

## **PART 1**

# Clinical Issues

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## CHAPTER 1

# Introducing Multicultural Psycho-oncology

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There is one short rule that should regulate human relationships. All that you see, both divine and human, is one. We are the parts of one great body. Nature created us from the same source and to the end. She imbued us with mutual affection and sociability, she taught us to be fair and just, to suffer injury rather than to inflict it. She bids us extend our hands to all in need of help. Let that well-known line be in our hearts and on our lips: *I am a man: I deem nothing pertaining to man is foreign to me (Homo sum, humani nihil a me alienum puto).*

Lucius Annaeus Seneca, *Epistulae Morales ad Lucilium*,  
Book XV, Letter 95:52–53 (62–65 AD)

According to the World Health Organization (WHO) projections, it is estimated that the incidence of cancer will increase by the year 2030, with new cases of cancer jumping from 13.3 million in 2010 to 21.3 million in 2030 and cancer deaths rising from 7.9 million to 13.1 million. At the same time, earlier diagnoses and improvement in cancer therapies have also noted an increase in survival for about 25 million people (long-term survivors) throughout the world.<sup>1</sup>

It is clear that this epidemiological data has a specific value if evaluated through a global perspective which takes into account the important issues of quality of life and psychosocial needs

of cancer patients. In fact, cancer is not only a series of very different diseases needing complex treatments, from many professionals, but also a devastating and 'traumatic' event with physical, emotional, interpersonal and social implications that should be constantly monitored across the disease trajectory, and into survivorship. Being affected by cancer means an overall transformation of the sense of one's own self, in which the parameters of time (the past, the present, the future), of space (one's own individual space, one's own home, one's own world context) and of existence (*Umwelt*, the biological dimension, my body; *Eigenwelt*, the relationship with myself, my-being-in-the-world; *Mitwelt*, the relational dimension with others; *Überwelt*, the spiritual dimension, the meaningfulness) are altered by the diagnosis and treatment, recovery and recurrence or transition to palliative and end-of-life care.

Starting from the work of a small group of psychiatrists,<sup>2–6</sup> interested in examining the psychophysiological and emotional factors implicated in cancer and cancer treatment, oncologists quickly started showing a specific need for more precise indications about the psychosocial, behavioural and rehabilitative issues in cancer care. This determined the rapid growth of the psycho-oncology discipline in the USA from the 1970s<sup>7–10</sup> and subsequently, from the early 1980s, in many other countries,

#### 4 Clinical Issues

such as France, Germany, Italy, the Netherlands, the United Kingdom, to cite just a few.<sup>11</sup>

Over the last quarter of a century, a large number of psycho-oncology studies have in fact indicated that 30–40% cancer patients fail to adapt, and present emotional disorders – mainly depression, anxiety and adjustment disorders according to the ICD-10 and DSM-IV taxonomic systems – as a consequence of cancer and cancer treatments.<sup>12</sup> A further 15–25% present other significant psychosocial conditions, such as health anxiety, irritable mood, demoralization, or general emotional distress which are not identified by the usual categorical systems (e.g. DSM-IV and ICD-10) but by other systems (e.g. the Diagnostic Criteria for Psychosomatic Research), and which are dysfunctional and maladaptive symptoms.<sup>13</sup>

The implications and the impact of psychosocial disorders for patients and their families are of paramount importance in oncology with several studies demonstrating that clinically significant distress is associated with maladjustment, reduction of quality of life and impairment in social relationships, longer rehabilitation time, poor adherence to treatment and abnormal illness behaviour, and possibly shorter survival.<sup>14</sup> Significant levels of emotional distress have been reported also to affect family members and there is evidence that unrecognized and unmet psychosocial needs are an important predictor of psychological morbidity in caregivers in every phase of the illness.<sup>15–18</sup> Various types of psychosocial interventions have also been shown to be effective in reducing psychological symptoms and improving quality of life among cancer patients.<sup>19–21</sup>

