PSYCHO-ONCOLOGY CARE SERIES:
COMPANION GUIDES FOR CLINICIANS

Management of Clinical Depression and Anxiety

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OXFORD

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PSYCHO-ONCOLOGY CARE SERIES: COMPANION GUIDES FOR CLINICIANS

Published and Forthcoming Books in the Psycho-Oncology Care Series

Management of Clinical Depression and Anxiety

Psycho-Oncology in Palliative and End-of-Life Care

Sexual Health and Relationships

Cancer Survivorship and Health Promotion

Preface

Psycho-oncology is a subspecialty of oncology that focuses on psychosocial problems experienced by cancer patients and their families and carers; it provides evidence-based approaches to management of these specific problems.

The companion guides in the *Psycho-Oncology Care Series* are intended to make clinical management information accessible to either oncology clinical staff, who may not have had specialized mental health training, or those professionals still in training as mental health specialists seeking to increase their psycho-oncology skills.

Mental health problems in cancer patients can be both preexisting and arise within the context of the cancer's diagnosis and treatment. This companion guide covers clinical depression and anxiety and provides information relating to diagnosis, treatment, and service issues presented in a brief condensed format, which can be used as a quick access source to support clinical decision-making.

The authors of this Companion Guide are experienced clinicians and researchers with many years of experience in the care of patients with cancer and families. We thank them for sharing this expertise. As editors, we also thank the staff of Oxford University Press for their support and the International Psycho-Oncology Society for its assistance with distribution.

The psychosocial care of cancer patients and their families is a basic human right. We hope that the readers of this book will find it helpful to advance the quality of this care delivery to thus enrich the lives of all patients with cancer and their families.

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Contents

Contributors *ix*

1. **Distress, Adjustment, and Anxiety Disorders** *1*
   Daniel McFarland and Jimmie C. Holland
2. **Depression in Cancer Care** *23*
   Daisuke Fujisawa and Yosuke Uchitomi
3. **Diagnosis and Treatment of Demoralization** *42*
   David W. Kissane
4. **Recognizing and Managing Suicide Risk** *61*
   Maggie Watson and Luigi Grassi
5. **Psychopharmacologic Management of Anxiety and Depression** *78*
   Madeline Li, Joshua Rosenblat, and Gary Rodin

Appendix 1: NCCN Distress Thermometer and Problem List *109*
Appendix 2: Demoralization Scale-II *111*
Appendix 3: Brief Screening Tools *112*
Appendix 4: Tools for the Assessment of Suicide Risk *113*
Appendix 5: Answers to Chapter Quizzes *114*

Index *117*

Chapter 1

Distress, Adjustment, and Anxiety Disorders

Daniel McFarland and Jimmie C. Holland

Learning Objectives

After reading this chapter, the clinician will be able to

1. Provide background that will help him or her assimilate and contextualize distress, adjustment disorders, and formal anxiety disorders in patients with cancer.
2. Describe the presenting problems. This includes grasping the diagnostic dilemmas and therapeutic applicability between these clinical disorders to provide quality supportive care for patients with cancer and their families.
3. Outline key investigations for making a diagnosis. The clinician should be able to describe the most useful investigations for distinguishing between differential diagnoses.
4. Describe clinical management options. The clinician should be able to appreciate the management decisions and available clinical options.
5. Clarify professional issues in managing distress and anxiety disorders in the cancer setting.

Background Evidence

Cancer frequently causes emotional turmoil for patients and families. Its psychological symptoms may be just as insidious or extreme as its physical symptoms, but historically they have largely gone unrecognized. Increasingly recognized is the prevalence of distress and/or psychiatric disorders in approximately 30% to 60% of patients newly diagnosed with various types of cancer.[1–3] Psychological disturbances may present at any time but with increased frequency at certain points in the cancer trajectory: at diagnosis, with cancer recurrence or progression, and during advanced cancer states or survivorship.[4] Clinician barriers to the identification of distress include a perceived lack of time, inadequate training or interview skills, a low index of suspicion, and low awareness of mental health complications.[1]

Distress

Distress was chosen as a word to use with patients because it did not cause embarrassment. It can serve as an umbrella term for the range of emotional problems that arise during a patient's illness in response to physical symptoms, sadness, worry, or concerns for family or one's own existence as well as severe symptoms of depression and anxiety. The National Comprehensive Cancer Network (NCCN) noted in 1996 that distress has multiple causes related to physical, social, psychological (e.g., concern for family), and existential or spiritual concerns. Although a clinical assessment is always necessary for a complete evaluation of distress, several validated scales are used to identify those patients who would benefit from further psychological care. The most commonly used measure is the NCCN Distress Thermometer and Problem List (DT&PL), similar to the zero to 10 Likert scale that has been successfully implemented for pain management (see Appendix 1 on p. 109). In 2008, the Institute of Medicine's report *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* noted there was a sufficient evidence base for both psychosocial and psychopharmacologic interventions to necessitate a policy statement that quality cancer care must integrate psychosocial treatments into routine cancer treatment.[5] In 2010, the International Psycho-Oncology Society (IPOS) and the International Union Against Cancer endorsed its use as the sixth vital sign, after pain.

