

CLINICAL PSYCHO-ONCOLOGY: Indian Perspectives and Research

for

Cancer Specialists, General Practitioners, Nurses &
Mental Health Professionals

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Consultant Psychiatrist
Former Dean Behavioural Sciences &
Senior Professor of Psychiatry [Retired]
National Institute of Mental Health & Neurosciences
Bangalore India

Foreword

Luigi Grassi, M.D., MPhil

President Emeritus
International Psycho-Oncology Society (IPOS)

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Disclaimers: Medical sciences are not precise, and medical knowledge is constantly changing with addition of new findings and discoveries from research opinion differ. The views expressed in the book are those of the editor. Readers are advised to consult the latest information about treatments including pharmacological, psychosocial and alternative therapies and to be guided by their local guidelines. It is the responsibility of the practitioner to exercise judgement regarding treatments they provide to their patients. Neither the publisher, nor the editor is responsible or liable for any damage caused to an individual, organization or property from the publication.

The author and publisher of this book, Dr Santosh Kumar Chaturvedi, MD (Psychiatry) FRCPsych (UK), was previously a faculty at the National Institute of Mental Health & Neurosciences, NIMHANS, Bangalore as Dean, Behavioral Sciences, and Senior Professor and Head of Department of Psychiatry. He was also the Head of Department of Mental Health Education, and Head of Psychiatric Rehabilitation Services at NIMHANS, Bangalore.

The author has more than three decades of clinical and research experience and more than a hundred publications in the area of Psycho oncology and Palliative Care.

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Dedicated to

Peter Maguire

Director, Cancer Research Campaign,
Christie Hospital &
University Department of Psychiatry,
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United Kingdom

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Preface

Psycho oncology is now a well-established field of practice in cancer care and as an important part of consultation liaison psychiatry. The International Psycho Oncology Society has been active since 1986, and most cancer care centres have some services or other to address the emotional and psychological components of cancer care in the person, their families and caregivers, and the staff.

The practice and research on psycho oncology in India are not well known, though some research has been going on for years. Either readers are not aware of the publications or do not have access to such literature. I have been compiling a list of publications ever since I started my journey in this field. It is so encouraging to see almost a hundred or publications in the last five years, listed in Pubmed!

This Short handbook attempts to share the practice of psycho oncology from an Indian perspective. This also provides a good reading list and shares list of publications on this theme, year wise and also topic wise and according to the organ system affected.

Lastly, the author shares his contributions and publications, many of which are available freely or can be obtained from common journals and books.

This book thus provides a resource book on psycho oncology from Indian perspective and provides information about Indian researches and literature.

This is not a textbook, but should help clinicians and researchers looking after cancer patients and their families. The book is a short introductory book and not a comprehensive one, for which the readers should look for more voluminous and detailed books. This book is a pragmatic one and simplifies this complex field for clinicians and researchers. Doctors, nurses, psychologists, social workers and others involved in the cancer care would find this book useful, I hope.

Santosh K Chaturvedi

Editor

Foreword

The World Health Organization (WHO) estimates that by 2030 cancer incidence will increase by 40% in high-income countries and more than 80% in low-income countries. In 2018, there were about 18 million new cancer cases and almost 10 million cancer deaths, which will escalate to over 13 million deaths in 2030. As the WHO states “the cancer burden continues to grow globally, exerting tremendous physical, emotional and financial strain on individuals, families, communities and health systems. Many health systems in low- and middle-income countries are least prepared to manage this burden, and large numbers of cancer patients globally do not have access to timely quality diagnosis and treatment. In countries where health systems are strong, survival rates of many types of cancers are improving thanks to accessible early detection, quality treatment and survivorship care.” In fact, early diagnoses and improvement in cancer therapies have also determined an increase of survival that regards millions of people (long survivors) throughout the world.

