

Volume 1, Issue 1

2012

# NEUROPATHOLOGICAL DISEASES

**TULLIO GIRALDI**  
EDITOR-IN-CHIEF



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## AIMS AND SCOPE: NEUROPATHOLOGICAL DISEASES

The aim of this journal is to provide a periodical publication acting as an effective vehicle for collecting and transferring to the widest audience recent and updated information regarding the role which is played by psychological factors, through the mediation of the functions of the central and autonomic nervous system and of the neuro-endocrine network, in pathology and therapeutics.

A large body of evidence obtained through rigorous experimental and clinical research has accumulated, and continues to grow, showing that the natural history of many somatic diseases, as well as their susceptibility to successful treatment and healing, displays a significant contribution played by the immune system, and by the modulation of its functions via the central and peripheral nervous system and endocrine responses. Recent results also indicate that personal genetic constitution and polymorphism may determine individual susceptibility to diseases and healing, alone or in combination with subjective experience of life events, by means of a gene-environment interaction.

This picture of multiple mechanisms, each related to each other in a non-linear relationship, indicates the risk of the application of mechanistic and reductionistic approaches to analyze these complex phenomena, and indicates the need of the consideration of approaches methodologically adequate to deal with these complex systems.

This journal publishes the main presentations and expert opinions of selected congresses and workshop in regular and special issue in the series. The authors of the articles (and workshop participants) are chosen from a small number of basic scientists and clinical investigators. As a result, each issue of the journal will deal with a particular subject. The manuscripts are reviewed in the usual manner by guest editors and by the series Editors. The special issue will be published no later than three months after final review by the series Editors. A major goal of the journal is to attain further integration of the various presentations and discussion topics.

Professor Tullio Giraldi  
Editor-in-Chief

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*Neuropathological Diseases* (ISSN: 2160-2468) is published 4 times per year and is owned by Begell House, Inc, 50 Cross Highway, Redding, Connecticut 06896, Phone (203) 938-1300. USA subscription rate for 2012 is \$650.00. Add \$10.00 per issue for foreign airmail shipping and handling fees for all orders shipped outside the United States or Canada. All subscriptions are payable in advance. Subscriptions are entered on an annual basis, i.e., January to December. For immediate service and charge card sales, please call (203) 938-1300 Monday through Friday 9 AM — 5 PM EST. Orders can be faxed to (203) 938-1304 or mailed to Subscriptions Department, Begell House, Inc. 50 Cross Highway, Redding, Connecticut 06896.

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**Printed January 27, 2012**

# NEROPATHOLOGICAL DISEASES

## EDITOR-IN-CHIEF

**Tullio Giraldi**

Professor of Pharmacology  
Faculty of Medicine, Department of Life Sciences  
University of Trieste, I-34100 Trieste, Italy  
[giraldi@units.it](mailto:giraldi@units.it)

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Email: [MAES@FSW.leidenuniv.nl](mailto:MAES@FSW.leidenuniv.nl)

# NEUROPATHOLOGICAL DISEASES

Volume 1 / Issue 1

2012

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# Preface: Psycho-Oncology: Integrating Science into Clinical Care

Luigi Grassi<sup>1,\*</sup> & Tullio Giraldi<sup>2</sup>

<sup>1</sup>Section of Psychiatry, Department of Medical and Surgical Disciplines of Communication and Behavior, University of Ferrara, Italy; <sup>2</sup>University of Trieste, Italy

\*Address all correspondence to Luigi Grassi; Section of Psychiatry, Department of Medical & Surgical Disciplines of Communication and Behavior, University of Ferrara, Corso Giovecca 203, 44121 Ferrara, Italy; Tel.: +39 0532 236409; Fax: +39 0532 212240; Luigi.grassi@unife.it

**ABSTRACT:** Psycho-oncology, as the specialty aiming at studying the psychological, social, and spiritual factors that affect the quality of life of cancer patients and their loved ones, has grown exponentially over the past 30 years, with a specific role in the multidisciplinary approach to cancer and in patient-centered cancer treatment planning. Guidelines and recommendations on psychosocial care in cancer have been developed and implemented in a number of countries throughout the world. The International Psycho-Oncology Society (IPOS) and the Federation of the Psycho-Oncology societies *Statement on Standards and Clinical Practice Guidelines in Cancer*, represents an important result with regard to psychosocial care of cancer patients. The right that any person has to receive optimal care, with all components of the healthcare system explicitly incorporating attention to psychosocial needs into their policies, practices, and standards is at the center of the declaration of psycho-oncology in cancer care as a human right that the IPOS is launching in collaboration with international advocacy movements throughout the world. In summary, psycho-oncology has reached a level of evidence and experience making it a specialist discipline within the vast field of the psychosocial/psychiatric specialties aiming at improving the quality of life of ill people.

**KEY WORDS:** psycho-oncology, cancer care, treatment

## I. INTRODUCTION

Cancer is a severe traumatic event with physical, emotional, interpersonal, and social implications that should be constantly monitored across the disease trajectory. Therefore, the psychosocial implications and the impact of cancer on the patients and the families are of paramount importance in oncology in consideration of both the high prevalence of psychiatric and psychological disorders secondary to the disease and treatment (approximately 30–40%) and the consequences of maladjustment to cancer (e.g., reduction of quality of life, impairment in social relationships, longer rehabilitation

time, poor adherence to treatment and abnormal illness behavior, and possibly shorter survival).<sup>1</sup>

For these reasons, psycho-oncology, as the specialty aiming at studying the psychological, social, and spiritual factors that affect the quality of life of cancer patients and their loved ones, has grown exponentially over the past 30 years<sup>2</sup> and has today a specific role in the multidisciplinary approach to cancer<sup>3</sup> and in patient-centered cancer treatment planning.<sup>4</sup> Guidelines and recommendations on psychosocial care in cancer have been developed and endorsed by a number of national scientific societies of psycho-oncology.<sup>5</sup> Numerous examples include (1) the Canadian *National Standards for Psychosocial Oncology* and clinical guidelines on the assessment of psychosocial needs of cancer patients and on the screening, assessment and care of psychosocial distress in cancer (available from [www.capo.ca](http://www.capo.ca))<sup>6-7</sup>; (2) the Australian *Clinical Practice Guidelines for the Psycho-social Care of Adults with Cancer*, (available from [www.nhmrc.gov.au](http://www.nhmrc.gov.au))<sup>8,9</sup>; (3) the *Management of Distress* guidelines of the National Comprehensive Cancer Network (NCCN) (available from [www.nccn.org](http://www.nccn.org)) in the United States<sup>10</sup>; (4) the “Psychological Support” guidelines within the document *Improving Outcomes Guidance for Supportive and Palliative Care* published by the National Institute of Clinical Excellence (NICE)<sup>11</sup>; (5) the “Psychological Support Measures” within the *Manual for Cancer Services of the National Cancer Peer Review Programme* in the United Kingdom<sup>12,13</sup>; and (6) the *Patient Education and Psychosocial Care* guidelines of the Dutch National Cancer Control Programme, in The Netherlands.<sup>14</sup> All are examples of the involvement of psycho-oncology within the National Cancer Acts and/or Governmental Agencies of several countries, consistent with the indication that “[...] attending to psychosocial needs should be an integral part of quality cancer care [...]”, since “it is not possible to deliver good-quality cancer care without addressing patient’s psychosocial health needs.”<sup>15,16</sup>

This has been recently stressed, at an international level as well, by the International Psycho-Oncology Society (IPOS) and the Federation of the Psycho-Oncology societies through the *Statement on Standards and Clinical Practice Guidelines in Cancer* (available from [www.ipos-society.org](http://www.ipos-society.org)), which indicates that “quality cancer care must integrate the psychosocial domain into routine care” and that “distress should be measured as the 6th Vital Sign after temperature, blood pressure, pulse, respiratory rate and pain.”<sup>17,18</sup>

The right that any person has to receive optimal care, with all components of the healthcare system explicitly incorporating atten-

tion to psychosocial needs into their policies, practices, and standards addressing clinical care is also at the center of the declaration of psycho-oncology in cancer care as a human right that the IPOS is launching in collaboration with international advocacy movements throughout the world.

For all these reasons, this first issue of *Neuropathological Diseases* is dedicated to psycho-oncology as the clinical area that healthcare professionals, scientist and researches, trainers and educators as well as administrators and healthcare policy makers involved in cancer care should know and be aware of. Some central clinical themes are the topic of this issue, specifically the importance of routine screening for emotional distress as the sixth vital sign, the most significant psychosocial and psychiatric disorders secondary to cancer, the family implications of cancer and cancer treatment, and the specific and extremely important area of child psycho-oncology. The therapeutic implication for cancer patients and their families, as well as the current status of training in psycho-oncology will be the aim of the next issue, as the expression of how to integrate science and clinical experience in cancer care.

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# Psychiatric Disorders Related to Cancer: Prevalence, Etiology, and Recognition

*Rosangela Caruso, Anna Clara Morelli, Mara Giulia Nanni, Bruno Biancosino, & Luigi Grassi\**

Section of Psychiatry, Department of Medical & Surgical Disciplines of Communication and Behavior, University of Ferrara, Italy

\*Address all correspondence to Professor Luigi Grassi; Section of Psychiatry, Department of Medical & Surgical Disciplines of Communication and Behavior, University of Ferrara, Corso Giovecca 203, 44121 Ferrara, Italy; Tel.: +39 0532 236409; Fax: +39 0532 212240; Luigi.grassi@unife.it

**ABSTRACT:** The evaluation of psychiatric disorders related to cancer has been the subject of intense research in psycho-oncology. Psychopathological disturbances have an average prevalence of 35–45% and may be classified as “classical” psychiatric disorders (e.g., adjustment, anxiety, depressive disorders) and neuropsychiatric disorders (e.g., cognitive disorders secondary to treatment, delirium). Several problems have emerged in using the most common nosological systems, such as the *International Classification of Diseases (ICD)* and *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, because of their limits in specificity and sensitivity and in catching certain clinically significant dimensions (e.g., health anxiety, demoralization, irritable mood), which can be identified through other systems, such as the Diagnostic Criteria for Psychosomatic Research. The need to monitor psychosocial morbidity (i.e., “caseness”) in cancer has determined the development of screening tools that have shown good levels of sensitivity and specificity. Among the psychopathological conditions that are strongly related to biological factors, the most common are cognitive disorders secondary to treatment (so-called chemo-brain) and delirium. The knowledge of the risk factors for both psychiatric and neuropsychiatric syndromes, including some specific problems, such as suicide, should be part of the training of healthcare professionals working in cancer centers. Furthermore, the barriers that still prevent comprehensive care to cancer patients should be identified and overcome.

**KEY WORDS:** psycho-oncology, psychiatric morbidity, cancer

## I. INTRODUCTION

The definition and careful assessment of mental disorders related to cancer, the analysis of the consequences for the patient as well as family members, and the implementation of therapeutic interventions play central roles in psycho-oncology and clinical oncology.<sup>1</sup>

The emotional and behavioral responses to the dramatic changes and to the threat that a cancer diagnosis, its development, and treat-

ment evoke, occur in a variety of ways that can hardly be defined by categorical criteria, i.e., the extremes ranging from normal to abnormal or from physiological to pathological. A dimensional approach, more appropriate with respect to assessing the many facets of patient distress that cannot simply be described by the concept of comorbidity between categorical diagnoses, is difficult in this context, due to the overlap between biological, social, and psychological mechanisms.<sup>2</sup> This also applies to clinical psychiatric (or neuropsychiatric) disorders closely linked to the biology of the disease or treatments; cognitive impairment is related to chemotherapy and confusion (delirium), with multiple etiologies often seen in cancer patients. However, even at this level, personality and relational characteristics must not be forgotten, and a balanced categorical–dimensional approach is necessary in order to find sensitive and specific tools for the assessment of the psychological and psychopathological condition and to provide the most appropriate intervention according to an integrated model.

The relevance of what has been said is very important considering that, as in many other areas of medicine, in oncology practice a tendency to “medicalize” and to have a “disease-centered approach” is a problem; psychosocial dimensions of the patients and their families are often undervalued and underestimated. This means that a high percentage of patients with a high level of psychological (e.g., existential, spiritual) suffering do not receive appropriate psychological care.

Research on distress and psychopathology in oncology is vast and has gradually changed over time, depending on the improvement of the measuring instruments, on the criteria used for the assessment of individual psychopathological disorders, and on the accumulation of knowledge in clinical psycho-oncology,<sup>3</sup> as being reviewed here. To clarify these factors, we separate the ‘classical’ psychopathological disorders from neuropsychiatric conditions (in a broad sense, psychorganic syndromes, according to older classifications), discussing the most common disorders and analyzing the outstanding problems.

## II. PSYCHIATRIC DISORDERS

Since the end of the 1970s, scientific research in both psychological and psychiatric areas has begun to verify the incidence and prevalence of psychological distress in cancer, describing the main clinical disorders and psychosocial dimensions that interfere with quality of life and the most useful methods of assessment for recognizing distress. The description of these disorders can be made by taking

into consideration the information collected through more traditional nosographic systems [e.g., *International Classification of Diseases* (ICD) and *Diagnostic and Statistical Manual of Mental Disorders* (DSM)], systems more specifically aimed at identifying the psychosocial dimensions in medicine [e.g., *Diagnostic Criteria for Psychosomatic Research* (DCPR)], and psychosocial distress screening tools (e.g., the distress thermometer and other instruments).

## **II.A. ICD-10 and DSM-IV**

The use of psychiatric classification systems for cancer dates back to the beginning of the 1980s, with the application of DSM-III and subsequent editions<sup>4,5</sup> and of the ICD-10.<sup>6</sup> The first and best-known multicenter study examining the prevalence of psychiatric disorders in oncology is the Psychosocial Collaborative Oncology Group (PSYCOG), which was conducted in four centers in the United States and involved 215 newly diagnosed cancer outpatients who were assessed using the DSM-III interview. The PSYCOG study indicated that 47% of patients showed symptoms satisfying the criteria of the DSM-III, in particular, adjustment disorders with depressed mood, or with mixed anxiety and depressed mood (25%), major depression (6%), and anxiety disorders (4%).

Several other surveys in subsequent years reported results in line with the PSYCOG study,<sup>7–10</sup> albeit with some variations depending on the system used (DSM vs. ICD); on the population; cancer site, stage, and progression; and on the clinical context (outpatient vs. inpatient).

Several problems and critical areas have, however, emerged with regard to the incompleteness of the diagnostic approach (e.g., sexuality disorders, although quite common, are certainly underestimated compared to the full extent of the problem)<sup>8</sup> and the difficulty in applying, in oncology, the categorical criteria, particularly for certain disorders (e.g., adjustment disorders and depression).

### **II.A.1. Adjustment Disorders**

Adjustment disorders represent by far the most frequently reported disorders at all stages of cancer; they describe the emotional reactions related to the multiple stressors linked to cancer, and involve 20–25% of patients. However, several different problems emerge, not only with regard to oncology but the medical condition as a whole, determined in particular by the low specificity of DSM criteria for the diagnosis of adjustment disorder, the vagueness of the symptoms, the weak-

ness of the concept of distress and/or the expected normal response, and the inconsistency of using time as a criterion (6 months), which is not plausible in describing distress in people with chronic medical illnesses, especially cancer.<sup>9,10</sup>

### ***II.A.2. Depressive Disorders***

Depressive disorders are another major area on which much literature has focused. The prevalence of depression among cancer patients is very different, depending on the studies, and it varies between 6% and 40%.<sup>10,11</sup> Major depression is the most studied disorder, although several investigations also indicate the importance of the ‘minor’ forms of depression, including subthreshold and anxious-depressive forms.<sup>12</sup>

With regard to major depression, the debate related to diagnostic problems has been very intense because of the limits of a categorical approach. More specifically, the DSM and ICD exclusion criteria indicating that symptoms of depression are not due to the direct physiological effects of a substance, including medications or a general medical condition (e.g., cancer), represent the first problem when diagnosing major depression in cancer patients.