Adjustment Disorders

Here symptoms occur in reaction to the stressor of cancer and are considered disproportionate or excessive. The development of impairment in interpersonal, social, or occupational areas of functioning is central to the diagnosis. This distinction requires clinical judgment, as receiving a cancer diagnosis is stressful under most circumstances and adjustment disorders are the least studied entities in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM). However, they are by far the most commonly diagnosed psychiatric disorders in patients with cancer.[1] Its previous stand-alone categorization in the fourth edition of the DSM did not encourage research in this area. The fifth edition of the DSM has placed adjustment disorders under the "Trauma and Stressor-Related Disorders" category, which makes the relationship to the stressor of cancer clearer and may potentiate research to understand and delineate it better. The lack of specificity, aside from a reaction to a stressor, should cause the clinician to expand the differential diagnosis and consider alternate diagnoses (e.g., demoralization).

Anxiety Disorders

Although anxiety is pervasive in patients with cancer, the prevalence rates of specific anxiety disorders are less well defined.[6] The majority of anxiety experienced in the setting of cancer is situational and not debilitating. It may be classified as an adjustment disorder with anxious features or as an anxiety disorder due to a general medical condition.[7] In addition, various medical situations in the cancer trajectory may exacerbate anxiety, or it may be

comorbid with depression or cancer (e.g., uncontrolled pain, medication side effect, dyspnea, nausea).[8,9] Anxiety is a normal response to cancer and can even be helpful for some people who take steps to reduce the anxiety (e.g., information-seeking, reaching out for social support). More significant anxiety disorders are typically present before the cancer diagnosis and may be identified as a generalized anxiety disorder, panic disorder, phobia, or posttraumatic stress disorder (PTSD).[10]

A high-quality oncology practice requires the recognition and treatment of comorbid distress and anxiety in accordance with clinical practice guidelines. The oncology team on the "front line" is central to delivering quality psychosocial cancer care. This high-quality, evidence-based management strategy essentially requires a truly "caring" approach that fosters a trusting therapeutic relationship, as trust is influential in determining clinical outcomes. This chapter outlines the management of these symptoms in accordance with these principles.

Presenting Problems

Fear

Fear is a reaction to a known threat. It may be provoked by the inevitability of death, uncertainty, worry about proposed treatments, or negative reactions from treating physicians, nurses, and other staff members, for example.

Anxiety

Anxiety is a reaction to both real and imagined threats. It may be provoked by the uncertainty of the cancer prognosis or even the diagnosis itself (5% to 10% of cancers are unknown primary), the impact of the illness on one's identity and livelihood, the effects on one's body, or anxiety about interacting with strangers or being alone in the hospital. At the same time, anxiety in the cancer setting may not be directly related to cancer. For example, in the face of a cancer diagnosis or recurrence, a primary anxiety or mood disorder may be exacerbated or one may worry about interpersonal relationships. The diagnosis may exacerbate a patient's social situation, which then impairs psychic equilibrium (e.g., financial instability, spousal and/or family interactions). Patients with cognitive impairment or dementia frequently experience anxiety with changes in daily routines.

Coping

Patients may convey a sense of poor coping. Understanding "normal," adaptive reactions to the cancer stressor helps the clinician to determine what might be a pathological response (see Box 1.1). A sense of poor coping may vary over the course of the illness as well (e.g., acute anxiety at diagnosis, chronic anxiety related to the fear of recurrence or hereditary genetic testing) or may be comorbidly present with depression or a medical condition (e.g., uncontrolled pain, medication side effect, dyspnea, nausea) and remit with medical attention. At the same time, patients may develop a de novo anxiety disorder during the cancer trajectory.

Box 1.1 Issues Complicating the Presentation of Distress and Anxiety in the Cancer Setting

- Clinicians do not recognize impaired functioning and pathological symptoms
- Patients underreport their symptoms
- Differences in cancer center psychosocial resource allotment
- Diagnostic confusion with medical conditions

Stigma and Masked Distress

Patients may conceal or minimize symptoms that they feel are less important than dealing with the cancer. Also, they may fear that their oncologist may not treat them the same as other patients, fearing the stigma associated with a label of poor coping.