The burden of cancer, however, can be only understood and dealt with if a specific biopsychosocial approach is taken. All the dimensions of the person, the physical, the emotional, the interpersonal and the spiritual, should be taken into consideration when treating cancer, also considering that it is a series of very different diseases with very different needs for the patients and certainly complex and multiprofessional and multidisciplinary treatments. The number of documents regarding this mandatory approach has increased worldwide. In the US National Institutes of Health document published as a conclusion of the study commissioned to the Institute of Medicine of the National Academies of Sciences indicating that attending to

psychosocial needs should be an integral part of quality cancer care and that it is not possible to deliver good quality cancer care without addressing patient's psychosocial health needs. Likewise, the document published in 2008 by the Council of the European Union (EU) acknowledged the significance of psychosocial aspects of cancer care and stated that to attain optimal results, a patient-centred comprehensive interdisciplinary approach and optimal psychosocial care should be implemented in routine cancer care, rehabilitation and post-treatment follow-up for all cancers.

Psycho-oncology is, therefore, today part of a comprehensive and multidisciplinary model that every cancer patient and his/her family should expect to be routinely provided in clinical practice. As the International Psycho-Oncology Society's Standard of Quality Cancer Care re-affirms, Psychosocial cancer care should be recognised as a universal human right; quality cancer care must integrate the psychosocial domain into routine care; and distress should be measured as the 6th Vital Sign after temperature, blood pressure, pulse, respiratory rate and pain.

Clinical Psycho-Oncology: Indian Perspectives and Research by Santosh K. Chaturvedi, one of the international leaders in Psycho-Oncology, is in line with this worldwide vision. The book drives the reader's attention to the most significant clinical issues in psychosocial oncology: the extremely important topic of communication skills and the need for health care professionals to improve their modalities to relate and empathize with cancer patients and their families; the problem of diagnosis of psychiatric disorders secondary or subsequent to cancer (e.g. anxiety, depression, delirium); the management of psychiatric emergencies and the treatment of the common psychosocial disorders in cancer; the special issues of psycho oncology in childhood and adolescence and psychiatry in palliative care; the area of the ethical and spiritual implications in cancer care as well as the problem of stress and burnout among cancer health care professionals.

The work done by the author, as a synthesis of a whole life dedicated to research and clinical care in psychiatry and oncology, will be of extreme help for cancer specialists, general practitioners, nurses and mental health professionals in general, filling a gap relative to the extreme need to have a cross-cultural and social view of cancer, as it is for this book which thoughtfully examines the field from an Indian perspective.

Dissemination and application in clinical practice of what the book examines, will help patients and their families to receive a compressive high-quality cancer care and to experience a better quality of life as they go through the journey of disease.

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Ferrara, February 2021

Prologue

There are a very large number of cancer patients in the country, and most have some psychosocial and emotional problems or the other, but there are not enough mental health professionals to care for mental health conditions, let alone providing care for persons with cancer or other medical diseases.

However, there a large number of cancer centres which have been established, which are overcrowded, as expected. Luckily, almost all advanced methods of treatments, medications and facilities are available in the country. Providing psychosocial support services is still a challenge.

Health professionals often remark that there are not enough researches on psycho oncology or publications from Indian background. For years, such publications and researches were limited to a few leading institutes only. A search for publications on psycho oncology from the country was quite an eye opener and many such publications could be extracted from the internet, mainly Pubmed. There are probably many more which did not reach the internet, let alone the Pubmed or Medline. It was surprising to note that there are more than a hundred publications in Pubmed in the last five years!

This resource is still not known or freely available to those interested in psycho oncology in our country. Hence, one objective of this book is to share the publications which were identified with the researchers and readers. As mentioned, this is not exhaustive, and there are many more which are missed out. Please bring them to the notice of this author/editor, to continually update the list. In this book, the list has been presented by year wise as well as subject wise. The reason to share this resource is to

help clinicians and researchers practice psycho oncology from an Indian perspective.

This book also provides experiences from an Indian perspective, keeping in view the unique sociocultural, economic and traditional society and their practices. The role of family in every aspect of care is also emphasised. This leads to numerous ethical dilemmas, which are difficult to deal with. India is considered a country high on spiritual index, though most other countries are spiritual in their own way. Spirituality becomes an important part of care of cancer patients and their families, and of course, their doctors, nurses and other healthcare professionals. This book is expected to inspire clinicians to practice psycho oncology from an Indian perspective and conduct indigenous research for the benefit of Indian clinicians and cancer patients and their families.