Another problem related to the use of the DSM in oncology is that the somatic symptoms of depression (e.g., changes in appetite, sleep disturbances, weight loss, changes in libido, or pain) risk confounding the diagnosis, as they can be related to cancer, to treatments, or to depression itself (i.e., somatic symptoms of depression). For this reason, several authors have proposed to change the DSM criteria (Table 1), suggesting the replacement of somatic symptoms with affective ones, the addition of affective criteria using somatic symptoms that are clearly not derived from the medical condition to confirm diagnosis, or to exclude somatic symptoms from the criteria list.<sup>13-14</sup>

However, when using the substitute criteria to the DSM-III, it has been shown that the two methods tend to become more and more similar as the number of symptoms increases (i.e., from more than five up to nine).<sup>15</sup> Recently, in a study of more than 700 patients diagnosed with major depression, comparing the two different approaches, Acheiki et al.<sup>16</sup> outlined that, by using the changes in the DSM diagnostic criteria, different discriminating capacities emerged, and by using the item response theory analysis, some symptoms appear to be better indicators of the severity of depression. In particular, mild depression seems to be better discriminated by “tearfulness or depressed appearance” and “brooding and pessimism”; for moderate

**Table 1. Diagnostic Criteria and Changes for Major Depression in Cancer Patients**

**Inclusive Approach:** Criterion A + B + C + D + E. In criterion A all the symptoms are included, regardless of whether or not they can be attributed to neoplastic disease. The inclusive approach has poor specificity and inflating rates of depression, with accuracy compromised for reliability and excess expenditure of resources to rule out false positives.

- A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.
- (1) Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful)
  - (2) Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation made by others)
  - (3) Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day
  - (4) Insomnia or hypersomnia nearly every day
  - (5) Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)
  - (6) Fatigue or loss of energy nearly every day
  - (7) Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick)
  - (8) Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others)
  - (9) Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide
- B. The symptoms do not meet criteria for a mixed episode.
- C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- D. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).
- E. The symptoms are not better accounted for by bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.

**Exclusive approach:** Criterion A + B + C + D + E. In Criterion A: (3) Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day; and (6) fatigue or loss of energy nearly every day *eliminated* from the list of nine criterion symptoms, reducing the list to seven (out of which the necessary criteria must be met). Exclusive approach reduces the number of false-positive diagnoses but at the cost of sensitivity.

**Table 1. Continued**

**Substitutive approach:** Criterion A + B + C + D + E. In Criterion A: (3) Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day replaced by *tearful or depressed appearance*; (4) insomnia or hypersomnia nearly every day replaced by *social withdrawal or decreased talkativeness*; (6) fatigue or loss of energy nearly every day replaced by *brooding, self-pity, or pessimism*; (8) diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others replaced by *cannot be cheered up, doesn't smile, no response to good news or funny situations*).

**Alternative Approach:** Criterion A + B + C + D + E. Criterion A and B with the following proposed changes:

- A. Compared to previous behavior, at least *five* of the following symptoms are present nearly every day, for a continuous period of 2 weeks (at least *one* of the symptoms is depressed mood or loss of interest and pleasure in things or full of *hopelessness and helplessness*):
- (1) Depressed mood most of the day
  - (2) Markedly diminished interest or pleasure in all, or almost all, activities most of the day (*especially a loss of interest in people*)
  - (3) Feelings of worthlessness (*negative feelings towards oneself and not the situation*) or excessive or inappropriate guilt (*feeling that the illness is a punishment for something bad they have done*) nearly every day
  - (4) Diminished ability to think or concentrate, or indecisiveness, nearly every day (*unrelated to delirium, dementia, physical illness or therapy*)
  - (5) Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide (*not simply wishing to be dead in order to put an end to suffering*)
  - (6) Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day (*unrelated to physical illness, treatment or to being hospitalized*)
  - (7) Psychomotor agitation or retardation nearly every day (*unrelated to delirium, dementia, physical illness or therapy*)
  - (8) Insomnia or hypersomnia nearly every day (*unrelated to physical illness, treatment or to being hospitalized*)
  - (9) Tearful or depressed appearance, fatigue or loss of energy nearly every day (*unrelated to physical illness, treatment or to being hospitalized*)
- B. Symptoms cause clinically significant distress or impairment in social functioning (*unrelated to illness/disease or therapy*), *not participating in the medical care, despite the ability to do so, not progressing despite an improved medical condition and/or functioning at a lower level than the medical condition warrants.*

depression, the most discriminating symptoms seem to be “not progressing despite an improved medical condition and/or functioning at a lower level than the medical condition warrants” and “social withdrawal or decreased talkativeness”; markers of severe depression would be “cannot be cheered up, doesn’t smile, no response to good



news or funny situations.” Surprisingly, according to the authors, classic symptoms of depression such as suicidal ideation and feelings of worthlessness were not good indicators of depression, highlighting the difficulty of finding the core aspects of depression in cancer patients.

The diagnostic problems we have mentioned are particularly evident when dealing with palliative care patients, where a marked reduction in performance, pain and fatigue, as well as loss of a vision of the future, make it difficult to diagnose depression.<sup>17,18</sup> Recently, the European Palliative Care Research Collaborative on Depression (EPCRC) within the European Society of Palliative Care devised a set of guidelines and work packages on this issue, which are regularly updated.<sup>19</sup>

From the biological point of view, several factors (e.g., alterations of neuro-hormonal and metabolic systems and the activation of pro-inflammatory cytokines) related to chemotherapy, hormone therapy, or the disease itself can produce depressive symptoms, such as cytokine-induced depression (or sickness behavior), which are difficult to discriminate from classic depressive disorders.<sup>20</sup> Clarification is also needed with respect to other forms of depression categorized in the DSM-IV and ICD-10, such as minor depression, recurrent brief depression, and anxious-depressive syndrome.

### ***II.A.3. Anxiety Disorders***

Regarding anxiety disorders, along with specific phobias (in particular those related to well-known phenomena such as chemotherapy-induced anticipatory nausea and vomiting, overlapping the mechanisms of classic phobias),<sup>21</sup> posttraumatic stress disorder (PTSD) is of great interest in oncology. As a consequence of the extension of the diagnostic criteria between the DSM-III/DSM-III-R and the DSM-IV, PTSD, which received little attention until 1987, has become the object of much research.<sup>22</sup> This condition seems to affect, according to some studies,<sup>23–27</sup> 15% of cancer patients; with a smaller but still significant percentage seen in long-term survivors of cancer (at least 5 years after diagnosis.) A recent study of more than 800 non-Hodgkin’s lymphoma patients and survivors (2–44 years from diagnosis), showed that although the prevalence of PTSD was 7.8%, 61% of these patients presented some symptoms of PTSD that interfered with their quality of life.<sup>23</sup> These data should be taken into consideration when analyzing some aspects of PTSD in cancer diseases, such as the impossibility to define qualitative (i.e., exogenous stressors vs. endogenous stressors) and temporal criteria (i.e., acute stressor in PTSD vs. continuing and multiple stressful events in cancer). This factor has led to several authors questioning the accuracy



of the diagnosis and the need to also consider the sub-syndromic forms of PTSD (Table 2),<sup>24,25</sup> most significant in people with cancer.<sup>26,27</sup>

**Table 2. Diagnostic Criteria for Subthreshold of Incomplete PTSD**

At least 1 criteria between B or C or D

- B. The traumatic event is persistently re-experienced in any of the following ways:
- (1) Spontaneous or cued recurrent, involuntary, and intrusive distressing memories of the traumatic event(s). Note: In children, repetitive play may occur in which themes or aspects of the traumatic event(s) are expressed.
  - (2) Recurrent distressing dreams of the event . Note: In children, there may be frightening dreams without recognizable content.
  - (3) Acting or feeling as if the traumatic event were recurring (e.g., reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those on waking or when intoxicated) (Note: In children, trauma-specific reenactment may occur in play.)
  - (4) Intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event
  - (5) Physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event
- C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma) as indicated by at least three of the following:
- (1) Efforts to avoid thoughts, feelings, or conversations associated with the trauma
  - (2) Inability to recall an important aspect of the trauma
  - (3) Markedly diminished interest or participation in significant activities
  - (4) Feeling of detachment or estrangement from others
  - (5) Restricted range of affect (e.g., unable to have loving feelings)
  - (6) Sense of a foreshortened future (e.g., does not expect to have a career, marriage, children or a normal life span)
- D. Persistent symptoms of increased arousal (not present before the trauma) as indicated by at least two of the following:
- (1) Difficulty falling or staying asleep
  - (2) Irritability or outbursts of anger
  - (3) Difficulty concentrating
  - (4) Hypervigilance
  - (5) Exaggerated startle response
- A criteria + at least four symptoms among re-experience, withdrawal/ loss of interests, insomnia, avoidance of stimuli. <sup>30</sup>
- A. The person experiences a traumatic event in which both of the following were present:
- (1) The person experienced or witnessed or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others.
  - (2) The person's response involved intense fear, helplessness, or horror.

#### ***II.A.4. Sexual Disorders***

A very important, though underestimated, area in oncology is represented by sexual disorders, which involve an average of 25–40% of cancer patients.<sup>12</sup> Many studies have reported that diseases such as breast cancer, ovarian cancer, and uterine cancer to be associated with a decrease or loss of sexual drive, changes in female genital response (e.g., decrease or loss of lubrication), orgasm problems, and vaginismus and dyspareunia.<sup>28</sup> Studies of male patients show that testicular and prostate cancer have important consequences on sexuality, in particular low sexual drive, performance anxiety, premature ejaculation, erectile dysfunction, and inhibition of orgasm. Sexual problems have been also shown to affect patients with head and neck, bladder, or colon cancer, which regardless of gender have a very negative impact on sexual life. Various elements play multiple roles in determining these difficulties, including body image changes, the effects of chemo- and radiation therapy at a systemic level as well as on the reproductive tract, weight loss, stomas (e.g., urostomy or colostomy), the consequences of surgery, and incontinence.<sup>29</sup> In this context, applying the DSM or ICD criteria appears of little use, and it is necessary to have more specific tools that can correctly explore sexuality and sexual problems of patients and couples and that identify the level of distress.<sup>30–36</sup>

From the aforementioned results, the application of standardized systems such as DSM and ICD in oncology has clarified how people with cancer present significant disorders that must be carefully evaluated. Nonetheless, other problems must also be considered, including the facts that the illness can cause long-term consequences, that people healed from cancer or long-term survivors with cancer can maintain a level of psychological suffering, and that in advanced and terminally ill patients the impairment of somatic conditions leads to higher diagnostic difficulties.

Moreover, some dimensions of psychosocial suffering, such as demoralization, health anxiety, emotional repression, are not recognized by the DSM or ICD, or, if so, they are only partially mentioned in heterogeneous and vague paragraphs (e.g., DSM Code V and “Other conditions that may be a focus of clinical attention,” and ICD Code Z00-Z99 “Factors influencing health status and contact with health services”).<sup>31,32</sup>

## II.B. Diagnostic Criteria for Psychosomatic Research (DCPR)

The development of the Diagnostic Criteria for Psychosomatic Research (DCPR), as additional or substitute diagnostic criteria for the DSM, has been an important step forward in dealing with the problems we have outlined.<sup>33</sup> The DCPR offers an extremely interesting system for medical contexts by providing the opportunity to better identify psychological distress and psychological reactions, particularly in the medical setting. It consists of 12 dimensions: health anxiety, disease phobia, thanatophobia, illness denial, functional somatic symptoms secondary to a psychiatric disorder, persistent somatization, conversion symptoms, anniversary reaction, type A behavior, irritable mood, demoralization, and alexithymia.

Recent data have shown that some DSM disorders, such as major depressive disorder or adjustment disorders, do not necessarily overlap with some DCPR dimensions, including

demoralization, health anxiety, or irritability.<sup>34,35</sup> In cancer clinical practice, certain attitudes and health perception styles, as abnormal illness behavior such as affective inhibition, illness beliefs with no responses to medical reassurance, interpersonal conflict attitudes, could be related to a depressive condition that does not meet the usual DSM or ICD diagnostic criteria.<sup>36–37</sup> Furthermore, maladaptive coping strategies, such as hopelessness–helplessness and anxious preoccupation, are linked to other psychosocial dimensions such as a lack of social support and personological variables like external locus of control, without a proper psychiatric diagnosis.<sup>38</sup>

More recently, Grassi et al.,<sup>39</sup> using both the DSM-IV and the DCPR in 146 cancer patients, showed that 71.2% had symptoms belonging to at least one DCPR syndrome [in particular health anxiety (37.7%), demoralization (28.8%), alexythymia (26%), irritability (11.6%)], compared to the 44.5% of patients receiving a DSM-IV diagnosis [i.e., adjustment disorders (28%), mood disorders (10.3%)]. An overlap between DCPR and DSM-IV diagnostic systems was possible only for 39% of the patients, while 58% with no DSM-IV diagnosis (i.e., 55.5% of the whole sample) received a DCPR diagnosis (i.e., 39.2% of the whole sample). In a different study of 105 breast cancer patients, the same authors<sup>40</sup> noticed that 38.1% of this sample showed symptoms for at least one DCPR syndrome, and 28.6% showed symptoms for more than one DCPR syndrome. Higher levels of anxiety and depression, more physical symptoms, a more intense sense of sickness, less

recreational activities and fewer interpersonal relationships, and a higher preoccupation with and fear of illness were related to the DCPD dimensions of health anxiety and demoralization. Regarding the latter, the phenomenology of the demoralization in cancer care and in general medical practice<sup>41</sup> has been described as a condition not necessarily associated with major depression,<sup>42,43</sup> not overlapping with subthreshold depression and characterized by some core-symptoms.<sup>44,45</sup> The symptoms suggested for demoralization diagnosis are shown in Table 3.

**Table 3. Criteria for the Diagnosis of Demoralization (from Kissane et al., adapted)**

- 
1. Symptoms of distress include despair and loss of meaning/purpose of life
  2. Pessimistic attitude and thoughts, fatigue/helplessness, feeling trapped, personal failure or lack of a positive vision of the future
  3. Prolonged lack of motivation
  4. Characteristics associated with social alienation or isolation and lack of support
  5. The intensity of the symptoms fluctuates
  6. The primary condition is neither a depression disorder nor any other form of psychiatric disorder
- 

## II.C. Distress

As better described elsewhere in this issue (see the article by Anunziata and Muzzati), from the late 1990s, a multidisciplinary panel of psychiatrists, oncologists, psychologists, nurses, social workers, and pastoral figures within the National Comprehensive Cancer Network (NCCN, [www.nccn.org](http://www.nccn.org)) has given priority to the development of guidelines for the assessment and management of distress in people with cancer. The word “distress” does not mean a specific psychiatric disorder diagnosis according to a categorical model but a condition on a continuum that ranges from normal feelings of vulnerability, sadness, and fear to disabling problems such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.<sup>46–47</sup> The development and application of simple tools such as the distress thermometer (DT) and the problem list (PL, i.e., an assessment of problems that the person may have in the areas of daily life as well as emotional, spiritual, and physical life) have revealed that approximately 40–45% of patients present clinical levels of distress needing psychological/psychiatric assessment and specialist interventions.<sup>48</sup> The DT-PL has

been proposed for use as a routine screening tool and to be included in the medical records of cancer departments (i.e., outpatient and day hospital centers, inpatient wards).<sup>49</sup> Some other instruments have been suggested for the identification of cancer patient distress, both in terms of maladaptive coping styles (e.g., hopelessness-helplessness and anxious preoccupation), and in terms of specific symptoms (e.g., depressive, anxious, or somatoform symptoms).<sup>50,51</sup>

### III. THE PROBLEM OF SUICIDE IN ONCOLOGY

Suicide is an important theme that deserves both special attention when speaking of psychological distress among cancer patients and knowledge of its risk factors (Table 4). Numerous data exist in psychological literature regarding cancer and suicide,<sup>52,53</sup> in particular, the correlation between suicide and depression<sup>54</sup> and the relation between suicidal ideas and the request for euthanasia or assisted suicide in the advanced stages of disease.<sup>55</sup>

**Table 4. Risk Factors for Suicide in Patients With Cancer (from Grassi and Riba, 2008, mod)**

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#### General factors

- Family history of suicide
- Remote psychiatric history of depressive episodes and suicide attempts
- Current psychiatric diagnosis
  - Major Depression
  - Personality Disorders
  - Substance Abuse
  - Recent stressful events of loss (e.g., grief, real or symbolic loss)
- Lack of social support

