patients with recurrent disease; 5) patients in terminal stage.

Given that in the Romanian hospital environment there is no permanent monitoring of cancer distress and cancer patients are not readily given the possibility to access psychosocial services at the moment of diagnosis or in any stage of the disease justifies the creation of a guideline for screening, assessment and psycho-oncological intervention covering the initial, intermediate and final stages of the psycho-oncological intervention.

1) The initial stage of the psycho-oncological intervention(sessions 1-3) has the following objectives: building of a therapeutic relationship characterized by empathy, unconditional acceptance and congruence; creation of an overview of the patient's main psychosocial needs, including elements of his/her life history; normalization of the patient's emotional reactions; strengthening of the existing coping mechanisms; creation of new coping mechanisms; permanent provision of emotional support; and provision of information support.

The following areas are worth exploring for the initial assessment and creation of an overview:

- patient's emotional mood;
- patient's illness trajectory to date;
- patient's mental representation of what cancer means (what does this health problem mean to him/her, causes of his/her disease, how does cancer evolve);
- changes he/she experienced so far;
- main coping mechanisms that he/she appealed to and considers useful;
- patient's emotional and social support;
- patient's life trajectory until the onset of the health problem;
- coping mechanisms used in other emotionally difficult moments;
- other psychological/psychiatric issues prior to this health problem (current or previously recommended medication - prior to cancer diagnosis);
- patient's state of hopelessness (a significant predictor for depression/suicide risk);
- other issues not related to the neoplastic diseases;
- family structure (including possible history of cancer cases in the family – as it can influence the patient's perception of the disease and therapy options);
- any instrumental or pragmatic (e.g., financial) issues;
- other personal or medical details.

At this stage, it is very important to tell the patient that he/she has all the time he/she needs to tell his/her disease-related story or to reiterate his/her life trajectory. Verbal and non-verbal feedback that one listens and empathizes is essential for a patient to perceive quality of the emotional support.

A useful material is "The Oncology Patient's Guide"⁴ leading the patient through various coping strategies. The first part of the guide refers to the impact cancer diagnosis can have and its consequences onto the patient's life. Part two focuses on the problems the patient may face when learning the diagnosis and reveals coping strategies that may prove to be useful in dealing with recent changes in the patient's life. Two chapters towards the end of the guide are covering the management of several issues common to most cancer patients, including insomnia and fatigue.

Normalization of the patients' emotional reactions can be achieved by explaining the difference between functional negative emotions („normal” distress expressed through fear, worries or sadness) and dysfunctional ones (medium or severe distress manifested as anxiety, depression, hopelessness, etc.).

The need to normalize patient's emotional reactions can come up any time throughout the psycho-oncological intervention. It is recommended to identify this need and bring it into discussion at a timely moment (see also page 11 of "The Oncology Patient's Guide"). At this point of the psycho-oncological intervention it helps to be as clear and creative as one can and to be permanently focused on the therapeutic relationship.

Adaptive coping mechanisms are extremely important throughout the cancer trajectory. Given that one generally refers to adult patients, one can assume that throughout their life they were confronted with various problems requiring emotional composure and have thus validated certain adaptive coping mechanisms. These could be "recalled to active service" and, depending on the patient and his/her resources, other functional/adaptive coping mechanisms could be discussed and actually included in the process of adaptation to cancer.

An important issue in the initial stage is psycho-education (for disease and treatment). It is indicated to be implemented but when the psycho-oncologist considers the time is right for the patient he/she works with.

An intervention method that may be useful at this stage is practicing relaxation techniques with the patient (e.g., autogenic training, breathing exercises - particularly useful for patients experiencing panic attacks). Relaxation leads to a reduction of the neurophysiologic activation, one of the issues that need to be fixed when dealing with anxious reactions. One supportive material that deserves to be added to the Oncology Patient's Guide would be an audio support material on the

⁴ <http://www.iocn.ro/PENTRU-PACIENTI/Servicii/Servicii-psiho-logice/Psiholog-Florina-Pop--eID440.html>

Cluj-Napoca's Institute of Oncology site.⁵ Relaxation techniques are most effective if practiced regularly and an audio support could motivate such action.