This book is dedicated to Peter Maguire, a psychiatrist who did most of his work in a cancer institute in Manchester, and was an expert in teaching communication skills and psychiatric oncology. I worked with him closely for more than a year and collaborated for almost two decades, till he passed away.

Santosh K Chaturvedi
Editor

Chapter 1 Introduction to Psycho Oncology

Cancer not only affects a body part or organ; it also invades the mind.

Psychiatric or clinical psycho-oncology in its broadest sense deals with the detection and management of psychiatric problems in patients who are screened for, diagnosed with, being treated, facing impending death due to cancer or are surviving cancer. Psychiatric oncology as a sub-specialty, focuses on a number of other issues, which include

- the role of life events, stress, and other psychological factors in the causation, maintenance, and prognosis of cancer;
- psychological and emotional reactions to diagnosis of cancer, its recurrence, metastasis;
- psychiatric disorders in relation to cancer and its treatment;
- psychological methods of treatment, and counseling,
- communicating with cancer patients and their relatives;
- terminal care and palliative care;
- study and management of grief and bereavement associated with cancer; and
- staff stress and burnout among professionals treating cancer patients.

In spite of significant psychological issues in cancer patients, the topic has not received clinical and modest research attention it deserves, at best. It has been demonstrated time and again that most health care professionals are not adequately trained for picking up psychiatric disorders in cancer patients, and hence miss out on even clinically significant causes of morbidity.

Psychosocial distress is commonly noted in persons suffering from cancer. A variety of psychiatric and psychosocial disorders are also observed in cancer patients, at different stages of their disease. The psychosocial disorders are related to the diagnosis of cancer, its physical effects, different treatments and interventions, as well as the outcome of the disease. The commonest psychiatric disorders observed in cancer patients are adjustment disorders, depression, anxiety, delirium and specific cancer related psychosocial disorders. Many times, the psychiatric disorders are mild and / or short lasting, but at times these disorders can seriously impair the functioning, compliance and quality of life of the cancer patients. Earlier, depression was considered as the only emotional response to cancer and a natural reaction to the disease. Most of the early literature on psychiatric morbidity of cancer was drawn from clinical experience or unstructured interviews with patients and was largely anecdotal. There are considerable methodological problems in assessing the psychiatric morbidity especially, depression and anxiety, among cancer patients. A patient with cancer is expected to have a certain level of psychological distress but when this distress becomes a clinical problem, it needs to be addressed.

A majority of the studies have revealed a significant level of psychiatric morbidity among cancer patients. In clinical practice and in epidemiological studies of cancer patients, psychiatric disorders have been noted in varying prevalence rates. About 50% of patients with advanced cancer meet criteria for a psychiatric disorder, the most common being adjustment disorders (11%–35%) and major depression (5%–26%). Generally, studies have found adjustment disorder as the commonest psychiatric syndrome in cancer patients with major depression, delirium and anxiety disorders as the next common diagnoses. Conditions like personality disorders, psychoses and substance abuse are comparatively less frequent.

Cancer and mental health

A majority of the studies have revealed a significant level of psychiatric morbidity among cancer patients. A study conducted on an outpatient cancer population reported 34% to have a clinically significant level of psychological distress, and another study of cancer patients admitted to three centers in U.S.A also revealed similar results. In the Indian setting, 38% of cancer patients were found to have identifiable clinical anxiety or depressive disorder. Earlier studies did not differentiate the psychiatric morbidities related to different types of cancer. Differential effects of other factors like, the impact of the diagnosis, stage of disease and the type of the treatment were also not given due attention in these studies. While in the early stage of the disease it is the impact of the diagnosis and the treatment which have most effects, in advanced disease the physical symptoms and impending death assume importance.

Cancer is considered to invade the mind as much as it does the body!

