Distress Factsheet

Anxiety and depression affect up to 29% of cancer survivors.[1] The multiple stressors, vulnerabilities and challenges they face have been highlighted as contributing to cancer survivors' high risk. Survivors can experience physical compromise, social isolation, work and financial problems following treatment for cancer.[1] Fear of cancer recurrence is a chief concern and can persist long after treatment ends.[2]

Key facts

The impact of uncontrolled anxiety and/or depression in cancer survivors is significant:[1]

- reduced quality of life
- double the incidence of completed suicide compared with the general population (US data)
- reduced adherence to recommended surveillance
- reduced engagement in health-promoting activities

Aetiology and contributing factors

Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that can interfere with an individual's ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common and normal feelings of vulnerability, sadness and fears to problems that can become disabling such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.[3] Fear of recurrence is elevated among survivors and their caregivers who find less meaning in the cancer experience and who experience more concomitant family stressors.[2]

All individuals diagnosed with cancer experience some level of distress associated with the diagnosis.[3] Those who perceive they have poor support are more likely to experience greater psychological distress. Partners and children of people with cancer are also vulnerable to psychological distress and need support.[4] Established risk factors for distress in the person affected by cancer have been identified. Further investigation is required to establish their ongoing contribution to distress in survivors:[4]

Individual factors	> Younger age > Single, separated, divorced, widowed > Living alone > Having children younger than 21 years > Economic adversity > Poor marital functioning > Past psychiatric treatment especially depression > Cumulative stressful life events > History of alcohol or other substance abuse > Female gender
Disease/treatment factors	> Advanced stages of disease > Poorer prognosis > More treatment side effects > Greater functional impairment and disease burden > Lymphoedema > Chronic pain > Fatigue

Assessment and monitoring

All individuals should have baseline screening for distress, and further assessment at appropriate intervals and as clinically indicated, particularly at periods of increased vulnerability. These include:[1]

- Times of disease transition
- Surveillance
- Significant loss
- Major life events
- Periods of social isolation

Regular screening for distress allows the health professional to elicit any potential concerns for the cancer survivor, and facilitate the joint development of early strategies to address these concerns.[1]

A number of different tools exist to screen for distress, but recent studies have found that shorter tools are both reliable and easier to use.[3] The National Comprehensive Cancer Network Distress Thermometer and the accompanying Problem List are recommended to assess the level of distress and to identify causes of distress.[3] The Problem List is not specific to the post-treatment phase and may not include all issues that survivors may experience. The consumer resource, Cancer – how are you travelling?[5], contains several copies of the Distress Thermometer that individuals may use independently or prior to a follow-up appointment.

The score identified on the distress thermometer may guide clinical decision making.[3] Any score should lead to a discussion to explore the individuals' concern/s. A score >4 may indicate significant distress and warrants further clinical assessment and referral to specialised care as required.[3]

It may be challenging for health professionals to discuss psychological difficulties. The following general question prompts have been suggested to assess emotional well-being: [4]

- "In addition to looking at the medical/surgical issues, I am interested in hearing how things are going more generally for you"
- "How have you been feeling emotionally"
- "Could you tell me how your mood is?"
- "How would you say the diagnosis and treatment has affected you?"

Health professionals should further ask about specific clinical issues including:[4]

- Anxiety
- Depression
- Interpersonal functioning
- Coping with physical symptoms
- Body image and sexuality

Prevalence rates for depression in people affected by cancer range from 20% to 35%:[4]
Symptoms of depression include: [4]

- low or flat mood or loss of interest in things that used to be enjoyable
- anorexia, insomnia, anergia, fatigue, weight loss and reduced interest in sex which may be also related to the cancer or its treatment effects
- feelings of hopelessness, guilt and worthlessness, and the presence of suicidal thoughts
- recurrent tearfulness, often accompanied by social withdrawal and loss of motivation
- inability to control negative feelings

There are also measures of unmet need that have been developed for cancer survivors. These have the advantage of defining areas that are of concern and warranting attention.