Physical Symptoms

Tremor, palpitations, sweating, breathlessness, and hyperventilation can all be markers of anxiety. Patients with cancer can have numerous physical ailments that tend to change over time and complicate comorbid psychological symptoms or psychiatric diagnoses. Disorientation, confusion, and cognitive impairment may represent delirium. A patient with an intracranial mass (e.g., common in lung and breast cancers or a primary mass) or thyroid dysfunction (e.g., from a pituitary mass or endocrine tumor) may present with apathy or irritability and appear to be depressed or, conversely, could exhibit hyperactivity, disinhibition, or mania-like states. The underlying biological effects of anticancer treatments may also confound the psychological presentation.

Distress

This is defined by the NCCN as "an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness, and fears, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in a spiritual crisis." It is identified by the patient and may or may not coincide with functional impairment. Patients experience distress and interpret its meaning in a variety of ways. It may be a healthy reaction to a stressor, or it may lead to functional impairment and can be a harbinger for future psychiatric complications during cancer treatments or into survivorship.

Assessment of Distress as the Presenting Problem

A patient's distress should always be assessed clinically, as it may or may not be associated with decreased function, which is an indication for a more significant intervention. The reason for distress is often discovered through use of an instrument (e.g., the problem list component of the DT&PL; see Appendix 1 on p. 109) in conjunction with a clinical interview.

Key Questions:

- How have you been dealing with the stress of the diagnosis?
- How has it affected your life?
- How would those who are close to you say you are doing?
- Is there anything that you are no longer able to do because of its impact on your life?
- Do you feel safe and in control?

Problem List

Screening with a valid instrument is encouraged but should always be followed up with a clinical assessment (see Box 1.2). Although the NCCN recommends the DT&PL, there is not one accepted gold standard for distress screening. Researchers have advocated for a two-step screening with the DT&PL and another short screening measure, such as the Hospital Anxiety and Depression Scale (HADS).

Vulnerability Factors

The NCCN distress guidelines define time points when assessments for distress, adjustment disorders, and anxiety should be made. Certain time points in the cancer trajectory may exacerbate anxiety (e.g., at initial diagnosis, in anticipation of check-ups, during diagnostic studies that might detect recurrence, with advancing disease, with news of a poor prognosis, or at the end of active treatment, when surveillance intervals are increased). Special attention should be placed on distress screening at the cancer diagnosis, at recurrence, or during any vulnerable period (see Box 1.3); every six months; and into the survivorship period. The best method of triaging is one of the crucial issues with regard to initiating a comprehensive appraisal of patients with cancer.

Box 1.2 Patients at Increased Risk for Distress as Identified by the NCCN

- History of psychiatric disorder/substance abuse
- History of depression/suicide attempt
- Cognitive impairment
- Severe comorbid illnesses
- Uncontrolled cancer-related symptoms
- Spiritual/religious concerns
- Social issues (e.g., family/caregiver conflicts, inadequate social support, living alone, financial problems, limited access to medical care, young or dependent children, younger age, female, history of abuse [physical, sexual], other stressors)

Adapted with permission from the NCCN.

Box 1.3 NCCN Designated Periods of Increased Vulnerability

- Finding a suspicious symptom
- During a diagnostic workup
- At diagnosis
- Awaiting treatment, changing treatment modalities, or at the end of treatment
- Significant treatment-related complication(s) or treatment failure
- Discharge from the hospital following treatment
- Transition to survivorship
- Recurrence/progression
- Advanced cancer conditions, and at end of life.

Adapted with permission from the NCCN.

Comprehensive Psychiatric Workup

It is essential to thoroughly review a patient's psychosocial issues and also to ensure that a complete medical workup has been performed. A previous psychiatric history may antedate and help to elucidate the manifestation of ongoing events, for example. Once distress has been identified and established with the patient, a comprehensive interview process should begin. Some key questions to begin the interview process are listed in Box 1.4.

Once distress-related issues are identified, a comprehensive interview should follow. Its integral components consist of a review of the present social support system (e.g., key relationships or their absence), social history (family, friends, occupation, hobbies, habits/addictions), development history (e.g., education, life-course milestones), and present functional impairment in daily or otherwise important activities. Clinical assessments should be made in a confidential manner that enhances or builds trust. They should

Box 1.4 Comprehensive Psychiatric Workup—Key Questions to Ask Distressed Patients

- Help me to better understand your distress. What is it that worries you the most?
- Are there other sources of anxiety?
- What aspect of your illness is most frightening?
- Are there physical symptoms that make it hard to cope?
- Do you have a past history of anxiety or chronic worry?
- How has your sleep been? What happens when you try to sleep?
- Do you have any symptoms of panic? tension? restlessness? tremor? any other symptoms of concern?
- Does all that you've been describing spoil your quality of life? interfere with your activities and how you function?