Response to the diagnosis of cancer:

A diagnosis of cancer is a life-changing event and brings in its wake a plethora of negative feelings such as shock, disbelief, confusion, anger, despair, hopelessness and guilt. The severity of a patient's distress after diagnosis of cancer is the most important predictor of later adjustment disorder. There might be significant guilt about any past wrongdoings and sexual or moral transgressions. In India, chronic disease is usually taken as an atonement for past sins (*Karma*). An adjustment disorder is the most common psychiatric diagnosis with reported prevalence from 12.5% to as high as 68%. As a reaction to the information about the diagnosis of cancer, majority of the patients have been found to have adjustment disorder mainly with depressed mood, anxious mood and mixed emotional disturbances. A diagnosis of adjustment disorder should be considered when an acute stress response persists in a stereotyped fashion and interferes significantly with functioning.

STRESS-CANCER LINK

A significant association between stressors and progression of cancer has been observed since long time. Studies have found increased stressful life events in the year before the diagnosis of breast cancer and malignant melanoma. In breast cancer, stressful events like bereavement, loss of a job were also associated with relapse.

Stress can lead to immunosuppression and increased substance use, which in turn can lead to cancer. It can lead to a decreased ability to repair damaged DNA, thus contributing to tumour formation. Neuroendocrine effects of stress might predispose to tumour progression. Stress hormones can suppress body's natural immune resistance to tumours. Tumour cells might also become more resistant to catabolic actions of cortisol, leading to shunting of more energy towards tumour cells. An association between elevation of glucocorticoids and more rapid tumour growth has been found in animal models. This field of psycho-neuro-immuno-endocrinology has made great progress in understanding the link between stress and development and progress of malignancy.

Depressive symptoms are associated with reduced white blood cells (WBC) as well as Natural Killer (NK) cell counts, and reduced NK cell cytotoxicity. However, inflammatory activation, produced by either cancer or with treatment also predisposes to depression. Raised interleukin IL-6 levels have been observed in cancer patients who have depression as compared to those who do not.

Depression leads to a higher 24-hour mean cortisol and a flattened circadian cortisol rhythm. Circadian rhythm of cortisol is also disrupted in breast and ovarian tumours, which is associated with earlier mortality among metastatic breast cancer patients. There is evidence that psychotherapy normalises cortisol levels. In two separate studies, experiential-existential group therapy and cognitive behaviour therapy (CBT) were found to lower cortisol levels in breast cancer patients.

Thus, the link between depression, stress and cancer is being understood better and soon, this knowledge might have clinical applications in the form of effective treatments for both cancer and depression that target the immune cascade.

Chapter 2 Distress in cancer

Cancer is bound to cause stress and distress; talking about distress may reduce the distress

‘Distress’ in cancer is considered as the ‘sixth vital sign’, like ‘pain’ is considered as the ‘fifth vital sign’. This implies that pain needs to be assessed in all medically ill persons, just like pulse, temperature, blood pressure and respiratory rate. Additionally, in persons with cancer and severe diseases, it is important to assess ‘distress’ as the sixth vital sign. The term “distress” was chosen by the International Psycho oncology Society, because it is more acceptable and less stigmatizing than “psychiatric,” “psychosocial,” or “emotional”. ‘Distress’ sounds “normal” and less embarrassing; further, it can be defined and measured by self-report. It can be translated and expressed in most Indian languages, as ‘*sankata*’.

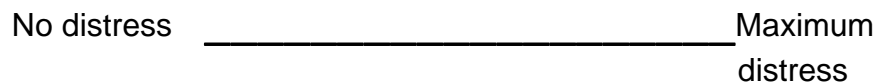
What is distress in cancer?

Distress is a multifactorial, unpleasant emotional experience of 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, which extends from a continuum from normal feelings of sadness, fear and vulnerability to disabling problems such as depression, anxiety, panic, social isolation and spiritual crisis.

Distress is in a continuum, from normal to severe, and can be marked on a visual analogue scale of a ten centimetres line. The ‘distress thermometer’ is used to assess psychological distress in cancer patients. One can ask, how much is the distress at present, if zero indicates no distress at all, and ten centimetres means maximum distress possible. In Indian situation, one could also enquire in terms of paisa or rupees – zero paisa or rupee means

no distress and one hundred paisa or rupees means maximum possible distress. One could similarly, ask in terms of percentages, zero percent to a hundred percent. Distress could also be categorised as mild (when it causes personal distress only, but does not affect sleep, appetite or social, occupational functions), moderate (disrupts sleep and appetite, but not social, occupational functions) and severe (disrupts sleep, appetite, social, and occupational functions).