Thus, 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 today a specific and unquestionable role in the multidisciplinary approach to cancer. This role has been defined, in several countries, through the development of psycho-oncology services, programmes and/or departments with the mission of providing specific activities in terms of clinical care, education and research. Furthermore, guidelines and recommendations on psychosocial care in cancer have been

developed and endorsed by national and international scientific societies of psycho-oncology as well as by advocacy movements.<sup>22</sup>

The *National Standards for Psychosocial Oncology* published by the Canadian Association of Psychosocial Oncology (CAPO) (1999) includes today standards of care, organizational standards, educational standards and integration of all phases of the cancer control trajectory, including prevention and survivorship.<sup>23</sup> Several agencies and institutions, such as the Canadian Association of Provincial Cancer Agencies, the Canadian Cancer Society, the Canadian Strategy for Cancer Control, and the Canadian Council on Health Services Accreditation, have endorsed CAPO's recommendations. Furthermore, clinical guidelines on the assessment of psychosocial needs of cancer patients and on the screening, assessment and care of psychosocial distress in cancer have also been developed ([www.capo.ca](http://www.capo.ca)).<sup>24,25</sup>

Comprehensive clinical guidelines are available in Australia ([www.nhmrc.gov.au](http://www.nhmrc.gov.au)) where the first document, *Psychosocial clinical practice guidelines: information, support and counselling for women with breast cancer* (National Breast Cancer Centre, 1999),<sup>26</sup> represented the basis for the subsequent development of the *Clinical practice guidelines for the psychosocial care of adults with cancer*, published by the National Breast Cancer Centre and the National Cancer Control Initiative.<sup>27</sup>

In the United States, the National Comprehensive Cancer Network (NCCN) Distress Management Panel, consisting of multidisciplinary health care professionals developed the guidelines on distress, starting from 1997<sup>28</sup> to the most recent version I.2011.<sup>29</sup> The work of the panel has been recognized throughout the world, where an ultra-short tool, the distress thermometer, has rapidly become one of the 'gold standards' for the rapid screening of distress, identified as the 'sixth vital sign', with the same importance as blood pressure, temperature, heart frequency, respiratory rate and pain.<sup>30,31</sup>

In more recent years, at the request of the National Institutes of Health (NIH), the Institute of Medicine (IOM) of the National Academies of Sciences published the conclusions of a specific working group<sup>32</sup> indicating that enough evidence

exists for the inclusion of psychosocial health services in cancer care, and stressing 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.'

Similarly, the conclusions of the European Council<sup>33</sup> clearly acknowledge the significance of psychosocial aspects in cancer care, indicating that 'to attain optimal results, a patient-centred comprehensive interdisciplinary approach and optimal psycho-social care should be implemented in routine cancer care, rehabilitation and post-treatment follow-up for all cancer'(par. 5), and emphasizing that 'cancer treatment and care is multidisciplinary, involving the cooperation of oncological surgery, medical oncology, radiotherapy, chemotherapy as well as psycho-social support and rehabilitation and, when cancer is not treatable, palliative care'(par. 11).

Thus the general results of the above-mentioned reports are that the evaluation and treatment of psychosocial consequences should be mandatory in every cancer centre. This is in accordance with the statement 'No health without mental health',<sup>34</sup> which sets out to guarantee the quality of life of any individual in society to receive optimal medical and psychiatric care, incorporating attention to psychosocial needs into policies, practices and standards of clinical care.<sup>35,36</sup>

This is also the message launched 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 Care*, 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' ([www.ipos-society.org](http://www.ipos-society.org)).<sup>37</sup> A number of organizations and associations throughout the world, including the International Union Against Cancer (UICC), the International Society of Paediatric Oncology (SIOP), the Canadian Cancer Society, the Clinical Oncological Society of Australia, the World Psychiatric Association (WPA), as well as advocacy movements, such as LIVESTRONG and

Reach to Recovery International, have endorsed this statement. The webcast lectures series on psychosocial aspects of cancer care (communication, psychological assessment, distress management, anxiety, depression, family issues, bioethics, palliative care, loss and grief, psychological intervention) developed by IPOS and available online in several languages (Chinese, English, French, German, Hungarian, Italian, Japanese, Portuguese, Spanish) is also in agreement with the concept that account should be taken of multicultural and cross-cultural relevant issues.