#### Specific factors

- Pancreatic, head/neck, lung cancer (often associated with alcohol abuse)
  - Advanced stage of disease
  - Poor prognosis
  - Intractable or inadequately treated pain
  - Physical symptoms of high psychological impact (e.g., loss of autonomy, loss of bowel or bladder functions, severe amputations, paraplegia, inability to eat, severe fatigue)
-

Although thoughts about death and suicide are often reported by people with cancer, it is necessary to determine the difference between general thoughts and more specific suicidal ideation, which is reported by approximately 5–10% of cancer patients, regardless of site and stage of diagnosis. Recently in a study of nearly 3,000 patients, Walker et al. reported that 7.8% had suicidal ideation [Item 9 from the Patient Health Questionnaire (PHQ)] related to emotional distress, high pain levels, and to a smaller extent, old age. Many studies have shown that thoughts, expressed as a desire for hastened death, are commonly reported by 9–17% of patients in advanced stages of disease.<sup>56</sup> More recently, a study<sup>57</sup> of 326 patients in advanced stages of cancer has shown a lower level of desire for hastened death (2%), but it also found an association between this desire and some specific parameters, such as feelings of hopelessness, depressive symptoms, physical distress symptoms (e.g., pain, difficulty in breathing, fatigue) and reduced performance, lack of spirituality, lack of social support, and loss of self confidence, confirming the data reported in many other recent studies.<sup>58–59</sup> In adults affected by cancer in childhood and in long-term survivors, Recklitis et al.<sup>60</sup> underscored the presence of suicidal thoughts in approximately 13%. More recently the same authors,<sup>61</sup> in a controlled study of 9,126 long-term survivors affected by cancer in developmental age and 2,968 brothers and sisters recruited in a childhood cancer survivor study, demonstrated that suicidal ideas are higher in cancer survivors (7.8% vs. 4.6%) and that these ideas were independent of age, age at diagnosis, sex, antineoplastic treatment, recurrence, time from diagnosis, secondary cancer, while they were correlated with central nervous system (CNS) cancer, depression, a reduced health perception, a chronic condition, pain, and an overall poor state of health. Suicidal ideas are more frequent in people affected both by cancer and depression, where thoughts of ending their lives was present in 50% of cases.<sup>62</sup>

Regarding the event of suicide, many longitudinal catamnestic studies in the past 30 years have shown that people affected by cancer are at higher risk of suicide than the general population, with a double incidence.<sup>63–64</sup> A study of almost 350,000 patients with prostate cancer, showed a higher risk of suicide than the general population, especially in the first few months after diagnosis,<sup>65</sup> while a study of more than 700,000 women with breast cancer indicated that even after many years from diagnosis, suicide risk

is between 1.5 and 2 times higher than the general population, in particular for women in advanced stages of disease.<sup>66</sup> Cohort studies on a population from 100,000 to 1 million cancer patients showed that some factors, including the site of cancer (e.g., pancreas, lung, head and neck), male sex, old age, time from diagnosis (the first 5 years) were associated with a higher risk of suicide (80–100 per 100,000 inhabitants per year, corresponding to approximately 10 times the incidence in the general population).<sup>67–68</sup> Depression is certainly one of the most important risk factors for suicide, as shown in studies comparing different psychiatric diagnoses and the incidence of suicide in cancer patients.<sup>69</sup> Recently, in a clinical research of more than 35,000 patients affected by pancreatic cancer (in which usually the prevalence of depression is between 30% and 70%), the incidence of suicide was approximately 135.4 per 100,000 per year, approximately 11 times higher than that of the general population.<sup>70</sup>

#### IV. NEUROPSYCHIATRIC SYNDROMES

In addition to mood disorders, anxiety disorders, adjustment disorders, and different dimensions of suffering already described, cognitive disorders represent an important issue in oncology, both in terms of cognitive impairment related to treatments and acute confusional states (delirium). With regard to cognitive impairment related to treatments, an increasing number of studies have indicated that chemotherapy and chemotherapy associated to radiation therapy can imply impairment of some neuropsychological domains, such as memory, attention, concentration, learning functions, calculation, and visuo-spatial perception. Although no agreement exists among different authors on these conditions, defined as cognitive impairment related to chemotherapy or *chemo-brain* (or *chemo-fog*),<sup>71–72</sup> a careful cognitive assessment has an important role in cancer patients. The impairment may assume a variable phenomenology according to how and to what degree cognitive function is affected. Non-cognitive disorders, such as loss of emotional control, behaviour and personality modifications, movement disorders, and posture and coordination disorders, might also be associated with cognitive impairment.

Other possible cognitive impairment conditions, up to dementia, might be caused by primary disease (e.g., primary brain tumors) and by the consequences of the treatment on the CNS.<sup>73</sup> With frontal-lobe



tumors, mental impairment is very common and includes activity reduction, attention loss, storage memory impairment, disinhibited behavior, mood disorders, euphoric states, as well as apathy and indifference. In meso-diencephalic tumors, disorders can be variable and can include consciousness impairment, Korsakov's syndrome, and thalamic dementia. Brain metastases can also induce psychopathological disorders, in particular memory impairment associated with personality modification, as well as aphasia, alexia, acalculia, agnosia, apraxia, amnesia, and mood disorders. The incidence of dementia in patients undergoing radiotherapy of the brain for the treatment of brain metastases is estimated to be 2–5%. Symptoms can appear from a few months to several years after radiation treatment and can make a slow, progressive, irreversible impairment of cognitive functions, associated with psychomotor retardation and apraxic walking. In all of these situations, the evaluation aims to determine or quantify the intellectual impairment and emotional changes through a standardized case history, an appropriate neurological and mental status examination, and formal neuropsychological tests and imaging studies (e.g., EEG, CT scan, MRI, PET).<sup>74</sup>

Finally, much of the literature is focused on delirium, which is one of the most common cognitive disorders in the advanced stages of disease.<sup>75,76</sup> Delirium is characterized by an acute alteration of cognitive function and level of vigilance, with a prevalence of 10–80%. In the last days of life (terminal delirium) it has a prognostic value, together with other symptoms or symptom clusters. Although most of the delirium conditions are hyperactive-agitated (with marked alterations in behavior, rich “production” of symptoms, associated with disturbances of perception and thought) and mixed, on a phenomenological-clinical basis, even hypoactive delirium conditions (e.g., decreased level of consciousness or lethargy) are very common. Even for the delirium condition, the diagnostic approach requires an integration between etiopathogenetic variables (e.g., careful collection of medical history, review of medical records, meeting with family members, liaison with doctors and nurses) and clinical variables (e.g., onset of delirium, general and neurological examination, assessment of the state of mind and consciousness, monitoring over time). Cognitive assessment instruments, both of general functions (e.g., mini-mental state examination, clock drawing test, phrase-writing test) or of the specific domains for delirium [e.g., Memorial Delirium Assessment Scale (MDAS), Delirium Rating Scale (DRS-Revised-98)] are helpful in clinical practice.



## V. ETIOPATHOGENETIC FACTORS ASSOCIATED WITH PSYCHIATRIC DISORDERS IN ONCOLOGY

### V.A. Biological Factors

The variables related to cancer and cancer treatment are the first biological factors to consider. It has already been indicated that some sites of disease, particularly head and neck, colon, pancreas, and lung are more often than other sites associated with depressive disorders and distress. The stage of disease is also important; in advanced stages the risk of depression and confusion is higher.<sup>77</sup> Therapies prescribed to treat cancer can play a significant role, in particular chemotherapy, antibiotics, other anti-neoplastic agents (e.g., interferon, hormones, and steroids) and analgesic drugs that may be associated with several psychopathological conditions, including depression, delirium, and dysphoric states.<sup>78</sup>

Regarding depression and other behavioral symptoms, many studies have attempted to test the predictive role of biological variables.<sup>79,80</sup> Some data suggest that depressive symptoms are associated with elevated plasma concentrations of IL-6 (five times higher in depressed than in non-depressed patients with cancer), higher blood levels of cortisol, and an altered HPA axis function with a reduced diurnal variation of cortisol.<sup>81</sup> Although other authors did not confirm these results,<sup>82</sup> more recent data seem to indicate that the association between depression and factors such as cytokines and cortisol is stronger in depression, with marked vegetative symptoms but not in marked affective component forms.<sup>83</sup> The more general condition of cytokine-induced depression (i.e., sickness behavior) should also be considered, which has overlapping symptoms with major depression (e.g., anhedonia, fatigue psychomotor retardation, anorexia, and decreased libido) and where neuroimmunomodulation has an important role.<sup>84</sup>

Recently, the role of genetic polymorphism of the 5-HT transporter has been considerably investigated regarding to the problem of depression, with data indicating that people with short alleles (*s* / *s*) are more at risk for developing depression when facing stressful events compared with people with the long alleles (*l* / *l* and *l* / *s*). A single study available in the psycho-oncological literature carried out by Grassi et al. on people with breast cancer has not confirmed these data; this study found no relationship between the genetic types of polymorphism of the 5-HT transporter and various param-

eters investigated (e.g., depression, personality variables, distress, maladaptive coping).<sup>85</sup>

Regarding cognitive disorders related to treatments, as indicated previously, both radiotherapy of the brain and chemotherapy (e.g., methotrexate, nitrosourea, interleukins and interferon, cytosine arabinoside, carmustine, and fludarabine) may result in cognitive impairment over time. In delirium, both cortical and subcortical structures (e.g., ascending reticular activating system and thalamus), as well as various neurotransmitters e.g., cholinergic system dysfunction associated with dopaminergic hyperfunction) are involved. Several other biological factors are also implicated in the etiology of delirium: multi-sensory deficits, the advanced stage of disease, pre-existing cognitive impairment, renal insufficiency, alcohol abuse, low levels of performance, dehydration, severe electrolyte abnormalities, malnutrition and the use of opioids, anticholinergics and neuroleptics drugs, and deficiency of vitamin B1, the simultaneous administration of more than three psychoactive drugs, and the use of bladder catheter.

## **V.B. Psychological Factors**

The way patients deal with stressful events caused by disease (i.e., coping styles) are the basis of the resulting emotional and affective response. Coping styles are determined by subjective life experiences that modulate the development and the establishment of schemes for the evaluation of inner reality and stress management. A disposition to perceive events as inevitable (i.e., external locus of control) is associated with an increased risk of depression and anxiety compared to the tendency to perceive events as manageable, even if only partially, through one's own direct intervention (i.e., internal locus of control). The temperamental disposition to pessimism has been associated with an inadequate psychological reaction to diagnosis and to surgery, with the risk of developing depressive symptoms persisting at 1 year.<sup>86</sup>

Some items, such as resilience and hardiness, are also promoting factors to cope with the disease. In all studies, attitudes based on actively facing what is happening, on the redefinition of problems and assessment of alternative solutions, on the research of information, and on the drive to fight and not to give up, have been shown to be the best strategies to protect against the risk of depression. Previous psychopathological episodes and a high incidence of stressful events about loss in lifetime or during the course of illness, are additional

elements that facilitate the development of depression and that should be examined in the history of patients.<sup>87</sup>

### **V.C. Interpersonal Factors**

Another variable is represented by the social context, since the manner the individual perceives and deals with the existential events is influenced by the support from his/her interpersonal relationships. A good support implies an adequate function of emotional, informative, and material assistance, arising from relational exchanges with present and available reference figures belonging to the family or to the social context. Surely the family plays a major role as the most important source of support for people suffering from cancer, acting as a first line.<sup>88</sup> In addition, figures from the social support in a wider sense (e.g., friends, confidantes, and doctors) act as another important mediating factor. Some data suggest that receiving such a support from the earliest stages of the disease, in people without risk factors for psychological disorders, is associated with positive psychological outcomes, such as post-traumatic growth, even after several years of survival after cancer diagnosis.<sup>89</sup>

The support available in the patient's context is not always suitable to his/her needs and/or able to counter the disruptive effects of the disease. In particular, problems related to communication about diagnosis and course of the disease ("the conspiracy of silence") may represent an obstacle, bringing the patient and the family to isolate from the outside world and prevent possible sources of support that can fulfil its function. Multiple stressors, both prior to and concurrent with the disease, also have an important role in modulating the psychological resistance or vulnerability to illness. A very interesting series of studies suggest that severe trauma can be transmitted trans-generationally from parents to children, exposing them, in case of a cancer diagnosis, to a greater risk of psychopathological conditions, such as PTSD. Such research has focused in particular on women affected by breast cancer, whose parents were Holocaust survivors.<sup>90,91</sup>

## **VI. HOW TO RECOGNIZE PSYCHIATRIC MORBIDITY IN ONCOLOGY**

On the basis of what has been presented, healthcare professionals need a basic knowledge of psychosocial morbidity, its main symptoms features, the way in which these are expressed and can be elicited,

and the possible risk factors. However, only 25–35% of patients with a remarkable psychological suffering condition or who are affected by a psychiatric disease are correctly diagnosed in the clinical context.<sup>92</sup> Passik et al.<sup>93</sup> noticed that diagnostic skills paradoxically decreased with the increase of the severity of the depressive symptoms, which were identified in only 13% of cases. Doctors are prone to overestimate the symptoms of anxiety in cancer patients without anxious symptoms or with slightly anxious symptoms and to underestimate them patients with higher levels of anxiety.<sup>94</sup> Among the patients that oncologists assess as needing psychological intervention, only half actually present clinically detectable symptoms, in particular those related to depressive (23%) and anxiety (30%) disorders.<sup>95</sup> Clearly, if healthcare professionals do not explore their patients' problems, such problems may be thought to arise rarely or may be thought to occur spontaneously. In the survey by Sharpe et al.<sup>96</sup> of more than 5,000 patients, of those who were suffering from major depressive disorder (8%), only half discussed their difficulties with their general practitioners; one-third were taking antidepressant drugs, of whom a small minority in adequate doses and for an adequate time, and an even lower percentage benefitted from psychological interventions provided by mental health services. In line with these data, a parallel lack of use of psycho-oncology services where they exist, has been reported, with referral by the oncology staff of 4–5% of all their patients. This seems to be independent of the cultural context and similar in surveys conducted in the United States,<sup>97,98</sup> in Australia,<sup>99,100</sup> and in Italy.<sup>101</sup>

Several reasons may explain this trend. One reason resides in the distorted perception of medical disciplines toward mental health and psychiatry, perceived as a specialist area concerned only with psychoses. Another is the tendency, of psychiatry and mental health agencies to consider “reactive” conditions to existential events as not pertinent to them; in addition, there is the lack of trust toward the psychosocial field in oncology and a perception of a lack of preparation and training in psychosocial science. There are also several barriers related to patients: the lack of information about existence of psycho-oncology services and the available treatments; socio-cultural mechanisms which consider inability to cope as expression of a personal weakness, resulting in feelings of shame and withdrawal from those who would actually need help; and the general stigma of psychological and psychiatric disorders frequently associated *tout court* with “madness.”

## VI.A. ROUTINE SCREENING

In recent years in several countries, through the joint action of psycho-oncology scientific societies and advocacy movements, the diffusion of guidelines in psycho-oncology has addressed some of these problems. As reported, guidelines on psychosocial care in cancer care specify the need for the routine monitoring of psychological distress, as a sixth vital sign, in all patients and continuously, at different stages of the disease.<sup>102–103</sup> For that purpose, the DT-PL of the NCCN has been translated and validated in many languages and is used in different clinical settings, demonstrating the capability of this instrument to detect not only the spiritual or existential distress conditions related to cancer but also the psychological distress interfering with the patient and his family quality of life.<sup>104</sup> In several surveys, specificity, sensitivity, and positive and negative predictive value of the DT were measured to identify the most appropriate cutoff to assess the general psychosocial morbidity in oncology (i.e., “caseness”). This cutoff is generally reported to be 4 for moderate forms of distress and 7 for the severe forms of distress, including major depression.<sup>105</sup> Only two studies, respectively by Grassi et al.<sup>106</sup> in Italy and by Thekkumpurath et al.<sup>107</sup> in The Netherlands, compared the DT with a psychiatric interview, confirming the validity and reliability of this instrument to identify clinical conditions diagnosed as affective syndromes according to the ICD-10. Other short diagnostic instruments that can be used in routine clinical practice are able to identify distress more properly than a visual analogue scale (VAS) specific to forms of distress such as depression. The Hospital Anxiety-Depression Scale (HAD-S) and the Brief Symptom Inventory-18 have been widely used in oncology as screening tools for depression and anxiety<sup>108,109</sup>; they have been demonstrated to be more sensitive and specific than the DT, despite their brevity of compilation and analysis, made easier in many centers by software and touch-screen systems.