2) The intermediate stage of psycho-oncological interventions (sessions 4-7) aims to create a list of problems and set up the main goals for a better adaptation to the neoplastic disease, to provide continuity in the offering of emotional support, to introduce, conceptualize and practice techniques validated for oncology patients. The most recommended therapeutic strategies are presented as useful working tools in "The Oncology Patient's Guide".

Another module that should be consulted is, Psychosocial Intervention. Evidence and Methods to Support Cancer Patients⁷(the Romanian language audio presentation is to be found in the IPOS curricula).⁶

3) The final stage of psycho-oncological interventions (sessions 8-11) has the following objectives: strengthening of the adaptation mechanisms to the neoplastic disease, prevention of emotional relapses, fear of relapse therapy, psychological reassessment, including objective scores regarding the patient's emotional state such as the Distress Thermometer – DT (Dabrowski et al., 2007; Gil, Grassi, Travado, Tomamichel, & Gonzalez, 2005; Hoffman, Zevon, D'Arrigo, & Cecchini, 2004; Holland & Bultz, 2007) or Emotional Thermometers – ET (Mitchell, 2010; Mitchell, Barber-Gleen, Granger, & Symonds, 2010) tool and any other assessment tool validated for clinical use.

The following questions can be useful for psycho-oncologists who want to improve their ability to make more effective decisions when working with cancer patients. Such questions may be taken into consideration after the psycho-oncological meeting (in the early intervention stage):

1. How attentive and supportive did I manage to be during the meetings?
2. Was there a time when I felt that the therapeutic relationship was damaged? If so, is it necessary to think of new ways to enhance the therapeutic relationship?
3. What is the patient's emotional problem? Can the emotional reaction be considered as a normal or severe distress reaction?
4. In regard of the clinical interview, does the patient meet the criteria of a DSM V – Axis I or II diagnosis?
5. Did I manage to normalize the patient's reactions?
6. Was the conceptualization sufficiently clear? Was it accepted by the patient?
7. What other specialists could exert a meaningful influence in this case (an oncology social worker, a psychiatrist, a priest)?

⁵ <http://www.ioen.ro/PENTRU-PACIENTI/Servicii/Servicii-psihologice/Servicii-psihologice-adulti--eID436.html>

⁶ http://docs.ipos-society.org/education/core_curriculum/ro/WatsonBultz_interv/story.html

8. What progress have I seen so far regarding the emotional disposition, affective symptomatology and behavior of the oncology patient?
9. What would be the most useful therapeutic direction at this point of the therapeutic process depending on the time resources I have?

During the intermediate and final stage of the psycho-oncological intervention the following questions might be useful for self-assessment:

1. What clinically and evidence-based techniques are more useful in this case?
2. Is the therapeutic relationship sufficiently supportive?
3. Did I establish together with the patient his/her expectations and goals concerning the psycho-oncological intervention?
4. Did I adapt and argue well enough the tasks to be fulfilled between our meetings?
5. Is my care for the cancer patient obvious, visible?
6. Did I mention him/her that we can stop the session without any questions if he/she feels tired or is not in the best physical health to continue or any time he/she wants to stop?
7. Every time when we formulate a rational alternative response, was I being attentive if the patient considered it truly applicable for him/her?
8. Did I notice if such alternative rational response helps to reduce emotional distress?
9. If needed, did I turn to other literature-recommended techniques for reducing emotional distress?
10. Was the psychotherapeutic approach flexible and sufficiently adapted in this case?
11. Did I use directed exploration in a helpful and not harming manner in regard to the therapeutic relationship?
12. If the cancer patient experienced understanding difficulties, does it help to wonder why? Were the explanations I offered not clear enough? Did anything intervene to disturb the therapeutic relationship? Are the understanding difficulties due to patient distress?
13. Did the patient practice sufficient coping modalities to prevent relapses, or, if they occur, to manage them efficiently?

Rather frequently in the Romanian medical system the patient is recommended only one session of psycho-oncological intervention, either at the end of the treatment sessions (the last day of hospitalization or ambulatory treatment) or when the patient experiences a crisis (e.g., when the cancer is diagnosed or when experiencing a relapse).

After finalizing the treatment, the main issues worth pursuing are those mentioned in the initial stage, completed by a package of materials (e.g., The

Oncology Patient's Guide, information leaflets or referral towards external psychosocial resources).