Distress Continuum

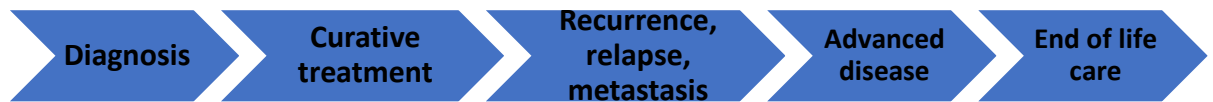


When can distress occur or what causes distress?

Distress can occur at any time during the course and progression of cancer. Periods of increased vulnerability for developing distress are many. It is not always at the time of diagnosis or during advanced stages or end of life. The distress can manifest right from the time the initial symptoms are detected to the end stages, like:

- Finding a suspicious symptom
- During workup
- Finding out the diagnosis
- Awaiting treatment
- Change in treatment modality
- End of treatment
- Discharge from hospital after treatment
- Stresses of survivorship
- Medical follow-up and surveillance
- Treatment failure
- Recurrence/progression

- Advanced cancer
- End of life



The distress in cancer patients can occur due to a number of factors. Many of these are manifest as concerns in the cancer patients.

Concerns in cancer can be related to:

- Physical symptoms – pain, fatigue, vomiting, cachexia, and distressing symptoms,
- Psychological symptoms – fear, sadness, depression, anxiety, demoralization
- Social concerns – for family and their future, social stigma
- Spiritual concerns – seeking religious, philosophical and spiritual beliefs
- Existential concerns – seeking meaning and purpose of life and disease, and suffering

Patients at increased risk for distress:

Cancer patients with the following characteristics are prone to develop distress to a greater extent than others:

- i. History of psychiatric disorder/drug abuse
- ii. History of depression/suicide attempt
- iii. Cognitive impairment
- iv. Communication barriers
- v. Severe comorbid medical illnesses
- vi. Social problems
- vii. Family/caregiver conflicts

- viii. Inadequate social support
- ix. Living alone
- x. Financial problems
- xi. Limited access to medical care
- xii. Young or dependent children
- xiii. Younger age; woman
- xiv. Other stressors

Prevalence of Distress in practice

Surveys have found that 20-40% of patients show a significant level of distress. However, less than 10% of patients are actually identified and referred for psychosocial help. The impact of unidentified distress can be varied. Failure to recognize and treat distress leads to several problems:

- Patients in distress may make extra visits to doctors and the hospital emergency department.
- Distressed patients have trouble making decisions about treatment and adhering to treatment;
- Distressed patients become dissatisfied with their physicians and medical care.
- Management of the extremely distressed patient adds to the time demands as well as the stress on the busy oncologist.

Systematic screening may prove to be essential for the early evaluation and effective management of psychological distress in cancer patients. Psychosocial interventions have been shown to be effective in reducing distress and improving overall quality of life among cancer patients. Commonly, distress is managed by family members by providing support and guidance. Many patients and their families seek help from religious places and figures to contain the distress.

It is common to seek help from traditional healers also. There are few health professionals who systematically identify and manage distress. Health resources are few for such service. In cancer hospitals and institutions, distress in cancer is low priority '*don't ask, don't tell policy*' is

what is routinely followed. Health professionals focus only on the physical aspects of the disease and its symptoms. They do not ask about distress due to the disease or any other related features, and there is no possibility of assessing or managing distress.

Management of distress

Distress should be detected, recognized, monitored, documented and treated promptly at all stages of the disease. All patients should be screened for distress at the initial visit. Screening should identify the level and nature of distress. Distress should be assessed and managed by evidence based and consensus based guidelines as provided by the International Psycho Oncology Society. The Goal should be that: No patient with distress should be unrecognized and untreated. The management of distress will vary from person to person, depending on the factors contributing to the distress.