Recently Thekkumpurath et al.,<sup>110</sup> have verified on a wide range of more than 4,000 outpatients with cancer, that the PHQ, a short self-reported scale consisting of items corresponding to DSM-IV criteria for major depression, is a good application in oncology, useful for its specificity and sensitivity (ROC curve 0.94; sensitivity 93%; specificity 81%) .

Although screening scales present several limitations in clinical practice as non-diagnostic instruments, their regular use in clinical

settings may help the doctor–patient (or nurse–patient) dialogue on issues related to subjective areas such as emotions, spirituality, and interpersonal relationships, which remain frequently unexplored, and they may promote a biopsychosocial culture in treatment centers which results in a better identification of patients levels of distress that need psycho-oncological interventions.

## **VI.B. Educational Programs and Liaison**

To achieve these objectives, educational programs are needed to communicate the rationale for the use of tools and their application methods. Screening is only the first step in a complex sequence and does not necessarily coincide, by itself, with a better treatment of distress.<sup>111</sup> On the other hand, the development of a psychosocial culture in oncology, with its consequences in terms of organization of care, is one of the most significant goals in psycho-oncology, when regarding cancer in terms of diagnosis to treatment phases, rehabilitation to long-term survival, and recurrence to palliative care. In recent years, the effectiveness of several methods have been tested, such as intensive training initiatives on communication, aimed at improving the recognition of individual and family distress from a widened perspective, including social and spiritual dimensions.<sup>112</sup> The use of different training models has shown significant results in terms of ability to overcome cultural barriers on communication in oncology, physician satisfaction, improvement of the relationship with patients, and communication skills.<sup>113–114</sup>

Some educational tools promoted by scientific societies play a significant role in spreading the psycho-oncology culture in services and in educational contexts (e.g., psychological and medical students, residency programs, healthcare professionals in oncology, and palliative care). An example is the online core curriculum developed by the International Psycho-Oncology Society (IPOS, [www.ipos-society.org](http://www.ipos-society.org)), currently available in nine different languages (i.e., Chinese, French, Japanese, English, Italian, Portuguese, Spanish, German, Hungarian), with the involvement of national scientific societies (e.g., the Italian Society of Psycho-Oncology, the Portuguese Society of Psycho-Oncology, and the Chinese Society of Psycho-Oncology).<sup>115</sup> The curriculum consists of ten key areas of clinical psycho-oncology: communication and interpersonal skills in cancer care, psychosocial assessment in cancer patients, anxiety and adjustment disorders in cancer patients, depression and depressive disorders in cancer



patients, guidelines for distress management in cancer, palliative care for the psycho-oncologist, cancer: a family affair, loss, grief and bereavement, ethical implications of psycho-oncology, psychosocial interventions—evidence and methods for supporting cancer patients.

Several other liaison programs have been implemented in recent years in order to implement the guidelines that we have discussed. The Depression Care for People with Cancer (DCPC) protocol, for example, has been designated to be integrated into oncology services and has been tested using a rather interesting experimental model, the Symptom Management Research Trials (SMART). The project involves the presence of a care manager who, through close supervision by a psychiatrist with psycho-oncology training, coordinates the management of the depressed patient (i.e., counseling, psychopharmacologic therapy), maintaining a direct connection with the general practitioner and the oncology team.<sup>116</sup> According to recent data, the protocol has proven extremely useful in reducing depressive symptoms in cancer patients; symptoms are rapidly identified, allowing optimal treatments.<sup>117</sup>

## VII. CONCLUSIONS

The evaluation of various forms of psychopathology secondary to cancer is one of the most extensive areas of clinical psycho-oncology. Studies aimed at understanding the prevalence of psychiatric disorders showed that 6–15% of patients suffer from major depression disorder; 10–15% of patients suffer from anxiety disorder, 20–25% of patients suffer from adjustment disorder; 10–80% (depending on the stage of disease and treatments) suffer from psycho-organic disorders (e.g., cognitive impairment and delirium); 25–40% have sexual disorders; and an additional 15–30% show symptoms related to different dimensions of pain not assessed by DSM and ICD, such as demoralization and health anxiety.

The need to monitor and investigate emotional distress in different clinical settings has led to the development of short or ultra-short screening tools, such as DT or other multidimensional systems, which have shown sufficient sensitivity and specificity in highlighting the most frequent causes of distress, although many areas, such as sexuality, are often not covered in the interviews used. In the context of diseases with a marked biological component, a number of studies have focused on some clinically important disorders such as cognitive disorders secondary to treatments (chemo-brain) and delirium. The

latter is certainly one of the most important problems to be addressed in the context of palliative medicine.

The biopsychosocial approach in oncology has clarified the fact that a complex interweaving of biological, psychological, and interpersonal variables contribute to different facets of emotional suffering, yet this approach acknowledges the need to balance the role and weight of each of these variables depending on the specific disease or clinical condition. The knowledge of risk factors for psychiatric disorders and their manifestation is certainly a focal point for both mental health and oncology and/or palliative care professionals, in order to overcome the barriers that prevent comprehensive assistance to cancer patients in clinical practice. Several studies have shown, however, that the rights of cancer patients to receive optimal medical care and psychosocial services are often poorly pursued for different reasons, including the scarcely “psycho-socially oriented” organization of oncology services and, on the other hand, the scarcely “medically oriented” organization of mental health departments. It is equally true, however, that the development and dissemination of psycho-oncology guidelines by many institutions and in many countries is making it necessary to define these aspects more clearly. This has been facilitated in the past 30 years by research in psycho-oncology, which has outlined numerous problematic areas (e.g., limits of diagnostic classification, of intervention models when applied to specific contexts such as oncology, of service organization and of liaison with other medical disciplines) that represent a challenge for medicine and need to be dealt with in the immediate future.

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# Psychosocial Issues in Cancer Care

*Maria Antonietta Annunziata & Barbara Muzzatti*

Psychological Oncology Unit, Department of Clinical-Specialty Services & Support, National Cancer Institute, Aviano, Italy

\*Address all correspondence to Dr M. Antonietta Annunziata, Psychological Oncology Unit, Department of Clinical-Specialty Services & Support, National Cancer Institute, Via F. Gallini n. 2, 33080 Aviano, Italy; Tel.: 0434/659258; Fax: 0434/652182; annunziata@cro.it

**ABSTRACT:** In this study, we analyzed the main psychological and psychosocial issues of cancer, namely emotional distress, body image, sexual functioning, interpersonal relationships, cognitive functioning, cancer-related fatigue, and post-traumatic growth. For each aspect, we supply definition and prevalence data. We also investigated potential moderators and mediators, and here we discuss assessment instruments updated reviews and refer to recent international literature. In conclusion, we discuss the clinical and research implications of a “comprehensive” care approach to cancer patients.

**KEY WORDS:** cancer, psycho-oncology, psychosocial issues

## I. INTRODUCTION

The diagnosis of cancer may dramatically alter the life vision and organization of patients and their families. Changes concern both the physical (i.e., somatic symptoms, body image, and treatment side effects) and the psycho-social domains (i.e., emotions, personal experiences, psychological symptoms, and socio-relational issues).

“Cancer” does not exist in epidemiological terms. Rather, it is a whole series of diseases, with different etiopathological processes which may affect each organ and tissue of the human body. This heterogeneity has, as a consequence, many different implications in terms of diagnosis, prognosis, and treatment that, in addition to influencing survival, also influence both the quality of life and the way of coping with the disease. Moreover, cancer is a long disease process. Cancer patients can be considered “recovered” or “long-term survivors” only after a 5-year cancer-free and treatment-free period. This specific stage is characterized by different phases with corresponding different psychological and coping responses. Communication of the diagnosis is a traumatic event for cancer patients, who

have subsequently to face a further crisis<sup>1</sup> once they begin treatment. This crisis is then followed by a long or short period of remission that eventually may ensue in long-term survivorship or in a relapse of the disease. Such a long and complex trajectory can be an obstacle to the evolution tasks and life prerogatives that each person should pursue during his/her life as theorized, for example, by Erik Erikson.<sup>2</sup> Therefore, psychosocial assessment must be contextualized from the time the patient becomes ill and must take into account individual and social variables (e.g., gender, age, education, socio-economic status, coping styles, and real or perceived social support).

In spite of this complexity, some common psychosocial characteristics that are common in cancer experience can be delineated. Knowledge of them is useful for a full comprehension and multidimensional biopsychosocial care of cancer patients.

## II. EMOTIONAL DISTRESS

Once diagnosed with cancer and referred to surgery, chemotherapy, or radiotherapy, patients experience a whole range of emotions, usually conceptualized under the term of “emotional distress.” The use of the word “distress” facilitates the reduction of the possible stigma that is frequently associated with psychiatric disorder and mental illness or their pejorative equivalents. Distress describes “a multi-factorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment”.<sup>3</sup> This unpleasant experience comprises a whole range of emotions, from the standard feelings of vulnerability, sadness, and fear to crippling conditions like anxiety, depression, panic, social isolation, and existential and spiritual crises. It is therefore a condition characterized by anxious or depressive states that may influence therapeutic adherence, patient well-being,<sup>4</sup> and needs<sup>5</sup> and that, when detected, calls for specific professional intervention.

A number of studies have indicated that the prevalence of emotional distress is between 25% and 50%,<sup>6–10</sup> a rate that is also confirmed in Italian data.<sup>11,5</sup> Women,<sup>7–8,10,12–17</sup> young,<sup>8,15,18</sup> unmarried patients,<sup>12,14</sup> lung and breast cancer patients,<sup>12,15,16,19,20</sup> and patients undergoing chemotherapy<sup>19</sup> show higher levels of emotional distress, although differences and variability in rates have been explained by the multiplicity of instruments, usually self-report tools, employed for screening.<sup>21</sup>

Emotional distress does not seem to be particularly influenced by disease stage, except in advanced stages of cancer.<sup>20,5</sup> These data indicate the utility for a constant monitoring of distress, interpreted as “the sixth vital sign”<sup>22</sup> during the trajectory of the disease.<sup>21,23</sup> Because emotional distress does not seem to have a spontaneous regression and, when clinically significant, it can indicate an underlying psychological/psychiatric disorder, professional intervention is frequently needed.

### III. BODY IMAGE AND SEXUAL FUNCTIONING

Body image is a component of the concept of self, involving the perception and evaluation of one’s body, of how it appears on the outside, and of how it works. Body image involves cognitive and functional aspects that influence the way of presenting oneself in the environment and in relation with others, disregarding the visibility of any possible anomaly.<sup>24–28</sup>

A vast majority of the literature relative to this issue concerns women with breast cancer. After surgery, breast cancer patients report lower self-esteem, higher preoccupation with one’s own image, and fear of being judged.<sup>29–33</sup> Moreover, a better body image seems to be associated with more effective strategies of coping with cancer<sup>34</sup> and to influence therapeutic choices.<sup>29,35–37</sup> Alopecia, edema, skin rash, scares, amputations, weight variations, loss of sexual desire, impotence, and painful sexual intercourse are some of the most common side effects of cancer treatments that may be temporary, long-lasting, or permanent.<sup>38</sup> Functional disorders associated with ingestion, phonation, evacuation, and/or the difficulty (objective or subjective) caused by the use of prostheses or medical devices (e.g., stomas, catheters, etc.), can present further difficulties. These aspects, independently from their being transitory or permanent, must be elaborated and integrated into one’s body image so that they will not compromise self-concept and one’s intimate and relational functioning.

As far as we know, a review of the most frequently used evaluation instruments for body image implications in oncology has not yet been published (but for a generic assessment of tools and methods, see Cash and Pruzinsky<sup>25</sup>).

The intimate-sexual sphere includes all behaviors, attitudes, fantasies, thoughts, and values connected with sexuality that, more than any other, have to do with vitality and life.<sup>39,40</sup> Sexual functioning does not depend only on the organic deterioration of the genital system;

it can also be influenced by a negative body image, by not accepting one's own body and by the consequent fear of rejection in sexually approaching one's partner.<sup>32,38,40,41</sup> Even though the quantitative research on this subject is limited by some ethical and methodological problems, the clinical experience of healthcare professionals and some descriptive studies endorses these data.<sup>39,40</sup> Moreover, patients' reticence in facing these issues (that are often placed in the background with respect to survival) must be taken into account, as well as the barriers often put up by healthcare professionals themselves.<sup>39,42,43</sup>

Another issue in terms of body image, sexual-relational functioning, self-esteem, and self-image is represented by induced infertility, whether transitional or permanent. In this case, as in the presence of a body image disorder and/or a disorder in the intimate-sexual sphere, psychological and/or sexuological professional help is recommended. Notably, these issues can arise at the end of therapy or as a late result of treatment.<sup>44-46</sup> Because breast cancer in women, prostate cancer in men, and colorectal cancer both in women and men, are among the most common cancers, the problems with body image and intimate-sexual functioning are extremely important.

#### IV. INTERPERSONAL RELATIONSHIPS

Cancer and cancer-related treatments undeniably influence interpersonal relationships, especially in the presence of some unresolved issues that may significantly predate diagnosis. A great bulk of literature has reported studies of the consequences of cancer on families as a whole or on single members and couples,<sup>47,48</sup> but only a few studies have described the social dimensions from the patient's point of view.

A helpful construct is *self-perceived burden*, that is, the experience of frustration, pain, and suffering arising in care recipients as a consequence of depending on someone else (i.e., the caregiver), based on a patient's real or presumed mental and health condition, deterioration of quality of life, and financial aggravation.<sup>49,50</sup> These experiences are commonly reported in daily clinical practice, but they were described in only few studies limited to advanced cancer patients.<sup>52</sup> Simmons proposed to adapt a haemodialysis self-report scale to measure self-perceived burden by also considering that this dimension is associated with adherence and therapeutic choice.<sup>51,52</sup>

Another aspect concerns marriage and family issues among cancer patients. Recent research by Glanz et al.<sup>53</sup> showed that marriages involving a cancer patient ended in either separation or divorce at the

same rate as the general population. However, the authors found a significant disparity in gender, with only 10% of divorces in the population study involving a male patient, while in 90% female patients were the affected partner. It is then possible to argue that cancer does not represent a threat for stable relationships. This seems to be in line with those studies,<sup>54-60</sup> indicating that social support from partners is associated with quality of life, mortality (in general), and cancer-related mortality.