For all these reasons, we have realized that the time has come for an international perspective on psycho-oncology, with contributions by specialists from different parts of the world, sharing their long-standing experience in the psychosocial care of patients with cancer, and their families.

More specifically, a first aim of the book is to discuss contemporary themes in psycho-oncology, such as genetic counselling, bioethics, advocacy and to provide practical suggestions for dealing with special populations, such as children, the elderly, long-term survivors, or disadvantaged or minority groups. A second aim of the book is to present the challenging clinical problems encountered when caring for cancer patients and their families, by describing the best responses to these challenges, including assessment, diagnosis and treatment, and by summarizing the evidence base and digesting clinical experience where evidence from clinical trials is lacking, and noting, through clinical examples, international and multicultural perspectives.

With respect to this, the book specifically emphasizes the possible cultural implications determined by cultural diversity, particularly where immigration and other social phenomena have influenced the creation of multiethnic and multicultural societies. Specificity and culturally relevant issues on several topics of psycho-oncology are discussed throughout the book. It is clear that language, ethnicity, race and religion have an important role in affecting patients' and families' perception of illness. We need to understand how culture may influence communication and the doctor-patient relationship (e.g. disclosure of information related to diagnosis and prognosis, role of patient and

## 6 Clinical Issues

family in decision-making), coping mechanisms, psychological response and psychopathological disorders (e.g. phenomenology of anxiety or depression, abnormal illness behaviour, somatization), treatment options and acceptance of psychological intervention. We also need to better understand how the culture of the organization and health care system influence the response of patients and families to cancer and cancer treatment.

The book consists of three parts. In Part 1, clinical issues are discussed in detail by experts in the field. Butow and Baile explore in Chapter 2 how culture impacts on the relationship between patients, family members and clinicians, and how communication across cultures can be challenging, especially if language barriers are present. Chapter 3, by Jacobsen and Donovan, describes the psychosocial instruments commonly used in psycho-oncology research for the assessment of anxiety, depression and distress, including a number of brief tools that could be used for screening purposes, and summarizes evidence regarding the relative merits of these instruments. In Chapter 4, Costantini, Navarra, Ashing-Giwa and Yeung discuss the most significant aspects related to sexuality and gender in patients with cancer, by addressing the type of cancer and treatment influencing a person's appearance, body image, sexual functioning, and the role of cultural variables in different parts of the world, with comparison between Western countries, Asia and Africa. Chaturvedi and Uchitomi (Chapter 5) examine the most common psychiatric and psychosocial disorders in relation to cancer, including the challenging situation of somatization and abnormal illness behaviour in cancer patients, where cultural determinants can play a particular role, and the problem of emergency psychiatry in cancer care. Chapter 6 by Ahles, Schagen and Vardy focuses on cognitive changes associated with cancer and cancer treatments with careful analysis of the studies that have examined the role of patient characteristics and genetic factors in increasing the risk for post-treatment cognitive decline and of the problems and lack of data regarding the role racial and ethnic issues and socio-economic factors have on this area. Bultz, Loscalzo and Clarke describe, in Chapter 7, how screening

for distress, considered as the 6th vital sign, is an essential component of clinical care that facilitates the conversation within the clinical team, with positive effects in terms of better understanding of the full range of patient concerns and better integration of the different health care professionals working in an interdisciplinary fashion.

In Chapter 8, Watson provides a comprehensive overview of psychological intervention in cancer care, with particular emphasis on the best approaches to build into clinical practice, the available evidence on efficacy of psychological therapy, the differences between psychiatric and psychological models and the cost-effectiveness issues. Thekdi, Irrázaval and Dunn (Chapter 9) examine the vast and important area of psychopharmacological intervention in cancer care carefully summarizing the role of antidepressants, antipsychotics, benzodiazepines, anticonvulsants and mood stabilizers, and exploring their clinical use, safety profile, side-effects and possible interactions, also from a cultural perspective. Chapter 10 by Mehnert and Koch review the effects of cancer rehabilitation programmes in reducing the impact of disabling conditions, in enabling people with disabilities to achieve optimal social integration and in improving quality of life, social participation and return to work.