Thus, also described as the 6th vital sign, distress in cancer can be multidimensional viz, physical, mental, emotional, spiritual and existential. Other causes of psychological distress among cancer patients include problems due to finances, family worries and spiritual and existential doubts. Unpleasant symptoms due to cancer therapy such as pain, nausea, fatigue are also an important cause of distress and reduced quality of life.

Chapter 3 Adjustment disorders

Coping with stress of living with cancer is not easy.

Adjustment disorder refers to someone who is distressed and 'not coping', having recently encountered a disease related stressor, like a malignant diagnosis, a treatment complication, a non-response to treatment, or the awareness of impending death. In some diagnostic systems, adjustment disorder is considered as the development of emotional or behavioural symptoms in response to an identifiable stressor(s) occurring within 3 months of the onset of the stressor(s). In the case of adjustment disorder "related to bereavement", 12 months of symptoms are required after the death of a close relative or friend, before the diagnosis may be employed.

i. Prevalence:

These are the commonest psychiatric syndromes seen in cancer patients. The majority of patients have adjustment disorder mainly with depressed mood, anxious mood and mixed emotional disturbances. Prevalence of adjustment disorder alone was 15.4% (10.1-21.6) in palliative care settings and 19.4% (14.5-24.8), in oncological and haematological settings in a recent meta-analysis.

ii. Diagnosis, risk factors and severity assessment of Adjustment disorders:

A diagnosis of adjustment disorder should be considered when an acute stress response persists in a stereotyped fashion and interferes significantly with functioning.

Adjustment disorder is classified according to subtype, which corresponds with the presenting symptoms.

The subtypes of Adjustment disorder include those with

- depressed mood,
- anxiety,
- mixed anxiety and depressed mood,
- bodily symptoms
- dissociation
- disturbance of conduct,
- mixed disturbance of emotions and conduct, and
- unspecified.

Risk factors identified for development of adjustment disorders are –

- low ego strength,
- passive or avoidant coping style,
- inadequate or inappropriate information,
- poor social support,
- communication problems,
- treatment related stressors,
- number of unresolved concerns, and
- level of partner's distress.

Lack of coping flexibility may also predispose a person to cope with the stress of the malignant disease.

ii. Management & prognosis:

Management of adjustment disorders can be done effectively with supportive methods and counseling. Behavioural and cognitive behavioural approaches are also worth trying. The pharmacological treatment is symptomatic. Low dose antidepressant medications or benzodiazepines for a short period of time may be useful.

Adjustment disorders are likely to recur with repeated stressful situations during the course and progression of the disease. Cancer patients with Adjustment disorders can respond to psychiatric treatment, but some patients go on to develop major depressive disorders. Those suffering from pain, which can be managed or controlled, significantly predicted a good treatment response, whereas a worse performance status predicted a poor treatment response.

Chapter 4 Depression and depressive disorders

Just because it is natural to feel sad, scared and depressed due to cancer, does not mean these feelings can be ignored.

Persons who develop cancer are expected to feel sad and depressed. This is a natural reaction to the diagnosis of cancer. However, it is important to distinguish between 'sadness' and depressive disorder.

Depression has a great impact on the cancer patient's psychological distress, quality of life, and increase in the subjective perception of pain, suicidal ideation and attempts, decreased adherence to treatment, prolonged length of hospital stay, increased family distress and worse prognosis.

i. Prevalence:

Around 20-50% of cancer patients have mental health problems requiring intervention, with at least 25% meeting the criteria for major depressive disorder or adjustment disorder of the depressive type, which is the commonest diagnosis. The prevalence of major depression has been reported to be 13-40% in various studies. The risk of major depression also increases with recurrence, terminal disease and chronic intractable pain. Depression is directly related to the severity of cancer symptoms and leads to reduced optimism about the efficacy of treatment. The risk of suicide is higher in the early stages of coping with cancer. Chronic and sustained depression after diagnosis of cancer, as opposed to reactive depression, is associated with faster progression of cancer and shorter survival.

Depression occurs throughout the course of their illness. Studies on depression in cancer patients have revealed that 4.5 to 58% of patients experience some form of depression, including major depression, dysthymia, and adjustment disorders with depressive mood and that 1 to 38 % as having major depression. Recent meta-analytical pooled prevalence of DSM-defined major depression was 16.5% in palliative-care settings, and 16.3% in oncological and haematological settings.