For some types of cancers (i.e., breast, ovary, and colon in particular), a familiar or inherited genetic component has been identified. In these cases, in addition to the concern for one's own disease, patients report preoccupation and sense of guilty related to the possibility of having transmitted (or possibly transmit in the future) a severe disease to one's descendents.<sup>61,62</sup>

A third relevant aspect of the interpersonal relationships issue is represented by work, as an arena in which to establish relationships, to socialize, and to achieve self-realization and self-esteem. In 2009 in the United States, an entire volume was dedicated to the issue of work in oncological long-term survivor patients.<sup>63</sup> Even though research to date in this field can be poor (and often descriptive only), two major issues emerge that may affect cancer survivors' return to work, namely the discrimination and the importance of social support from employers, occupational health services, and workplace accommodations.<sup>64</sup>

## V. COGNITIVE FUNCTIONING

Cognitive functioning is the term used to describe a person's abilities (e.g., memory, attention span, executive function, language, and instrumental skills) that have a fundamental role in maintaining the personal, social, and working autonomy of the individual.<sup>65-67</sup> Surgery on central nervous system (CNS) tumors,<sup>67</sup> radiotherapy, and chemotherapy treatments<sup>68,69</sup> may lead to temporary or long-term cognitive impairment, due to the involvement of the nervous parenchyma. In particular, the expressions *chemo-brain* and *chemo-fog syndrome* indicate the persistent chemotherapy-induced cognitive changes that are independent from depression, anxiety, and fatigue in long-term oncologic patients.<sup>70</sup> A reduction in cognitive function may also be due to mood disorders or posttraumatic disorders secondary to the stress of cancer.<sup>71,72</sup>

Problems in short-term memory tasks and/or associated with alterations of frontal functions such as executive function, attention, and analogical judgment, seem to be the cognitive impairments



mostly associated with radiotherapy.<sup>69</sup> The range of chemotherapy-associated problems seems to be wider, by including loss of concentration, memory impairment, confusion, bewilderment, decrease in dexterity, and psychomotor skill impairment.<sup>66,68,69</sup>

Data on prevalence are heterogeneous<sup>68–70</sup> due to the complexity and the consequently difficult comparability of the treatments administered and to the problems in defining cognitive impairment and cognitive functioning. Data heterogeneity is also attributable to the absence of standard pre-disease and pre-treatment baseline measures that can facilitate longitudinal comparisons, and to the multiplicity of the instruments used (e.g., more objective measures such as neuro-images and neuropsychological batteries, or self-report tools).<sup>68,67,73</sup> Finally, considering that cancer is more common in older people, the diagnosis of cognitive disorders must be made after taking into consideration the normal process of primary aging and the degenerative pathologies typical of elderly patients.

Loiselle and Rockhill<sup>66</sup> reported a prevalence of cognitive impairment between 11% and 40% in CNS brain solid tumors and of 90% in primary brain tumors. Correa and Ahles<sup>74</sup> recorded a larger prevalence (17–75%) in breast cancer patients but still confirmed the possibly confusing factors already reported.

Finally, Schagen et al.<sup>73</sup> have underlined the discrepancy between cognitive impairment data resulting from neuropsychological testing and self-report complaints. These authors suggest that such a discrepancy may be related to the poor ecologic validity of neuropsychological batteries, with patients' "limited conscious access" to their cognitive impairment (with a consequent under- or overestimate of their cognitive problems) and with the fact that neuropsychological evaluations and tasks, unlike real life, are performed under conditions of minimal distraction and stress. Therefore patients "might be able to mobilize cognitive resources for a short time during a test session, but they might not be able to sustain this for longer periods of time during everyday activities."<sup>73</sup> All of these factors do not mutually exclude each other.

## **VI. CANCER-RELATED FATIGUE**

Cancer-related fatigue deserves a particular consideration in the field of the psychosocial repercussions of cancer and cancer-related treatments. Fatigue is one of the most frequent symptoms reported by patients along the disease course (during and after treatments, in

long-term survivorship, and in the terminal phase)<sup>75-84</sup> which negatively influences the quality of life in all its dimensions.

Its pervasiveness in cancer experience led to the identification of the Cancer Related Fatigue (CRF) syndrome, and to suggesting the need for a systematic and accurate measurement of fatigue in clinical practice<sup>75-85</sup> Minton and Stone<sup>86</sup> have made a complete and updated review of instruments. Nonetheless, distinguishing a physiological response to a stressful event resulting from a clinically relevant condition can be difficult;<sup>85-87</sup> tendencies to underestimate or overestimate CRF are possible. In fact, fatigue is a subjective experience that can involve everyone. In healthy people, it is a regulatory response to stressful events and it contributes to the maintenance of a healthy equilibrium between rest and activity.<sup>83</sup> Conversely, in people with specific diseases, including cancer, fatigue is often a disturbing symptom and a source of preoccupation. The National Cancer Control Network defines cancer-related fatigue as “a distressing persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning,”<sup>75(p. FT-1)</sup> and that cannot be relieved by rest.<sup>83,87,88</sup>

Fatigue reduces the individual capacity to perform personal, social, and working activities and deeply degrades a patient's quality of life.

Problems in differential diagnosis between chronic fatigue syndrome and other disorders, such as major depression and the use of different instruments, converge in very heterogeneous prevalence data. In a review by Servae et al., the prevalence was between 25% and 61%, with rates of 75% in advanced cancer patients and 99% when measurements were made with visual-analogue scales rather than with traditional questionnaires.<sup>83,84</sup> However, in the first study

on an American population, Cella et al.<sup>80</sup> reported remarkably lower percentages (37%). An Italian study on a small oncological patient sample (40 males, 40 females) reported a severe fatigue prevalence of 6.7% and a moderate fatigue prevalence of 56.7%.<sup>89</sup>

Finally, in agreement with the review by Servae et al., the principal sociopersonal and clinical variables do not seem to play an important role in moderating fatigue.

## VIII. POSTTRAUMATIC GROWTH

Defining cancer as a traumatic event implies giving this experience all the dimensions of trauma, including its meaning, value, and

positive aspects, summarized in the concept of posttraumatic growth (PTG). PTG can be described as a subjective experience of positive psychological change after a traumatic event.<sup>90–92</sup> Tedeschi and Calhoun<sup>90</sup> use the metaphor of trauma as an “emotional earthquake” to empathize the fact that growth develops after a traumatic event of “seismic” proportions, that may destroy an individual’s beliefs about oneself, about others and the world, and about one’s ability to manage emotional distress. With respect to the ability of the individual to resist (and not be impaired by) the traumatic event, PTG is a further change,<sup>93</sup> different from “resilience,”<sup>94</sup> which refers to the capacity of the individual to maintain his/her skills even in adverse conditions.<sup>93</sup>

In operational terms, PTG concerns the domains of self-image, relationships, and philosophy of life. It causes an improved sense of self-efficacy, of being able to master problematic situations, and a better appreciation of interpersonal relationships. It also results in an improved sense of altruism and empathy toward people in need, a reorganization of one’s priorities and values, and in renewed spirituality.<sup>91,93,95,96</sup>

In addition to constructive growth that can be measured with the acquisition of new competences and different attitudes, there may also be an illusory PTG, resulting from a pejorative cognitive elaboration of the past, which has been found in cancer patients treated with stem cells<sup>97,98</sup> Manne et al. proved that these aspects of PTG manifest themselves a few months after diagnosis and increase over time,<sup>99,100,101</sup> while Lechner et al.<sup>102</sup> described a curvilinear association between benefit finding and psychosocial adjustment to breast cancer.

Sawyer et al. recently conducted a meta-analysis on 38 research studies on PTG in cancer and HIV-positive patients.<sup>103</sup> They found that the principal moderators in the PTG/coping relationship are represented by time elapsed from the stressful event, age, and ethnic group.<sup>101,104</sup>

## IX. CONCLUSIONS

A diagnosis of cancer can cause significant changes in the worldview and the organization in the lives of patients and their families. In this paper, we have described the main psychological and psychosocial issues relevant to cancer experience in adults; we have provided definition and prevalence data, discussed the possible related mediators and moderators, and indicated, where available, updated measurement tool reviews, referring to international literature.

Prevalence data on one hand, and the pervasiveness and persistence of cancer consequences on another, confirm the need for psychosocial attention in caring for cancer patients starting from the early stages of the disease. This allows ongoing monitoring of the evolution of the psychological responses, with the aim of arranging psychosocial, together with medical, rehabilitation interventions when needed.

The comprehensive approach to patients may, in fact, contribute to maintaining the best possible quality of life and to increasing compliance and adherence to treatment. At the same time, the reported heterogeneity of data shows that even if some common psychological patterns can be identified, the experience of disease remains unique for each patient. This uniqueness should be the starting point of all clinical approaches (whether psychological, medical or nursing) to cancer patients.

Because psychosocial implications of cancer may be evident in every phase of the disease trajectory, psychosocial attention to patients should not end with the acute disease phase. It is fundamental for both healthcare professionals and patients to be “trained” to monitor these domains and aspects over time. For all of these reasons, psycho-oncology, as the specific discipline dealing with emotional, interpersonal, and spiritual dimensions of cancer, is constantly growing. In addition to specifically dedicated national and international journals (e.g., *Psycho-Oncology*, *Journal of Psychosocial Oncology*, *Revue Francophone de Psycho-Oncologie*, *Giornale Italiano di Psico-Oncologia*), most medical journals now regularly publish psychological studies. Psycho-oncology is a vast field that needs to be investigated further. In particular, while some characteristics, such as emotional distress, have been thoroughly investigated, some other issues, like body image and sexuality (although it has been recognized as relevant on a clinical-qualitative level) have not yet been fully explored. Furthermore, the concept of long-term survivorship, even if it was developed some years ago, has only recently been the focus of clinical research, especially in patients surviving 5 years from diagnosis and more. Further research should monitor the well-being and quality of life on long-term survivors at a distance of many years after diagnosis.

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# A Relational Approach to the Family in Psycho-Oncology

Paolo Gritti

Department of Psychiatry, SUN , School of Medicine University of Naples, Largo  
Madonna delle Grazie, 80110, Naples, Italy; Tel: 39 081 5666509; Fax: 39  
081.5666523; paolo.gritti@unina2.it

**ABSTRACT:** This review describes the family interpersonal dynamics due to the onset, the course and the outcome of cancer as well as a psychological treatment program for the family caregivers. The literature concerning the family environment of cancer patients highlights two issues: the first concerns the change in relationship patterns in the family as well as in the context of care, the second refers to the psychological and/or psychopathological consequences for the caregivers. These clinical features consist of adjustment disorders and post-traumatic syndromes often observed in the caregiver and in the patient's children. The structure itself of family relationships is negatively affected by the disease. Role conflicts, increasing communication deviances, social isolation, disorganized or enmeshed relationships are described. The knowledge of these processes suggests to schedule tailored psychological support programs for the patient's partner and the families. These interventions are aimed at improving the active collaboration between family, patient and medical team as well as at supporting the family during the critical phases of the disease and of cancer treatments. A treatment program, including a counselling module, called "Family Psychoncological Counseling" and a psychotherapeutic module, called "Phasic Family Therapy," is described.

**KEY WORDS:** Family, psycho-oncology, general system's theory, coping, counselling, psychotherapy

*"Happy families are all alike; every unhappy  
family is unhappy in its own way"*

– Lev Tolstoy, *Anna Karenina*

## I. INTRODUCTION

All somatic illnesses are not only an individual experience of physical and psychological suffering but also a psychosocial status which significantly modifies the patient's interpersonal relationships. According to this conceptual framework, oncological diseases can be considered prototypic of the relational processes due to the course and the outcome of all severe, weakening, chronic, or terminal illnesses.<sup>1</sup>

The two elective contexts of observation of these processes are the family of the patient and the community healthcare environment.

The literature dealing with the family milieu of cancer patients report two classes of phenomena: one concerns the metamorphosis of the affects and the relationships within the family, the other consists of the psychological and/or psychopathological outcomes of the disease for the caregivers.<sup>2,3</sup>

The emotional distress, the subjective as well as the objective burden and the strain are the main signs of the psychosocial effects of the disease on family members. The family coping behaviors are modulated by some concomitant variables: the social support for the family, the psychological resilience of each family member, the coexisting stressful events and, finally, the social representation of the disease.<sup>4</sup> The most common psychopathological symptoms consist of anxiety and depressed mood, diagnosed as an adjustment disorder or a post-traumatic stress syndrome. These clinical pictures are frequently detected in the caregivers and in the patient's children. Moreover, the disease causes role conflicts, increasing communication problems, social isolation, disorganized behaviors or, conversely, emotional enmeshment. Finally, the structure of family relationships is negatively affected by the disease.

These findings suggest the potential benefit of psychological treatments for the partners and the relatives of the patient. These interventions include of a wide range of techniques and strategies placed into a theoretical continuum ranging from hermeneutic/interpretative to supportive/expressive to informative/educational models. All of these treatments are aimed at improving collaboration and illness perception among family, patients, and healthcare professionals and support the family during the course of the disease and cancer therapies, with a focus on specific issues such as the first diagnosis, the adherence to treatment, the relapses, pediatric oncology, and finally, the palliative care and the terminal phase.<sup>5</sup> A main target of these interventions is the bereaved family.

Scientific literature on this subject includes a large number of empirical studies as well as original speculative contributions over the past 15 years, reflecting a growing interest of clinicians and researchers about the psychology of cancer in the family. This review summarizes the state of the art on this theme. The first part of the paper describes the processes of adjustment and change of family relationships after the onset of the disease, while the second sums up the programs of psychological support to families of cancer patients.

## II. AN UNEXPECTED GUEST

Getting sick of cancer is not an unusual event in family life. Veach et al.<sup>6</sup> estimate that three out of four families deal with a diagnosis of cancer during the life span of the members. If this observation embraces also the reminiscence or the narrative of similar diseases that have occurred across the past generations, we can estimate that cancer is a paranormative event in the family life cycle.<sup>7</sup> Nevertheless, every time a family member is affected by cancer, the event is always experienced as unexpected. Cancer is perceived as an unwelcome guest who resides in patients' homes in a very pervasive way, requires drastic changes in routine behaviors, influences relationships, and affects the family's future together. Indeed, cancer influences, sometimes forever, the family life becoming a "litmus test" of emotions and relationships. Although it disorganizes only some families, no family can avoid the changes that ineluctably descend from the intrusion of the disease in their life. These considerations, now extensively shared by researchers involved in the study of psychosocial dimensions of neoplastic diseases, support the point of view of clinicians who argue that the distress occurring in the families of cancer patients should be part of more studies and treatment planning in the field of psycho-oncology.

## III. THE FAMILY AS A RELATIONAL SYSTEM

Family social psychology points out the predominant functions of family bonds in different times, cultures, ethnicities and religious beliefs. Actually, throughout human history, the family has maintained a key role in the evolution of *Homo sapiens*. These functions may be better understood through systemic thinking. The General System Theory suggests that all natural phenomena should be investigated together as a whole.<sup>8</sup> Structure, processes, organizations are the variables regulating the life cycle of biological as well as social systems. Health and disease phenomena may be described as biopsychosocial systems, too.<sup>9,10</sup> Systemic thinking, a holistic approach to health and illness problems, conceives all human diseases in the context of psychosocial environment, balancing, day by day, the protective factors with the pathogenic factors. The family, as well, can be usefully described as a biopsychosocial system where the patient's illness behavior interacts with the interpersonal context.<sup>11</sup>



Cancer modulates the relational patterns of the family that embrace adaptive and transformative resources. Moreover, all severe somatic illnesses, like other significant events of life, can transform not only the family relationships but also the “doctor–patient–family” psychosocial system. These constructs, if related to the issue of human health, can aid in considering human diseases as a biological process embodied in a psychosocial environment. If the patient is “a suffering person in a specific context of life,”<sup>12</sup> the medicine is able to add a humanistic approach to the advances of diagnosis and treatment offered by biomedical knowledge. The study of family dynamics of cancer patients has confirmed the usefulness of the psychological assessment of families at risk of distress.

Kissane et al.<sup>13,14</sup> describe five types of organizations. This classification comes from the evaluation of family communication styles during longitudinal observations in the terminal stages of illness and grief following the death of a spouse. The family cohesion, the free expression of emotions and feelings, and the ability to resolve conflicts are rated with the Family Environment Scale (FES). The authors distinguish functional or dysfunctional families along a continuum ranging from “supportive” (30% of cases), characterized by strong and stable cohesion; “conflict resolver” (20%), in which is effective communication observed; “intermediate” (30%), “hostile” (6%), suffering from poor cohesion and frequent conflicts, and finally, “sullen” (9%), suffering from clinical levels of depression supported by hidden anger. Based on this typology, Kissane and Bloch have implemented a treatment program for families in the process of mourning: Family-Focused Grief Therapy.<sup>15</sup> In Italy, Cazzaniga, conversely, uses eight categories to describe family members, borrowing a systemic approach to delineate the disease process in the cancer family.<sup>16</sup> Finally, Rolland<sup>17</sup> suggests an multiaxial assessment model, the Family Systems-Illness Model, based on the assumption of a mutual interaction among the clinical features of the disease, the stages of family life, and the sociocultural context. Rolland includes the onset, course, and outcome of the disease and levels of concurrent disability within the first set of variables. The careful evaluation of these three dimensions aid in planning a family intervention aimed at enhancing their resilient resources and adaptive processes.