In crisis situations, the specialist's attitude (supportive, congruent and dominated by unconditional acceptance) is very important. In such cases, symptomatic intervention prevails, ethiopathogenetic treatments being implemented later. Dimensions worth pursuing are mainly those mentioned in the initial intervention stage. Calm, attention to the therapeutic relationship, focus on the most important elements that could stabilize patient's emotional state (i.e., tested coping strategies), tact and clinical judgment are essential ingredients in a crisis situation.

The oncological hospital environment also implies dealing with a number of complicated situations, therefore great adaptability and a highly flexible therapeutic attitude are required.

Psycho-oncological intervention techniques

Psycho-oncological interventions, including certain home assignments (personalized tasks) between sessions (adapted to patient and hospital particularities), are closely related to clinical conceptualization and aimed both at providing emotional support and changing pathogenic elements. A methodological eclecticism in psycho-oncological interventions may be promoted given the existence of a rigorous clinical conceptualization and training in the use of intervention packages.

Psycho-oncological intervention techniques include:

- a) Guided discovery
- b) Agenda setting for each meeting
- c) Supportive and collaborative therapeutic relationship
- d) Home assignments (tasks, to-do lists)
- e) Learning of cognitive and behavioral coping strategies
- f) Cognitive restructuring
- g) Other techniques of psycho-oncological intervention, e.g. hypnosis and relaxation techniques, guided imagery, mindfulness techniques, expressive writing techniques.

a) **Guided discovery** is a technique presuming the alternation of open questions with targeted questions related to coping styles agreeable for the patient. When applying this technique the psycho-oncologist's task is to assist the patient in finding the most helpful adaptive coping strategies.

Example illustrating this technique:

"If a very dear family member would be in your situation, what would you say? / What do you consider it would be useful for him/her to think about? / What do you think it would be useful for him/her to do? / What could be a different perspective on this situation? / Of the people with similar health problems you have

met during hospitalization who would you take as a model? How is this person thinking? How does this person react? / What could be done to change this situation? What else do you think would help?"

It is recommended to address these questions on the background of a therapeutic relationship dominated by empathy, unconditional acceptance and congruence.

b) **Agenda setting** is indicated to be taken into account at the start of therapy sessions.

Example: "Let me ask you what do you want us to focus on today? Is there one particular aspect that you specifically want to talk about today/ during this session/ meeting?"

c) **Supportive and collaborative therapeutic relationship**

The therapeutic relationship is generally characterized as a working alliance and is described as a supportive attitude of confidence and cooperation, driven by the patient's hopes that his/her affective/emotional symptomatology will diminish or be eliminated, but first of all by the unconditional acceptance of the patient by the therapist.

Literature sources (Lederberg & Holland, 2011 as cited in Watson & Kissane, 2011) state that supportive therapeutic intervention for cancer patients and their families should be the most important tool of a psychosocial professional (p.3).

In clinical practice, emotional support is recommended to be offered since the first session and to be reinforced during the intermediate and final steps of the psycho-oncological intervention. For example, in the early days of hospitalization, after surgery, when the patient's general physical condition is impaired, supportive psycho-oncological intervention is the most appropriate therapeutic procedure⁷.

The collaborative part of the therapeutic relationship is completed by techniques such as agenda setting and focusing on to-do lists (home assignments) between meetings. An important element to consider is that psycho-oncologist will work full time on the cancer patient's agenda (objectives and needs). Remember that the patient is the expert in deciding which coping strategies are the most useful adaptive in his/her case.

d) **To-do lists/ home assignments**

When a patient is involved in a psycho-oncological intervention it is easy to see that his/her cognitive and behavioral patterns involved in dysfunctional (maladaptive) emotional reactions are well sedimented. Psycho-oncological intervention sessions are essential in identifying and changing these patterns, but an

⁷ Recommended: Chapter 1, pages 3-13, Handbook of Psychotherapy in Cancer Care, First Edition. Edited by Maggie Watson and David W. Kissane (2011).

effective intervention is augmented by changes occurring in the patient's everyday life. To-do lists (home assignments) are in fact a prolongation of the psycho-oncological intervention session in everyday life.

Examples of home assignments for cancer patients: bibliotherapy (therapeutic stories, lecture of the Oncology Patient's Guide, psycho-educative materials), completion of various monitoring sheets concerning his/her emotional state, practicing of relaxation techniques, and building of coping cards.