Part 2 deals with the different approaches in psycho-oncology when applied to special populations. In Chapter 11, Stuber and Strom discuss the current situation in paediatric oncology and associated psychiatric issues by considering the normal developmental context in which children understand cancer and treatment, and examining the most common psychological and psychiatric problems of child cancer patients and their families. Fitzgerald, Nissim and Rodin (Chapter 12) examine the important theme of geriatric psycho-oncology by summarizing the main psychological and psychiatric implications of cancer on patients in the later stages of life, contrasting the problems and concerns of old age with young age and evaluating the efficacy of psycho-oncology intervention in this vulnerable segment of the population. Chapter 13, by Fielding and Lam, focuses on the significant problem of higher cancer incidence, lower

knowledge of cancer risks, prevention, less screening uptake, more difficulties in access to diagnostic services and fewer or different options for treatment, and more difficulties in reintegration following treatment among underserved and minority populations.

Part 3 addresses salient topics requiring special attention in clinical psycho-oncology. The significance of cancer within the family, as a basic social and ethical unit of care, is explored in Chapter 14 by Baider and Goldzweig who discuss how individual values and beliefs and the family convergence and diversity of meaning influence the psychological response to the disease. Chapter 15 by Surbone reviews the vast and important area relative to the bioethical aspects in cancer, specifically focusing on cultural competence and culturally sensitive communication as essential instruments for ethical contemporary practice of oncology, in order to negotiate different health care related values and goals in individual therapeutic relationships with patients of different cultures, and to facilitate clinicians' ability to interact more effectively with institutions, policy-makers and various stakeholders in lower income countries. The theme related to the positive life changes secondary to cancer experience, known as post-traumatic growth, is examined by Diaz, Cordova and Spiegel in Chapter 16 by exploring similarities and differences across cultures. In Chapter 17, Esplen, Hunter and Kash provide a detailed psychological framework regarding the use of new genetic technology and discuss the genetic testing process, the potential psychological impact, and the psychotherapeutic approaches useful to augment care. Chapter 18 by Ganz and Stanton addresses the trajectories of psychosocial and physical recovery for adults after primary treatments are complete, contributors to those outcomes (i.e. medical, individual, sociocultural and developmental contexts), and considerations regarding provision of effective medical and psychosocial care during re-entry and extended survivorship. Chapter 19 by Breitbart, Chochinov and Alici focuses on the role of psycho-oncologists in helping and guiding terminally ill patients through the dying process, by presenting the most salient aspects of end-of-life care including assessment and management of

a variety of possible problems, such as delirium, depression, desire for hastened death and suicide. Morris and Block describe in Chapter 20 how individual differences both within and between cultures increase the complexity of care when working with bereaved individuals and families, and how to correctly assess and provide support strategies and treatment for the bereaved. Chapter 21 is dedicated by Kissane, Lethborg and Kelly to providing a thorough description of the major religions worldwide, including studies of prayer, the power of placebo, the use of rituals, the role of meditation, in order to help clinicians to routinely make use of a spiritual assessment and integrate appropriate responses into a comprehensive and person-centred management plan. A comprehensive overview of some of the main advocacy movements is given in Chapter 22 by Travado, Geissler, Thiboldeaux, Dunn, Kaur and Merriman, who illustrate some of the actions undertaken in the five continents and how these have translated and influenced better policies in cancer care.

The book is designed to be easy to read and to reference, with information clearly displayed in concise tables and boxes accompanied by further detail within the text and clinical cases exemplifying the themes discussed in each chapter.

We hope that this book can give further insight into the multiple dimensions involved in psychosocial care of cancer patients and their families, and that it can help clinicians, teachers and researchers better understand the importance of the cultural backgrounds of patients and families as an important variable moulding the psychological response to cancer and cancer treatment.

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8 Clinical Issues

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