#### **IV. THE COUPLE DYNAMICS IN CANCER**

It is estimated that, during the course of cancer, 15 to 50% of patients and their partners can jointly express distress, which worsens in the terminal phases of illness.<sup>18</sup> Distress is characterized by depressive mood or anxiety, as well as by an impasse in the mutual reshaping of roles and functions.<sup>19</sup> The coincidence of these problems in both partners in terms of clinical traits and severity is a remarkable finding. Some demographic and psychosocial variables are associated with couple distress. Specifically, the quality of the social network of each partner and the family dynamics are predictive of levels of distress resulting from the disease.

Like in the family, even in the couple, strongly cohesive emotional bonds as well as cooperative adaptive processes are the best predictive aspects of adequate coping with the disease.<sup>20</sup> It is argued that the quality of the couple relationship is connected to the attachment style of each partner, and that the attitude of the caregiver is closely interwoven with the reciprocal attachment styles. Moreover, the gender identity and the social role of the patient and the caregiver affects the levels of distress and the coping strategies.<sup>21</sup> The difficulties, often substantial, in carrying on a satisfying sex life, contribute to the processes of emotional detachment, communication difficulties, and marital tensions. For instance, the literature describes four dyadic processes in breast cancer. Two of them are shared by the partners, whereas the others are managed by the caregivers. The first, "sharing in the recovery," consists of the predisposition of both partners to share information and emotions about the disease. The second, "helping her," is characterized by emotional and pragmatic support given by the partners. The third, "normalizing the household," is expressed by the competence of both partners to hold on an adequate organization of daily life. The fourth, "moderating the intrusion of cancer," describes the partner as building a protective boundary for the patient.<sup>22</sup> In other circumstances, however, adaptive or maladaptive responses of the partners are different. For example, when facing a surgical treatment, the patients and their partners may show divergent emotional responses with respect to the outcome.

#### **V. THE FAMILIES OF CHILDREN WITH CANCER**

Receiving a cancer diagnosis for one's own child is an event of incomparable and catastrophic sorrow.<sup>23,24</sup> Parents of children with cancer

suffer from severe distress that persists over time; they are often troubled by feelings of guilt, pain, mourning, and despair, and they sometimes show symptoms like recurrent and intrusive thoughts, consistent with a diagnosis of a post-traumatic stress syndrome.<sup>25</sup> Moreover, uncertainty about the future is a further significant source of distress. The belief that family life has changed forever persuades the parents that they are going to take care of their child for the rest of their lives. The care of other children and the wish to protect their health is an additional source of concern and daily commitment. Parents are often worried about having to share their time equally between all the children. The lack of support from relatives, friends, and colleagues provokes feelings of discomfort. Finally, they show considerable helplessness in establishing a therapeutic alliance with doctors. Even 5 years after diagnosis, some of these parents show symptoms of anxiety and depression.<sup>26,27</sup> Parents of children who suffer clinical relapses are at increased risk of distress, even more severe than the ones observed in parents of dead children. The mothers of patients experience more severe discomfort than the fathers, unless the father is the primary caregiver of the child. The personality structure of parents and previous episodes of mental disorders in personal biography, significantly influence their coping responses and distress. Parents' distress regarding children off therapy after 5 years is related to family resilience and, in particular, to their optimistic expectations. Conversely, if compelling anxiety and doubts prevail, parental distress persists over time.

## VI. PSYCHOLOGICAL TREATMENT

Treatments aimed at the psychological support for families of cancer patients are focused on communication skills and emotional expressiveness. They facilitate the sharing of feelings of frustration, anger and pain triggered by the depressive mood, and they aim to restructure the cognitive experience of illness. Some of these interventions use introspective techniques and are, in most cases, brief and focused, conducted by psychologists, doctors, nurses, and other professionals. These interventions aim to improve the adaptation to the disease and the management of the anguish of loss related to cancer. All of these treatments are considered effective in psychosocial care of neoplastic patients. The literature points out several "family treatments" in biomedical contexts, particularly in oncology, labeled in different ways (Table 1).<sup>28,29</sup> All of these treatments, although

designating various clinical goals and techniques, are similar in the theoretical assumptions. The most important shared aspect of these interventions consists of a setting for the joint meeting with the patient and family, if appropriate, about the clinical condition of the patient. Exceptions are terminal illness, physical debilitation of the patient, and obviously, unavailability of a family member. These interventions share common features: Modularity and flexibility as well as therapeutic eclecticism.

**Table 1. The Family Treatments in Biomedical Contexts**

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Family therapy
Family counselling
Family psychoeducation
Family conferences
Family meetings
Family information & support programs
Direct provision of health services to the family

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In advanced and terminal cancer and during palliative treatment, the location of the meeting is the hospice. In this case, the focus is to help the family make critical decisions at the end of life and to support their sadness and mourning. We will, briefly, describe two of these interventions. The aforementioned Family-Focused Grief Therapy<sup>15</sup> is a preventive program aimed to relieve the family distress during palliative care and terminal illness. This brief, focused program consists of 7 to 10 sessions in the space of 6 to 18 months. The goals are the evaluation of family dynamics and the therapeutic alliance (two sessions), the family empowerment (4–6 sessions), and, finally, the follow-up based on one or two sessions after 2 or 3 months. The therapist focuses on three issues: the processes of coping and mourning, the quality of communications, the conflicting or cohesive relationships. Medical Family Therapy (MFT)<sup>30</sup> includes a broader spectrum of indications and refers to a biopsychosocial system's model in implementing psychological treatments for families who have a member affected by chronic illness or disability. The family therapist works in regular collaboration with physicians and other professionals to help families facing severe diseases. The objectives of the MFT are described in Table 2.

**Table 2. The Goals of Medical Family Therapy**


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Improving the coping processes
Improving the adherence to treatments
Improving the doctor–patient–family communication
Improving the adaptation to the terminal illness
Changing the lifestyles

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## VII. FAMILY COUNSELLING AND PSYCHOTHERAPY IN ONCOLOGY: A PROPOSAL

Today counseling and psychotherapy are considered useful psychological tools in oncology both for the patient and the family. They are particularly appropriate on account of some of their features: the specificity of the aims, their focus and shortness, the high degree of integration with the medical and surgical treatment. Actually, Family Counseling can be directed to the sharing of information and knowledge about the disease and treatment between patient, family, and doctors (i.e., informative counseling); it can be focused to the psychological support required during the emotional crisis of the patient and the family (i.e., crisis counseling); it may contribute to the making of critical decisions to be shared with the doctors (i.e., decision-making counseling); and finally, it supports the family in solving problems related to the necessity of daily life to balance the burden of care with the habits, commitments, and the needs of each member of the family (i.e., problem-solving counseling).

The goals of family psychotherapy are an early involvement of family members in active adherence to disease management (i.e., cohesive function), the support of feelings' expression (i.e., expressive function), the enhancement of communication between doctor, patient and family (i.e., educational function), and the elicitation and handling of new life meanings by mean of the disease's experience (i.e., introspective function). On receiving a psychiatric or psychological referral for a cancer patient, the family is called, too, in order to establish a timely therapeutic alliance with all of them. This first meeting is defined as Family Psychoncological Counseling (FPC). In our experience FPC, in many cases, aids the family members in becoming aware of the psychological dimension of the disease and predisposes them to subsequent interventions in a psychotherapeutic setting.

## **VII.A. PLANNING AN FPC**

The FPC is useful in some of the crucial moments of the course of illness, such as the communication of the diagnosis, the beginning of medical or surgical treatments, and the clinical relapses. Of course, the sooner the family is involved, the better is the patient's probability of remaining in contact with the family during the disease.<sup>31</sup>

## **VII.B. PREPARING FOR AN FPC**

It is appropriate to consider a preparatory phase to the FPC, i.e., to coordinate the date and location of the meeting with the doctors and to gather preliminary information about the family. Counselors prefer to choose a quiet and secluded space for the meeting, and, if possible, apart from medical or psychiatric wards. In some cases, the utility of a home meeting is tested. The family at home feels more protected and available to the interview. Moreover, the domestic sessions give the counselor the opportunity to become familiar with the everyday environment and to collect valuable information about family dynamics. During the session, the availability of each member of the family to attend the meeting is evaluated, and the family is given the opportunity to meet even if some of them will be absent.

## **VII.C. THE STRUCTURE OF AN FPC**

In FPC, the counselor should adopt a very informal approach, like that of a conversation guided by respectful listening in search of the solutions to problems and the available resources of the family. The session starts with the introduction and some remarks about the goals of the meeting. The counselor asks all family members to explore whether they are clear about the purpose of the meeting. They are also asked details about the clinical condition of the patient, thereby revealing some aspects of doctor–family communication. The risk of misunderstanding between doctors and families about cancer diagnosis and treatment is constant, so family members are urged to maintain an open dialogue with oncologists about unclear medical information. The central phase of FPC is aimed at exploring the family's needs. Each member is asked to express all questions concerning the patient's disease. Comments on current medical treatments and therapeutic perspectives are encouraged, and the counselor reassures family members of his/her liaison position to report their problems to clinicians. Achieving this goal

requires a strong synergy with the oncologists, an alliance for the care in the context of consultation–liaison psychiatry. Then we carefully explore emotional dynamics within the family, taking care to support the positive feelings, the empathic sharing of the suffering, but also supporting to the expressions of anxiety and depressive mood. Finally, the family is asked about the ongoing problems in family everyday life, the burden of care, and the changes of habits forced by the disease. The intention to discuss realistic solutions at a future time is envisioned. The counselor needs to be competent on some specific communication skills. Therefore, he should not avoid the most challenging issues about the experience of illness, including these topics in a broader perspective open to other aspects of family life. The counselor should maintain focus on the present, accepting the silence of family members about the past and any anxieties about the future. Each family member may not be confident about the opportunity of sharing with someone own private feelings and events, so the counselor needs to meet elusive aspects of the conversation in the narrative of circumstances and emotional ties. As for the language, the specific medical, psychiatric or psychological lexicon is avoided as much as possible. On the contrary, the everyday language of the family is used and encouraged. Clear, direct but not intrusive open questions or comments are used, and remarks are carefully expressed. Questions and comments must frequently be repeated or clarified: *repetita iuvant* when dealing with the illness experience. As it was said, FPC is oriented toward both introspective and expressive functions, so the conversation supports the expression of feelings but also the personal considerations about meanings and memories, as well as metaphors and images. A listening rather than interpretative attitude of the counselor is encouraged. As the focus of the conversation is the patient, emphasizing the patient's suffering, communication difficulties, involvement to active participation in care, and finally, his or her increasing difficulties in relationships with family members.

#### **VII.D. THE PHASIC FAMILY THERAPY**

If, after the first session, the family becomes available for further consultations, the program is called Phasic Family Therapy (PFT). The FPC remains the basic unit of this psychological treatment for families, divided into modules shifting from the therapeutic counseling to the brief psychotherapy. This program is aimed toward the following goals:

1. Strengthening the affective bonds to alleviate the distress of the patient and family facing the experience of



physical suffering and the fear of death, but also look for new emotional resources to all members.

2. Reassuring the patient who fears the relatives' emotional detachment, the loss of intimacy, and a silent affective betrayal.
3. Supporting the family members when they face the strain of confronting with the everyday tasks, helping them to calibrate their mental and physical energies toward the patient without neglecting other commitments.
4. Supporting the family in searching for help in their social network.

PFT consists of four independent modules useful for different stages of the disease chosen according to the mental and physical condition of the patient as well as to the family needs and availability. The module called "crisis support" can be usefully scheduled at the moment of diagnosis to support the family in the emotional shock following such bad news. This module includes two or three sessions aimed at strengthening the supportive and cooperative strategies in the family and at facilitating communication processes. The module called "brief counseling" may be offered during the course of cancer. It consists of 2–4 sessions aimed at supporting the process of coping, to convert family relations according to the demands of therapies. The module called "brief therapy" consists of 4–8 sessions. It is suitable for intensive treatment of psychopathological disorders manifested by the patient or by family members or else when a crisis of family relationships threatens the family cohesion or the emotional well-being of the patient. Finally, "bereavement counseling" is aimed at the emotional support of family during the mourning phase after the death of the patient. During 2–4 sessions, the expression of painful feelings of anguish, anger, and guilt is facilitated. This module also explores the chances of the survivors to foresee a less traumatic future without their beloved one, without losing the memory of the deceased.

## VIII. CONCLUSIONS

A large number of empirical studies and controlled clinical trials indicate the risk of emotional distress or psychopathological syndromes in family members of cancer patients. Both conditions affect peculiar aspects in the course and outcome of neoplastic diseases, related

to the quality of life, to the adherence to treatment, to the coping strategies. These strong evidences, also, indicate the utility and the effectiveness of psychological support programs for family members of cancer patients in the setting of counseling or psychotherapy.

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# Psycho-Oncology in Childhood and Adolescence: The Italian Experience

*Marina Bertolotti*<sup>1,\*</sup> & *Pia Massaglia*<sup>2</sup>

<sup>1</sup>Psycho-oncology, Pediatric Onco-hematology Unit, Regina Margherita Children's Hospital, Turin, Italy; <sup>2</sup>Child Neuropsychiatry Section, Pediatric Department, University of Turin, Turin, Italy

\*Address all correspondence to Marina Bertolotti, Psychologist, Psycho-oncology, Pediatric Onco-hematology Unit, Regina Margherita Children's Hospital, Piazza Polonia 94, 10126 Turin, Italy; Tel.: 0039-011-3135991; Fax: 0039-011-3135487; marina.bertolotti@unito.it

**ABSTRACT:** In childhood and adolescence, cancer has a 100 times lower incidence rate than in adulthood and higher probabilities of cure (approximately 80%). These results are achieved through intensive treatments delivered in qualified medical centers in which identical protocols are applied. For a number of years, treatment has included structured care, provided by expert multidisciplinary teams, for the developmental needs of children and adolescents and for their and their families' quality of life. Nevertheless, the lengthy uncertainty about the outcome, apart from implying relevant psychological costs, can cause emotional reactions that prevent patients from getting over the experience if they are cured, and from preserving quality of life if the disease worsens. The main issues of a child's or an adolescent's cancer experience, concerning objective aspects (e.g., hospitalization and therapy) and subjective ones (e.g., self-image, fears, anxieties, hopes), are reviewed here. The need for and ways to establish a direct therapeutic relationship with the child or adolescent from diagnosis are outlined. The psycho-oncologist cooperates in the comprehensive care, based on open and honest communication, and performs specific interventions at different levels: prevention, support, and psychotherapy. Settings are flexible according to each patient's needs, as they arise in the care-giving experience, and individual and family resources and fragilities are fully respected. .

**KEY WORDS:** pediatric psycho-oncology, quality of life, communication, psychological intervention

## I. INTRODUCTION

Childhood and adolescent cancer care is conducted throughout Italy in a network of specialized centers that are members of the Italian Association of Pediatric Hematology and Oncology founded in 1975, an organization whose task is to evaluate and guarantee the quality and homogeneity of oncologic interventions.<sup>1</sup>

Constant collaboration among the national centers and regular exchanges with international centers in the International Society

of Paediatric Oncology (SIOP) have led to continuous adjustments of treatment protocols that constantly improve the relationship between therapeutic and collateral effects, especially late effects.<sup>2</sup> Overall, 5-year survival rates have gone from less than 20% in 1970 to more than 75% in the past 10 years (i.e., 78% for childhood tumors and 82% for adolescent tumors).