One of the most recommended and adaptive home assignments involves coping cards (which can also be used in functionally managing fear of relapse). These are usually 5 inch cards the patient keeps at hand and is encouraged to read them regularly (e.g., two times a day) and whenever he/she feels that the negative emotional state has intensified. These cards may have different contents, including an adaptive response to an automatic negative thought, examples of dysfunctional beliefs on one side of the card and the appropriate adaptive response on the other (Beck, 2010). An aspect to remember is that home assignments should be tailored to the patient and the hospital context. On the other hand, keep in mind that home assignments cannot be prescribed in every meeting/session.

If the psycho-oncologist notices that the patient is not compliant to home assignments, it helps to ask oneself the following questions: "Does this homework seem to be overwhelming? /Does it seem unnecessary? (Have I not argued well enough the benefits of its completion?)/ Might there be certain expectations/beliefs that interfere with the completion of this assignment? /Could there be any difficulties in understanding the requirements?"

e) Learning of cognitive coping strategies

When practicing psycho-oncological interventions it helps to start from the premise that the patient is an expert of his/her own emotions and behaviors, while the psycho-oncologist has expertise in different coping strategies that may be useful for modifying various dysfunctional thinking and behavioral patterns. This expertise can be supplemented by the usage of "The Oncology Patient's Guide".

f) Cognitive restructuring

At the moment, the best validated model of psychological intervention is the cognitive-behavioral one. It argues that the interpretation of a situation (rather than the situation itself) influences emotional, behavioral and physiological reactions/responses of the patient. So, for many cancer patients with clinically significant affective symptomatology connections between how they think about health issues and the emotional reactions they experience can be made. Monitoring thoughts and emotions helps the patient to find out how they interconnect. At this stage one can work with "The Oncology Patient's Guide" pages 11-18.

In applying this technique, it is recommended that identification and changing of dysfunctional/irrational negative thoughts to be instituted by the psycho-oncologist during the intermediate stage of the intervention, when a

therapeutic relationship is already established, otherwise this relationship might be damaged and psychological reactance may occur (Brehm, 1981), i.e. the patient might perceive the existence of a psychological barrier between him/herself and the psycho-oncologist.

g) **Other psycho-oncological techniques:** hypnosis and relaxation techniques, guided imagery, mindfulness techniques, expressive writing techniques⁸.

Conclusion of the therapy and relapse prevention

The ultimate objective of a finalized psycho-oncological intervention is to facilitate remittance of the patient's emotional distress or disorder and to educate the patient to become his/her own therapist. In the oncology hospital context, such an objective can be established for patients hospitalized for longer periods of time, such as for radio-therapeutic treatment. However, it is advisable to initiate relapse prevention from the first session of the psycho-oncological intervention, as soon as the normalization of emotional reactions is accomplished (see page 7 of the "Oncology Patient's Guide"). Given that the psycho-oncologist prepares the patient for fluctuations and relapses early in the establishing of the intervention process it is less likely that he/she will collapse when they occur.

An example of preparation for relapse: The cancer patient under psycho-oncological intervention begins to feel better, i.e. the situation is emotionally stable. At this stage the psycho-oncologist can ask him/her to imagine what would cross his/her mind if he/she will start to feel bad again. One listens carefully and then helps the patient to answer these thoughts and mental images and to write a coping card ("*I have a choice: I can concentrate on how I feel at the moment and this will intensify my emotional state and make me think that everything is hopeless and perhaps I'll soon feel worse, or I can think of what helped me in a similar situation and look over the guide I received at the hospital, remembering that relapses are a normal part of the process I am passing through*").

It helps if coping cards are built and adapted together with the patient to increase compliance of their use. It is recommended that notes made during the screening, assessment and psycho-oncological intervention meetings are retained.

A standard psychological observation file should contain the following items regarding the cancer patient:

- Name and Surname/ Contact details;
- Reason for requesting psychosocial services;
- A summary of the malignant diagnosis and oncological treatment followed;

⁸ Maggie Watson and David W. Kissane (Eds.), Handbook of Psychotherapy in Cancer Care, FirstEdition (2011), chapters 3, 4, 5, 9.