- Cancer Survivors' Unmet Needs measure (CaSUN)[6]
- Cancer Survivors' Partners Unmet needs measure (CaSPUN)[7]
- Survivors Unmet Needs Survey (SUNS)[8]

Recommended intervention strategies

Intervention strategies aim to promote adjustment and detect and treat distress across the range of emotional, psychological, physical and practical challenges. Prior to definitive treatment of any distress, contributing medical causes should be identified and eliminated if possible. Improved physical function usually leads to improved psychosocial adjustment for those with cancer, so addressing any issues that are impairing physical function may also prove helpful.[3]

All health professionals can use targeted therapeutic communication strategies to meet survivors' supportive care needs and promote adjustment through:[9,10, 11]

- development of a therapeutic relationship
- eliciting umet needs
- providing information
- expressing empathy and active listening

Promoting the development of self-management skills empowers and builds confidence in the cancer survivor which may reduce distress.[12]

Key guidelines recommend the following treatment approaches for specific disorders:[3]

Mood and Adjustment Disorders

- Psychotherapy (Cognitive-Behavioural Therapy, Supportive-expressive Psychotherapy, Family and Couples Therapy)
- Antidepressant medication with or without anxiolytics
- Referral to social work, counselling services and chaplaincy may be considered
- Individuals considered a danger to themselves or others should be urgently referred for psychiatric consultation

Anxiety Disorder

- Psychotherapy with or without an anxiolytic and/or antidepressant

Referral Indications

Many General Practitioners and specialist nurses have advanced skills to meet survivor's needs depending on the cause and intensity of distress. Referral is indicated for needs which cannot be met by the individuals' health care team. Referral opportunities are dependent on regional and site specific constraints, training of staff and availability of resources.[4]

In Australia, General Practitioners can refer an individual for subsidised treatment by a psychologist if they are eligible for a mental health care plan.

The following table outlines some of the issues cancer survivors may experience and the appropriate health professionals to refer to: [4]

Survivor concerns	Discipline to refer to:
Anxiety	Clinical psychologist / psychiatrist
Depression	Clinical psychologist / psychiatrist Social worker
Suicidal Ideation	Psychiatrist
Post Traumatic Stress Disorder	Clinical psychologist / psychiatrist
Body image concerns	Clinical psychologist / psychiatrist Social worker
Sexuality concerns	Clinical psychologist / psychiatrist Social worker Endocrinologist Gynaecologist / urologist
Interpersonal problems	Clinical psychologist / psychiatrist Social worker
Severe emotional problems	Clinical psychologist / psychiatrist
Physical symptoms	Clinical psychologist / psychiatrist Other specialists relevant to need
Fertility concerns	Clinical psychologist / psychiatrist Endocrinologist Fertility clinic / women's health nurse / family planning

The Psychosocial Care Referral Checklist[13] is an example of a comprehensive tool to identify factors contributing to the distress experienced by the individual and to document a referral plan.

Key Resources

Clinical practice guidelines for the psychosocial care of adults with cancer

Consumer resource: National Breast Cancer Centre. Cancer — how are you travelling?

Supportive Cancer Care Victoria, Scenario 2: Responding to emotional cues.

NCCN Clinical Practice Guidelines in Oncology. Distress Management Version 2.2013

ONS PEP – Putting Evidence into Practice: Anxiety

ONS PEP – Putting Evidence into Practice: Depression

National Cancer Institute Spirituality in Cancer Care

Journal of Clinical Oncology, Special Series on psychosocial care April 2012

Cancer Australia Frontline Psychosocial Support Tutorial – free of charge, registration required, video tutorial that focuses on anger, distress and depression management

IPOS Online Curriculum Communication and Interpersonal Skills in Cancer Care - US based on-line International Psycho-oncology Society (IPOS) presentation

IPOS Online Curriculum Psychosocial Assessment in Cancer Patients - US based on-line International Psycho-oncology Society (IPOS) presentation

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