This general situation is characterized by a high likelihood of therapeutic success, and the quality of present and future life has become, along with recovery, the main aim of cancer care. At the same time, progression toward the terminal phase remains an important reality; it involves one in four children and one in five adolescents. Cancer is the third highest cause of death in children and adolescents today (23%), after accidents (traumas and poisonings, 30%) and circulatory, nervous, respiratory, and digestive system diseases (24%).<sup>3</sup>

The onset of a malignant tumor in childhood causes a remarkable psychological and social impact, despite being a rare event. It has an incidence rate 100 times lower than that of adults and affects 1 in 600 people in the first 15 years of life, especially in the preschool and adolescent age groups. At present, it would seem that environmental and/or lifestyle factors have little influence on the cause and course of cancer. The most common cancers are leukemia, brain tumors, and lymphomas (which make up approximately two-thirds of all neoplasms). All pediatric tumors generally have aggressive clinical–biological characteristics, which make them sensitive to chemotherapy (tolerated at higher doses than in adults) and/or radiotherapy. Treatment protocols are usually intensive and short term (from a few months to 2 years), requiring the positioning of a central venous catheter, involving periods of hospitalization and/or isolation, and, at times, also including hemopoietic stem cell transplantation (HSCT) (Table 1).<sup>4</sup>

Cancer care for children and adolescents is aimed at their physical well-being, enabling both the patient and the family to enjoy full integrity at emotional and social levels. Optimal therapy is therefore based on both specific medical treatment and on comprehensive care guaranteed by an expert multidisciplinary team. In the care center, along with welcoming, open, and honest communication, attention is placed on maintaining aspects of normality as much as possible, preserving prospects of hope and facilitating the child's or adolescent's usual activities (e.g., play and school). For children who enter the terminal phase, the priority is quality of life, which also involves maintaining aspects of normality.<sup>2</sup>

**Table 1. Outstanding features of childhood cancer**

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**Reality**

- Uncertain prognostics
- Aggressive treatment
- Repeated hospitalisation

**Physical experience**

- Suffering
- Loss of integrity
- Transformation (even hideous)
- Self-image alterations

**Emotional events**

- Suffering
  - Loneliness/exclusion
  - Death anxieties
  - Dependency
  - Uncertainty
  - Anger
  - Hope
  - Activation of insights and early awarenesses
- 

A fundamental point, whatever the course of the disease, is that the sick child's growth receives support, with particular attention being placed on the specific age of development.

The specialized center is a well-structured environment in which healthcare professionals (i.e., doctors, nurses, psycho-oncologists) work together with welfare workers (i.e., social workers, educators, teachers, and volunteers): a close network of professionals who respond to various physical and psychological needs of these young patients and their families (i.e., parents and siblings). The diagnosis of a tumor in childhood is a traumatic experience for the whole family. The onset of the illness marks an abrupt interruption in the lives of the child and his/her family, opening up a chasm that threatens to swallow every resource. Because growth is age specific, development, and not only maintenance, is a difficult part of the cancer experience that greatly affects children and adolescents as well as parental behavior.<sup>5</sup> The aims of psycho-oncological interventions in pediatrics today, which were previously geared toward the terminal phase,<sup>6,7</sup> are to safeguard growth and to give particular attention to the complex emotional and relational problems of all involved: the patient, healthy siblings, parents, and members of the multidisciplinary team.<sup>8</sup> In this article

we focus on the experience of the children and adolescents to identify the critical aspects and areas of intervention.

## II. THE INTERFERENCE OF CANCER DURING CHILDHOOD AND ADOLESCENCE

In the age of development, physiologically characterized by continuous changes and accompanied by hopes and fears, life-threatening cancer appears to children and adolescents as a crisis, characterized by break-up and loss and/or by fixation or regression. Parental behavior may also be modified, especially with regard to hyperprotection and/or permissiveness.<sup>9,10</sup> Parents often forgo their educational role under the weight of their feelings of responsibility and impotence, and the young patient may no longer receive any limits, rules, warnings, or demands and may therefore be free to dominate those around them. Despite having an apparent benefit in terms of gratification and facilitation, this situation carries a double-negative message. On one hand it nullifies the normal figures of reference, leaving the child to his or her own devices and, on the other hand, it confirms the absolute and irreparable seriousness of the child's physical state, relegating him or her to the role of a "condemned person" who cannot be denied his or her last wish.<sup>11</sup>

Having cancer also involves a high psychological cost, even when it does not cause long-lasting remission, which can be integrated into the individual's and the family's history. Thus, while there is little certainty, for most pediatric cancers hope is realistic. Although it may be extremely precarious at an individual level, there is a concrete possibility of cure. When dealing with the difficulty of coping with uncertainty, the emotional state of the child and the family tends to swing between desperation and illusion.<sup>12</sup> When children, even very young children, are inevitably faced with the limits and the precariousness of the human condition, their thoughts and awareness surpass those of their own age group, and this comprises an inner difference between them and their peers. That is, together with the reality of being isolated from their peers, the cancer condition favors a life that deviates from the norm. Even when this difference is seen by the patient as an "added value" (*"I'm grown up ... I'm bigger than my friends..."*), social reintegration may be difficult.

Emotionally, the specificity of experiences in childhood is determined by compromise, not so much by a solidly acquired condition (as in adults), but rather by future possible achievements, which are mostly the object of nostalgic idealization. When faced with death



anxieties, a child's ability to make plans for the future is seriously limited. The experience of illness is itself characterized by a prevalence of negative feelings, which a child's mind manifests as a sense of loss, loneliness, and/or anger. These feelings may resurface in later emotional experiences of unfavorable circumstances. The extent of the trauma and the way it is faced and processed determines its influence on the sick child's future life.<sup>10,12-14</sup> Some authors<sup>15</sup> have emphasized the difficulty in registering the extent of the post-traumatic stress in children. Other authors report the diverse ways in which patients adapt themselves to the illness.<sup>16</sup> The earlier the onset of the illness, the less developed and more fragile the mental equipment of the child. The disease can pervade areas of personality and can contribute to their structure. Furthermore, the experience of cancer can become the interpretative key of successive personal circumstances, seen favorably as compensation or unfavorably as an inevitable and foregone consequence. The past cancer episode might later become an unassailable excuse when having to accept responsibilities in dealing with commitments, relationships, or life in general.<sup>17</sup>

### III. HOSPITALIZATION

Going into the hospital marks the diagnostic-therapeutic stage of the illness, and it generally involves longer and more frequent periods of hospitalization for children than for adults (Table 1). Several authors<sup>9,12,18,19</sup> have highlighted how this experience is unnatural, stressful, and destabilizing for the children and adolescents.

Hospitalization represents an experience of separation and loss, not only from the previous state of psycho-physical well-being but also from the family environment, with its relationships (particularly with peers), spaces, objects, habits, and activities (e.g., school, play, or sport). The hospital stay connotes aspects of depersonalization and anonymity, and feelings of boredom and loneliness that favor regression, isolation, and/or hostility and aggressiveness. The child has to cope with anxiety-provoking encounters including the illness, nurses, doctors, the other in-patients. All are reminders of weakness, pain, and death, which bring about fear and confusion, irrespective of the severity of the illness.

In pediatric oncology departments today, children can have a family member present throughout the hospital stay, and this presence represents a fundamental element of continuity for the child. Efforts are made to continue and maintain the patient's interest in regular

play and school activities. The chance to play and learn emphasizes the healthy aspects of children as well as their expressive and creative abilities in the context of their recovery. It also represents a chance to socialize, a moment of distraction and recreation, a space of life and hope,<sup>19</sup> and, lastly, some relief for parents.

However, hospitalization is not to be seen as a tragic event as much as an opportunity for alternative interventions. The hospital stay is more suitable the more it includes, together with the physical care, care for the emotional experience of cancer and therapy. As they develop, children need to be accompanied in their experiences; they need to be helped to fully understand what happens to and around them. Therefore, children must not be viewed as privileged interlocutors; children have the “leading role” in the hospital. Their own bodies experience medical checks, diagnostic tests, and the therapeutic interventions. And in cancer treatment, the lower the age, the higher the level of physical and psychological suffering.

The need to employ increasingly less invasive and/or painful techniques and to opt for preservative choices that improve the physical quality of life is essential. From the point of view of mental quality of life, there is a need to safeguard young patients’ chances to cope with their own experiences adequately and to preserve their ability to think and understand through direct, open, and honest communication with the medical team itself.

Without adequate support from the healthcare professionals, children may perceive actions connected to their therapeutic requirements as aggressions and/or tortures that are exclusively negative and harmful, even though they are medically very advantageous (e.g., the central venous catheter). On the other hand, when children encounter healthcare professionals in the hospital who “look after” them, they feel cared for and they develop trust.

The experience of “good encounters” is also essential to alleviate feelings of isolation and exclusion from outside life. During hospitalization, children may feel imprisoned in a difficult, precarious reality where time is marked by the stages of therapy. The periods of total isolation for aplasia or when HSCT is performed amplify these problems and may present critical issues for the whole family.

#### **IV. THE PHYSICAL EXPERIENCE**

Children affected by a cancer experience great suffering, especially physical pain, due to both the disease itself and the diagnostic

interventions.<sup>20</sup> In light of this, some studies have emphasized the importance of accurately recognizing a child's perception of pain, rather than appraising it exclusively via medical hypotheses or parents' opinions.<sup>21</sup>

From negative to symptomatic and ingravescient, a barrage of diagnostic checks faces new patients in the specialized center. This vortex of maneuvers, including the insertion of a central venous catheter, foreshadows the oncoming therapeutic interventions. Although the catheter helps avoid innumerable microtraumas (i.e., holes) and damage to veins, while permitting the administration of drugs at higher and more effective dosages, it limits the child's own body and is sometimes accompanied by feelings of vulnerability and/or shame.<sup>9</sup>

According to the type of tumor and the associated and/or radiotherapy, chemotherapy has aggressive side effects such as anemia and mucositis, and it causes notable somatic transformations at an esthetic level, from hair loss to a Cushingoid aspect, in which an increase in body weight can lead to a particularly serious identity crisis.<sup>22,23</sup> Treatment often seems devastating, yet at the same time it is of vital importance because the alternative is death, and therefore the patient is almost totally dependent. Along with the physical changes linked to the disease and/or the treatment, some emergency cases of dysmorphophobia and metamorphosis occur which, although short-lasting, are so intense that they precipitate features of breakdown that call for psychopharmacological treatment.<sup>9</sup> In general, physical changes tend to correspond to feelings of extraneousness of one's self with varying intensity. The continuous interaction between the physical and the psychic is a fundamental constitutive element of each human being, particularly at the during the developmental period of life.

Above all, psychophysical unity is greater in young children than in adults. A trauma to the body may be seen by children as being harmful to the personality and, as such, as damaging to one's integrity. Children experience identity as a subjective feeling of coherence and personal and cultural continuity that is based on the continuity of their own existence in space and time and on the possibility of recognition by others. In the cancer experience, children may feel that their identity is being undermined.<sup>24</sup> Loving and joyful expressions on parents' faces are replaced by the experience of confusion, pain, an avoidance of everyday contact. As one mother mentioned: "Every morning, when I look in the cradle it's tragic, what I have in my mind are his curls, but what I see is his baldness..."<sup>11</sup>

Even though they are increasingly rare, interventions which lead to mutilations<sup>25</sup> are particularly traumatic and hard to recover from because they cause persistent damage in a situation in which bodily integrity is already being threatened by the numerous violations due to tests and therapies, in addition to the impairment of hair loss. The loss of a part of the body is a devastating price to pay in the struggle against a malignant tumor; a patient is mutilated even as the final outcome is uncertain. Serious damage may occur not only for the patients themselves but also, and above all, for their rapport with the outside world, especially as far as the patients' affective relationships are concerned.<sup>9</sup> When internal organs are involved, experiences and imaginations of manipulation and emptying prevail. When limbs and other visible parts are affected, taking part in social life may be difficult. Not only is the child's body the object of stares and curiosity, but the way the patient projects his or her intolerance of the handicap on others is also under scrutiny.<sup>22</sup>

The head and neck area has a particular relevance in the psychological effects of cancer. Even though the whole body, with its structure and functions, represents a fundamental reality for the mind development and self-image, the face and the voice have a particular significance in the relationship with oneself and with others.<sup>26</sup> Unless the cancer is in an advanced stage, damage does not usually involve functions, but at an esthetical and relationship level patients feel "disfigured." The eyes and the mouth represent vital zones for knowledge, communication, and for survival itself. Sudden changes or disfigurement in these areas always represent a serious crisis. In rare cases in which surgery is highly destructive, the patient may be overwhelmed by a feeling of total alienation, which annuls a sense of belonging to the human race, sanctioning a monstrous transformation that often pervades the emotional-relational sphere. Patients thus become "robots" in order to deny their needs; they look on their fellow creatures with cynicism and contempt.<sup>27</sup> Progress in orthopedics and plastic surgery and the availability of improved prostheses in many cases make up for any losses at functional or esthetic levels. In some cases these interventions may become the object of idealization, while in others they may be seen as a foreign element and may remain problematic, even when it might well offer certain functional improvement.<sup>9</sup>

When the central nervous system is involved, functional deficits are also involved that provoke a notable destabilization of personal identity with a consequent modification of the quality of life: from

a malignant tumor the patient passes to dealing with a permanent handicap. This requires an important reorganization not only of the patient's previous self but also of wide-ranging changes to future plans. Schooling and professional fulfillment are areas that are less preserved than with other types of cancer. A handicapped outcome is particularly painful and difficult to cope with and accept. In most cases, however, a reactive depression in a phase of crisis is followed by a return to life and its residual potential.<sup>28</sup>

One particular condition, sterility, might occur due to either the removal of the gonads or to radiotherapy or chemotherapy. In general, during treatment, sterility is mostly a source of worry for parents who feel it is a lethal victory of the illness over possible future generations of their family. Presently, the collection and cryopreservation of the ovaries and seminal fluid leave great hope for future parenthood. As far as fertility phases are concerned, the onset of a tumor in adolescence is particularly critical.<sup>29</sup>

When adolescents thinking about their bodies, they are trying to experience it as a whole in its function, giving it a relational, social, sentimental, erotic, generative, and ethical meaning. This includes being able to hypothesize its development, aging, and its death, gathering and giving a meaning to new experiences. Adolescence means facing and fulfilling these tasks of development defined as "mentalization of the body," that is, to stress its central aspect, the mental construction of an image rich in affections, different from the construction of the "body scheme."<sup>30</sup> The body scheme is built through learning and experience, while the body image is structured through communication between subjects and through the signs, experienced day by day, of frustrated, repressed, or forbidden pleasure.<sup>31</sup> An adolescent's body gathers around it doubts, fears, and anxieties concerning changes that characterize it in a comprehensive way. Even in less problematic situations, a sense of embarrassment, of excessive modesty, or even of shame for this physicality that, as it develops, follows its own rhythms, and that is almost always different than the adolescent would have preferred and desired.<sup>32</sup>

A "natural" awareness of the body's development and its "limit," is a gradual process, but for the adolescents who live with cancer, this process may take on the character of a sudden and unexpected event. Maturation coincides with realistically recognizing one's limits and vulnerability, rather than fulfilling one's narcissistic ideals. This phase is followed by a substantial change in perspectives, especially for today's adolescents, who often make self-centeredness the foun-

dation stone of their own identity. Facing cancer means perceiving oneself as a source of confusion more than of self-assurance, with notable difficulty integrating the cancer experience in a subjectively acceptable view of oneself. Even children and adolescents know that life is not eternal and that death can be sudden or come after an illness. To use Charmet's expression, "The body has an unknown but ineluctable 'sell-by' date."<sup>30</sup> Nevertheless, the cancer experience is not easy for the child or adolescent to assimilate. The younger the child, the truer this seems to be. If the thought of mortality is indeed familiar to the adult mind and often constantly in the mind of the elderly, this is not so for adolescents, who must confront this idea as something unexpected, different, and strange.<sup>33</sup> An adolescent considers himself or herself to be "the owner of myself, my body, even my healthy splendor of youth"; however, the reality of cancer creates a limit, a boundary to this direction. Battles with weight, with shapes, with smells,<sup>34</sup> and attempts at manipulation (e.g., body-piercing and tattoos) are all examples of the ongoing rapport between oneself and a body that, biologically with cancer, goes its own way. The cancer experience marks the impossibility of being able to manage and control one's own body.<sup>33</sup> When the dramatic problem arises of an adolescent with a seriously ill body or with a past history of illness, the need to feel normal becomes even more crucial than at other less critical moments in life. Even simple or partial differences in the adolescent may make the idea of an imperfection unbearable. Illness points towards imperfections of the body, to a deterioration of the body's image, especially in more fragile and unstable individuals as, by definition, adolescents tend to be, and leads to a state of "loss of self."<sup>35</sup>

Inhibition of the processes of individuation and their frequent suspension or sectoring causes some typical manifestations of adolescence. In this developmental period, tensions, anxieties, depression, connected to regressive moments, to the resurfacing of conflicts from infancy, the mournful disinvestments of internal and external objects and parts of the self, all tend to merge and coagulate around central questions which have as their object the experience of the self and personal identity, such as "Who am I? What's happening to me? What do these things mean? And what's my relationship with others and myself?" More specifically, every adolescent's question, "Who am I?" is more or less defined by the individual's image of him or herself (Table 1).