- Main psychosocial needs;
- Social support;
- Coping strategies;
- Assessment of the first intervention session (including objective scores);
- Evaluation at the end of the intervention (including subjective scores);
- Information materials offered;
- Duration of the intervention (number of sessions);
- Other relevant comments (e.g., patient resources, motivation for change).

Management of suicidal behavior in cancer patients

Suicidal behavior is a serious public health problem, but among oncological patients the risk of suicidal behavior is about 1.5 times higher than in the general population (Anguiano, Mayer, Piven, & Rosenstein, 2012).

Experts of the National Cancer Institute (NCI, 2016) specify two categories of suicidal risks for oncology patients: general and specific. The category of general risks includes the following: the existence of a mental illness history (especially if associated with impulsivity), a family history of suicide or suicide attempts, depression, abuse of toxic substances, the recent death of the patient's spouse and low social support. The category of specific risks includes: the type of cancer (e.g., oral and pharyngeal cancers, usually associated with tobacco and the consumption of alcohol, occupy top positions), stage of the disease and its association with a poor prognosis, confusion, inadequate pain control, the presence of certain symptoms or deficits (e.g., loss of mobility, loss of sphincter control, paraplegia, inability to swallow, choking, fatigue, exhaustion).

Suicidal thoughts are common to oncology patients; therefore, an individual assessment of suicidal risk is recommended. Patients at risk may benefit of consultation, diagnosis and psychiatric treatment.

As recommended⁹, in preventing the development of suicidal behaviors it helps to remember the following issues:

- encouraging disclosure
- availability of the specialist (by allowing the patient time to talk while listening and showing concern one proves to the patient that he/she is not completely alone)
- calm and an attitude of non-judgmental unconditional acceptance on behalf of the specialist is very important as patients with suicidal ideation might already have a very low self-esteem
- checking the patient for persistent suicidal thoughts (see if the patient has a clear plan)

⁹ http://docs.ipos-society.org/education/core_curriculum/ro/WatsonGrassi_suicide/story.html

- exploring the patient's intentions and circumstances that could lead to suicidal behavior
- referring the patient to psychiatric emergency services

Psycho-oncological interventions addressing caregivers

Not just people passing through the stages of cancer treatment experience emotional distress, but caregivers as well¹⁰. Family members of the cancer patients receive too little information, support and training on the role of being a caregiver of a cancer patient. An information support that can be used to address informative needs of the caregivers is the “Guide for family members of seriously ill patients: Together until the last moment”¹¹.

Another type of intervention recommended for cancer patients is the supportive group intervention. This type of psycho-oncological group intervention proved to be effective in reducing distress and psychological problems, as well as in increasing quality of life in cancer patients (Shead & Maguire, 1999; Hoey, Ieropli, White, & Jefford, 2008; Osborn, Demoncada, & Feuerstein, 2006).

The main factors of success in a psycho-oncological group intervention are linked to the group’s social support, instilling of hope (seeing that some members of the group have succeeded, the patient understands that he/she might also succeed), learning through modeling (adaptive coping strategies in particular), psychosocial adjustment (the patient understands better that the difficulties he/she faces are not only his/hers, but others as well).

In order to increase the effectiveness of building a therapeutic group within an institute of oncology or a department of radiotherapy recommendations are that patient selection to be carried out on admission for the first session of radiotherapy, the number of members to be 8 to a maximum of 12 and the first selection phase to target a short semi-structured clinical interview focused on identifying personality problems (such persons not being eligible to participate in group therapy due to the risk of distorting group dynamics).

In the Romanian oncological context, the most eligible group of patients which could benefit from a psycho-oncological supportive group intervention is that of breast cancer patients undergoing curative radiation therapy treatment due to their longer hospitalization (from at least 3 up to 6 or 8 weeks) and the fact that generally their physical condition is not severely affected.

To conclude, in Romania the field where one can intervene at the moment is that of increasing the quality of the psycho-oncological care. This guide is intended to provide directions for clinical decisions meant to improve services offered to cancer patients.