Box 1.5 Distress Screening Overview

- Distress screening and psychological assessment at NCCN-designated time points and whenever symptoms arise
- Comprehensive clinical interview (e.g., reviewing social and development history and present functional impairment)
- Assess for safety
- Treatment interventions (psychological/pharmacologic)
- Treatment intervention follow-up/assess for titration
- Assess treatment effects at follow-up subsequent visits

be reassuring, comprehensive, and not hurried. The conversation should be allowed to flow in the direction of concern for the patient. The clinician should work to minimize stigma by paying attention to word choice and opting for words such as *distress, concerns, worries, uncertainties*, or *stressors* and avoid words such as *psychiatric, psychological, mental disorder, maladjustment*, or *mental illness*. An overview of distress screening is provided in Box 1.5.

Clinical Management

Nonspecific Distress

The management of distress should be problem-focused and directed toward ameliorating the cause of distress, if possible, in addition to symptom-directed management. Guidance from the primary medical team to fully assess the effects of an intervening medical or medication-related cause for the patient's symptoms is vitally important. In addition, a formal psychiatric diagnosis should be ruled out, depending on the safety assessment and severity of symptoms. The problem list that accompanies the DT&PL can be helpful in identifying the cause of distress along with a problem-focused clinical interview. (See the "Assessment of Distress as the Presenting Problem" section for details of the clinical interview assessment.) Referrals should be made to the appropriate clinician in order to obtain a comprehensive assessment. For instance, a social worker may best address financial issues and a chaplain may best address spiritual issues.

In general, acknowledging patient distress is the beginning of a therapeutic intervention. Many patients benefit simply from reviewing and clarifying information about their diagnosis, treatment options, and side effects. Frequently, patients receive information from various professional and lay sources that may run counter to their understanding.

Some key considerations for troubleshooting distress are

- Review how to interpret the information that is gathered in the medical system.
- Always assess for patient understanding and refer to appropriate sources (e.g., NCCN Treatment Summaries for Patients).

- Counsel patients on how to mobilize and avail themselves of resources. Ensuring continuity of care can also be highly therapeutic and help to establish rapport.
- Offer guidance on securing the following services (depending on need):
  - Counseling (e.g., support groups, family or individual counseling)
  - Symptom-directed interventions (e.g., relaxation techniques such as guided imagery, meditation, or creative art/music therapies)
  - Spiritual support
  - Exercise interventions
- Use collateral information and follow-up patient interviews to assess the need to escalate care.
- Re-evaluate after prescribed interventions.

Standards for distress management have been developed by the NCCN (see www.nccn.org/professionals/physician_gls/f_guidelines.asp). Distress should be recognized, monitored, documented, and treated promptly at all stages of disease and in all settings. The NCCN suggests that interdisciplinary committees review institutional standards for distress management. The training of professionals in distress screening is mandatory in order to ensure the proliferation of skill sets.

Case Study

Distress Management

Frank was diagnosed with prostate cancer two years ago after routine surveillance detected an elevated prostate-specific antigen (PSA). He opted for a surgical approach to treat his localized prostate cancer and underwent a radical prostatectomy. He tolerated the surgery well without significant postoperative complications and was able to urinate without difficulty and achieve erections. His urologist has been following his PSA and has noted a significant doubling time in less than six months. Imaging reveals no evidence of active prostate cancer, but it is recommended that Frank undergo local radiation to the operative site. He reports a distress level of 10 and identifies several emotional problems including nervousness, sadness, and fear and is concerned about the effects of radiation. He has many friends who have had terrible complications from radiation, including death. His clinician reviews his distress data and interviews Frank about his concerns. Frank feels devastated that the cancer has "come back," feels like he was not successful, and deeply fears the effects of radiation. The clinician decides to clarify that this "adjuvant" treatment will be done in order to prevent an actual cancer recurrence on imaging (i.e., Frank has a biochemical prostate cancer recurrence), and more patient-directed information packets are provided for Frank. It is decided that a staff member will follow up with Frank and that his distress will be assessed at the next visit. Frank tolerates the radiation well without complications and has subsequent distress levels between 1 and 3.

Adjustment Disorders

Adjustment disorders are the most commonly identified comorbid psychiatric diagnoses in the setting of cancer. They indicate poor coping.