## V. EMOTIONAL EXPERIENCE DURING TREATMENT

To understand what cancer means for children and adolescents, it is necessary, above all, to evaluate and recognize their awareness of the disease. This awareness is present from the onset due to possible modifications to their state of well-being (which tend to be protracted), an often difficult and urgent diagnosis, the reality of the hospital stays, changes in parents' behavior, fragments of information or things overheard in the hospital or at home, and changes in lifestyle as a result of treatment regimens. Feelings vary according to age (especially very young children) and prognosis, but in general cancer is seen as either an external, aggressive event that threatens a child's or adolescent's safety and poses an unbearable aspect of torture and/or punishment (for real and/or imagined faults), or as a situation that causes the loss of one's identity and integrity. In the latter case, the consequent fear of losing present or future relationships leads to painful feelings of loneliness. In both the cases there is intense suffering connected to the fear of pain and to death anxiety.<sup>36</sup> The onset of cancer is marked by the emergence of uncontrollable, rampant anxiety arising from the fear of an unknown danger. Only after the diagnosis has been made does the reality, albeit terrifying, become somewhat more contained.

An intensification of feelings of loneliness, lack of ability to communicate, and exclusion can lead to an attitude of deep isolation or of absolute despotism. At the same time, due to the real need for treatment, a state of dependence, even emotional dependence, tends to persist, disturbing the acquisition of a natural, developmental, progressive autonomy. Distressing feelings of uncertainty also emerge, which sometimes lead to an emotional state called "the Sword of Damocles syndrome." When faced with relapse, death anxieties emerge at greater intensities than those experienced at the outset, along with negative feelings, in particular anger and a lack of confidence. It is both painful and tiring to return to an uncertain path; the possibilities of recovery are lower and much more grievous, and therapeutic strategies become more intense.

If a patient undergoes a HSCT, the thought that the "bone marrow" (also seen as the innermost part) generates vital cells, that permeate the whole body, and do not stay put in any one place (as happens with organ transplants), feeds the imagination with the idea of a second life full of the donor's characteristics that "flow in one's blood" and may lead to an identity crisis, fears of metamorphosis or



invasion (i.e., that are naturally worsened and concretized by more or less intense graft versus host disease [GvHD]). The donor, on whom the patient's new life depends, may be seen as a third parent around whom various, often confused, feelings arise, such as gratefulness, debt, and dependency.<sup>9,37</sup> When the donor is a compatible sibling, the normal contrasts and conflicts may, due to the obligation of gratitude, be hampered or heightened because of feelings of envy for being so healthy that he or she might be able to save others as well.

When the terminal phase begins, anxieties of separation and loss take on a concrete meaning and bring about a fear of being abandoned in the patient, who then often asks to be allowed to go on being treated in the center. In today's socio-cultural context, aspects of omnipotence are increasingly promoted, as are aspects of well-being and immortality, connected to the negation of pain and death. These attitudes are even more marked when death and the risk of death concern children and adolescents. The death of a child is in itself unacceptable, contrary to the global design of life and the survival of mankind.

It is necessary to take into consideration the level of awareness (i.e., a dynamic, non-static dimension) of the child or adolescent who has reached the end of "active" treatment and then the close of his or her life. As adults who accompany patients, we modify our behavior in relation to the patient's need to activate different defensive methods and/or at the same time, the need to cater to his or her anxieties and questions. An open relationship and a good degree of containment are needed so that there are no discrepancies between the patient's desires and our answers, which are often the cause of great pain.

The maintenance of open, honest communication presents a chance for the patient to "keep his or her mind and thoughts alive." Likewise, the respect for a desire of silence, of a progressive, natural, final need to detach oneself from real things, helps the patient who is asking us to let him or her go. Closeness and being in tune emotionally helps us to adjust to the child's or adolescent's real needs.<sup>38-42</sup>

During the first three years of life, when the experience of physical pain is even more markedly psychosomatic, the state of prolonged uneasiness leads the child to a natural regression and withdrawal. Children express the awareness of their condition in various ways, which may be direct or symbolic, even, as Sourkes says, as regards the passing of time and its limits.<sup>12</sup>

Time, the natural flow of which is so harshly interrupted at the moment of diagnosis by an overwhelmingly real present with uncertain

developments. In this case, very young children often use the space “between the arms” to work out how much they love or are loved, how happy they are, how sad they are. In older children, together with their awareness of the serious illness and the uncertainty of the results of their treatment, it is enormously difficult to maintain a change of lifestyle that makes them so different from their peers, that may lead them to wonder whether the cancer treatment is worth it.

At times, the fear of death is mainly expressed through the somatic channel, at least until the child becomes more aware and is able to give “voice” to the fear. In adolescence, the awareness of having a short time left involves a desperate breakdown in plans “to grow up,” and this is often faced by trying to set goals to be reached in short, real spaces of time. In clinical experience, psychotherapeutic interventions (i.e., that guarantee the maintenance of an ability to think and therefore use the symbolic function of the mind) frequently mean a determination to take high school diploma exams in the hospital or to enroll at university a few days before dying. In the extreme, adolescents often make an angry effort to carry on living right up to the very last instant; struggling to retain the power to preserve meaningful relationships becomes of primary importance. Not all adolescents want to maintain social relationships with their peers: some keep themselves, more or less painfully, at a distance. Thus interfamily relationships and the rapport with the medical team become of even greater importance.<sup>43</sup>

At times, the awareness of being at the end of life fluctuates between acute psychic pain and the attempt to conceptualize the fear of dying. Caring for children or adolescents as their lives draw to a close is, for members the medical team, a well-known, painful experience. These caregivers find themselves sharing the parents feeling of not knowing or of helplessness. However, clinical evidence shows that when treatment moves to a control of the symptoms and maintenance of the “therapeutic relationship” is guaranteed, the moment of final separation can be less violent and can help prevent patients from feeling deeply alone.<sup>44</sup>

In off-therapy periods, feelings of omnipotence sometimes arise in patients who feel they have won the struggle against the disease. At other times a survivor syndrome can be seen, with profound sense of guilt toward their less fortunate companions. The experience of cancer tends to leave a permanent mark, which, in successive critical events in life, may represent an element of strength or of fragility. Some authors have underlined how children and adolescents and their

parents agree about the physical and scholastic aspects of quality of life, while parents find greater difficulty than their children with regard to the emotional and relational aspects. This discrepancy signals how parents continue to experience the image of their child in pain (Table 1).<sup>45</sup>

## **VI. CARING FOR THE CHILD'S AND THE FAMILY'S EXPERIENCE OF CANCER**

### **VI.A. Communication**

Communicating the illness, according to its severity, is often seen as a “giving” (or receiving) of bad news and thus involves high levels of anxiety for all those taking part in the meeting.

The communication of the diagnosis represents, for the patients and their families, the decisive moment in a relatively brief procedure that is often charged with anxiety as test results are awaited. Those who have to make the diagnosis and clarify the various therapies and prognostics are faced with the difficulty of dealing with such anxieties, or they may even feel the same deep emotions, though they might not always be aware of or recognize them. Such a moment is thus very delicate, especially in pediatrics, where the relationship with the patient is almost always mediated by the parents, and, at times, it is hard to approach the patient's feelings and emotions.

Literature and clinical experience have underlined just how much honest communication with the patient and the parents is crucial and how fundamental it is to establish a relationship of trust and the start of the therapeutic alliance. The quality of communication and the relationship build from the very first meeting.<sup>9,10</sup> However, not all cultures agree on the opportunity and the formality of telling children and adolescents about their diagnosis.<sup>46</sup> Most children and adolescents show inhibition in communicating verbally if they do not know the hospital staff, and this may be reinforced by the behavior of the parents who tend to foster regression in their children, making them younger still and taking their place in the direct rapport with the physician.

Even nonverbal communication, made up in the initial phase of gestures of accompaniment (often a nursing task), is an important safety factor that bears witness to the willingness of the healthcare professionals to help make the patients' new reality less painful and to lighten the sense of “not knowing.” The whole medical team

must respect the child's or adolescent's and their parents' states of mind, accept crying or silence or other emotions to support their feeling welcomed, that is, feeling well cared for. On the other hand, a cold, careless welcome, or, even worse, the strict dictation of rules or regulations, throws the patient and the family into even greater states of depression and loneliness and fuels a sense of wariness and fear toward the healthcare professionals. It is particularly important, whenever possible, to get to know and to speak to the child before starting any medical or nursing care (Table 2).

**Table 2. Cancer care for children/adolescents**

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**General aspects provided by the multidisciplinary team**

- Welcoming and listening
- Open, honest communication
- Attention towards each step of development
- Supporting growth process

**Psychological interventions**

- Prevention, in close collaboration with other team members
  - Loss of integrity
  - Assessment and short-term support
  - Long-term support and psychotherapy
- 

## **VI.B. The Moment of Communicating the Diagnosis**

From the preschool age onward, children can feel great emotional discomfort when faced with the silence of medical staff (i.e., saying nothing means not knowing; not knowing means not treating or hiding something incurable) or with the noncommunication of therapy, which may be felt as an aggressive intrusion and thus may provoke anger. Children need to acquire knowledge in order to face their situation and to reorganize their fears and imagination. In addition to hindering sharing, silence of healthcare professionals and in the family encourages subterfuge and deception. On the other hand, direct, honest communication throughout the various stages of the disease takes into consideration age, development, and individual needs. This type of communication helps children and adolescents to further their understanding of their situation and enables them to talk to the doctors and nurses, which helps them feel they are "contributing to" rather than "being subjected to" the treatment. In

addition, today's increasing diversity of ethnic and cultural groups requires greater attention to avoid attributing thoughts, problems, or solutions that may be a part of our experience but may be outside the cultural context of the patient.

Obviously, the moment when the diagnosis is communicated, especially when there are potentially fatal or disabling pathologies, calls for the presence of a physician who is fully trained in relating to the patient and the family. Indeed, this stage often proves painful for everybody, including healthcare professionals.<sup>47</sup> When healthcare professionals talk to a very young or adolescent patients or to the family about a serious illness or about painful treatment, surgery, or even uncertain outcomes, they often feel like harbingers of great physical and mental suffering.<sup>48</sup>

Communicating implies "listening" and, therefore, welcoming questions, uncertainties, anxiety, and even crying. It means accepting that such demonstrations are tied to an emotional need and providing a place where such expressions are safe. The interviews that accompany the diagnostic phase are thus fundamental to creating a relationship of trust between the child or adolescent patient and the medical staff.

As mentioned previously, open, honest dialogue, and being ready to listen all help in minimizing feelings of loneliness, difference, and alienation in both the patients and their parents. Simple and clear information about the disease and the treatment is fundamental in order to think, together, about how to face the cancer experience on practical terms.<sup>49</sup> Ways of communicating the diagnosis can take on a crucial meaning in either the negative sense of being condemned or in a positive sense of defining the course of treatment. The objective of treatment is recovery, but the quality of the treatment should be guaranteed, and the comprehensive care of the patient should be assured (Table 2).

### **VI.C. The Intervention of Psychological Support**

The fulcrum of psychological interventions has moved, thanks to medical progress, from containing anxiety in the terminal phase (although it is still present) to improving quality of life during and after cancer, by trying to limit any interference mental growth such as the passage from total dependency to autonomy and the construction of individual identity with adult characteristics.<sup>50,51</sup> In support interventions for children/adolescents and their parents, the latter

do not, generally, present psychiatric pathologies, even though they are living through a highly problematic situation that threatens to alter outer and/or inner stability and to prevent the child's normal mental development. In some cases, the traumatic encounter with a potentially fatal disease may reawaken previously compensated psychopathologies. The objective of the intervention is to foster the integration of this experience, distressing as it is, in the history and in the individual and family identity, to mitigate relational and emotional losses, and to safeguard the quality of present and future life, preventing collateral psychological effects in the long-term as much as possible. The aspect of irreparable breakdown can be limited by fostering elements of continuity, not only on a practical level (i.e., activities, interests, relationships), but also on a mental level, such as maintaining the ability to think about one's own experience and opening up to the awareness of the problems and the possibilities of help. Some family units doubtlessly preserve sufficient resources to maintain an adequate quality of life, but it is, in general, advantageous to guarantee an "open door" to meet individual needs and provide patients with the opportunity to be accompanied during their treatment according to their needs and choices.

Psychological interventions, carried out in the hospital, that address real problems, may be associated with applied psychoanalysis and correspond to the Bion model of restraint. In this model, we can modulate and transform other people's emotions if we are able to listen to them, to really accept within ourselves what the patient is expressing, to reflect it openly, and finally to create significant communication.<sup>52</sup> In itself, the condition of the illness cannot be changed, unlike strictly psychic events. However, emotional implications, particularly when associated with anxieties of separation and loss, can be shared; they are part of human experience from birth.

Without underestimating the importance of individual psychological treatment in specific cases, it is fundamental that psychological interventions aim above all at achieving suitable operational strategies to favor and support the quality of therapeutic care supplied by the healthcare team, especially for the reception, accompaniment and support of patients, but above all, for sharing. According to their role and function, sharing is really what healthcare professionals can offer. However, it is extremely difficult to guarantee a rapport based on sharing; it means giving up methods of negation and splitting, which, as human beings, we all engage in as an alternative to the painful awareness of our precariousness and limits.

When a network of accompaniment and support (to which social workers, teachers and volunteers also contribute) has favorable results, the process of recovering from the cancer experience can begin with full medical recovery. Should the situation become chronic (although this is rare), it the network makes it possible to live and cope with the illness and its treatment. Should the prognosis be poor, caregivers in the support network may evaluate the most adequate therapy to meet the child's wishes and to safeguard, whenever possible, quality of life.

From an organizational and operational point of view, when facing cancer it is important to be able to identify the level of "complexity" of the patient's and family's situation, appraising the close biological, psychological, and social aspects, as well as care interaction, all of which act in various ways.<sup>53</sup> Three different levels of intervention can be established with regard to this degree of complexity: (1) a basic level that all patients are guaranteed, which include a good level of communication with the medical-nursing team, the psychologist being present when communicating the diagnosis, the availability of groups for patients and parents to join if they wish;<sup>54</sup> (2) a second specialist level that can be activated when psychological assessment is advisable or when an exploratory session or short-term support are called for; (3) a third level that includes psychotherapy and psychopharmacology when necessary (Table 2).<sup>10,18</sup>

## VII. CONCLUSIONS

Although cancer in most patients in childhood and adolescence does not mean an end to life, it does represents a huge and prolonged trial to be coped with on unstable grounds of rising doubts and anxiety along with great hope. While the full cure of cancer may be guaranteed medically at a physical level, mental and emotional recovery should not be taken for granted. For every child or adolescent with cancer, proper attention to and understanding of the deep personal meaning of the behavior and messages from the physical illness, from pain to physical changes, from treatment or dead-end situations, must be given. Individual experiences and the multiplicity of relationships are complex and in each patient contradictions, mood swings, difficulty with resources, and the coexistence of needs and abilities do not always lead to a functional organization of growth. Positive behavior (e.g., rapid adaptation to the new situation) does not always point to real stabilization, just as the persistence of difficulty is not necessarily a



sign of excessive fragility. In the therapeutic environments of pediatric oncology centers, which also dedicate space for schooling, for expressive activities, for cheerful and delicate entertainment, respectful of individual needs, the psycho-oncologist can contribute (with flexible accompaniment) by helping the children and adolescents to rediscover a more integrated image of themselves. This image can grow and once again produce realistic perspectives of hope. At the same time, in their constant relationship with the healthcare staff, psycho-oncologists can keep the focus on the children and adolescents as people in a network of ties and family and social affections. In this way they support the favorable full return by patients to their familiar environment and, should progress be unfavorable, to safeguard to the utmost extent, quality of life through tailor-made care programs.

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