¹⁰ http://docs.ipos-society.org/education/core_curriculum/ro/Baider_fam/story.html

¹¹ <http://goo.gl/xHyDn>

Recommendations

As psychosocial interventions with cancer patients require a more complex organization, this section concludes with the following recommendations:

1. A first step in the process of identifying patients in need of psychosocial oncology care is to introduce quick and efficient tools for screening cancer distress that are already adapted and validated in Romania (Dégi, 2014b). Given that cancer distress has several dimensions, including a social one, distress screening tools should be inclusive instead of focusing on a particular symptom. Cancer distress can manifest anytime in the cancer trajectory and may go undetected if screening is conducted but once.
2. Coordination of comprehensive patient care through the national health system and piloting of an integrated plan for psychosocial screening and support during oncology treatment and care, taking into account case-specific physical, medical and psychosocial needs.
3. Establishing a coordinator of psychosocial support activities (case - manager) throughout the cancer trajectory to ensure that services meet the needs of cancer patients. A better integration of all aspects of the medical and psychosocial care addressing patient should be considered, especially in key points of transition (cancer diagnosis, treatment, remission, first recurrence and advanced/terminal stages), thus patients feeling better informed and empowered, exerting greater involvement in decisions regarding their own care, experimenting an improvement in personal experiences and quality of life.
4. Providing psychosocial support and care to patients diagnosed and treated for cancer and/or their caregivers/family members as an integral component of best practice clinical care. All members of the multidisciplinary team (including physicians, nurses, psycho-oncologists and oncology social workers) play a role in providing supportive care. Family, friends, support groups, volunteers and other community organizations complete the range of supportive care providers. Health professionals and/or different organizations provide supportive services including self-help, symptoms control, social support, rehabilitation, spiritual support as well as palliative care and bereavement support.
5. It is essential that at least 50% of the oncology patients receive a post-treatment plan. Such plan will take into account the individual needs of the patients regarding medical monitoring, psychological and social support.
6. Information services provided through multimedia platforms are vital in offering cancer patients and their families updated references on medical, social, legal and practical data relative to various forms of cancer. Increasing

the patients 'and informal careers' access to information on cancer and services available can be accomplished through various media such as information leaflets, access to help-lines, e-mail and other online facilities available in conjunction with the e-government strategy.

7. Better disease management and greater involvement in the decision-making process require the development of good practice codes for care centers and support groups, as well as of tools meant to facilitate the exchange of information on curative solutions/services, care and support. Enhancing patients' experience in all stages of cancer can be accomplished by disseminating follow up and treatment-resuming criteria, by facilitating a better cooperation between the medical community and patient support networks (family, volunteers) and by promoting the development of quality guides on various cancers, oncology services and care standards in collaboration with scientific societies, and patient or volunteer organizations.
8. Fighting against all forms of professional exclusion regarding persons affected by cancer, survivors or patients in remission, by providing support for reintegration into the workforce, assistance in return to work, with direct effects on improving patient/survivors' quality of life.
9. Romanian social worker with expertise in oncology can use in their activities with cancer patients the AOSW Good Practice Standards for Social Workers in Oncology, translated into Romanian and Hungarian languages.¹²
10. In their clinical work psycho-oncologists need to rigorously and responsibly personalize the following: 1) good practice recommendations on psycho-oncological intervention described in this guide; 2) their own professional expertise; 3) specifics regarding cancer patients and the psycho-oncology domain; 4) recommendations of the latest studies in the field of oncology; 5) the professional ethics code of certified psychologists¹³.
11. The risk of developing suicidal behaviors by inpatients and/or outpatients should be carefully managed in all oncology units, through implementation of a jointly agreed protocol addressing this issue according to existent professional standards¹⁴. In order to become functional such protocol outlining the distribution of responsibilities according to a general staff organigram for oncology units should be customized for each institution and made available to all personnel by being kept in the clinics' computer systems, emergency rooms and/or other areas accessible to staff only.

¹² <http://goo.gl/9S2EeP>

¹³ www.copsi.ro

¹⁴ http://docs.ipos-society.org/education/core_curriculum/ro/WatsonGrassi_suicide/story.html

12. A comprehensive approach to cancer care implies existence of multidisciplinary work teams and development within the oncology centers of psycho-oncology units consisting of psycho-oncologists, oncology social workers, nurses trained in psychosocial care, psychiatrists, and a pastoral counselor (priest). This multidisciplinary team will provide and monitor clinical support activities for cancer patients irrespective of treatment stage, professionals' training, and psychosocial oncology research (Păun & Anghel, 2003).

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