Although depression is common and treatable (but may be irreversible in the last 4 weeks of life, very few cancer patients receive beneficial psychosocial and psychiatric treatments. The recent systematic review provides evidence that antidepressants are effective in treating depression in palliative care settings as well. Their superiority over placebo is apparent within 4-5 weeks and increases with continued use.

Indian perspective

Available data regarding cancer and depression from India is primarily descriptive. Prevalence of depression was found to be 13% in a study of 60 in patients in an oncology unit in a general hospital. One-third of the patients were unaware of the diagnosis and 82 % perceived treatment as curative, this study suggested that being aware of the diagnosis significantly predicts psychological morbidity. Another study of 294 patients in a cancer hospital in southern India suggested 22% rate of depression amongst the patients and there was no difference of rates between aware and unaware patients. With regards to children, depression was significantly more prevalent in children with leukemia when compared to non-leukemic children with chronic illness. In a study of 54 terminally ill patients of palliative care unit of oncology department, 79.7% denied suicidal thoughts or any wish for early death whereas 9.2% had severe suicidal ideation. Presence of pain, awareness of diagnosis and understanding of illness contributed to depressive mood states. Suicidal ideation was associated with current depressive symptoms. Prevalence of depression in women undergoing post-operative adjuvant chemotherapy

and radiotherapy when compared to women undergoing post-operative adjuvant chemotherapy alone were both found to be 39%. 28.98% of patients diagnosed as hematological malignancies were found to have clinically diagnosable depression. Another study found 16.23% of cancer patients undergoing chemotherapy to have depression and female gender was associated with a significantly higher risk [25]. Preliminary validation study of the Malayalam version of the HADS involving 240 patients showed it as an acceptable, and reliable measure of psychological morbidity among cancer patients.

The barriers that interfere with appropriate treatment are; patient's reluctance to talk about psychological issues with medical staff, oncologist's thoughts that depression is understandable reaction to cancer, lack of oncologist's knowledge and skills about psychological assessment and management skills, lack of psychiatrist's knowledge about oncology, difficulties to distinguish from appropriate sadness to cancer and from depressive physical symptoms not attributable to cancer. Also, cultural, organizational and specific issues continue to represent a problem in the delivery of mental health interventions in medical settings.

ii. Diagnosis and severity assessment of depression:

If thinking of depression, consider asking cancer patients who may have depression two questions, specifically:

- During the last month, have you often been bothered by feeling down, depressed or hopeless?
- During the last month, have you often been bothered by having little interest or pleasure in doing things?

These are two core symptoms of major depression, namely depressed mood and a marked loss of interest or pleasure. To diagnose as major depression, one or both of the hallmark two core symptoms must be present for at least 2 weeks, along with at least four other symptoms (significant weight loss/gain or decrease/increase in appetite, insomnia or

hypersomnia, psychomotor agitation or slowing, fatigue or loss of energy, feelings of worthlessness or excessive guilt, diminished ability to think or concentrate, or indecisiveness, recurrent thoughts of death or suicidal ideation).

Difficulty in diagnosing depression comes from somatic and vegetative symptoms, such as fatigue, appetite disturbance or weight loss, sleep difficulties, and difficulties with memory and concentration, because these symptoms can be attributable to cancer and its treatment. More emphasis may need to be placed on psychological symptoms, such as feelings of worthlessness, excessive guilt, hopelessness, and helplessness. Persistent suicidal ideation is strongly associated with major depression.

Diagnosing depression in cancer

Three models were proposed to improvise the diagnosis of depression in cancer patients and to mitigate the effect of overlap of somatic symptoms due to cancer and treatment and those in DSM 4 TR criteria. This includes

- i. the 'inclusive model' which suggests that the somatic symptoms are counted regardless of the cause,
- ii. the 'substitutive model' which suggest that the non-somatic symptoms are substituted for somatic symptoms and
- iii. the 'exclusive model' which suggest that somatic symptoms may be disregarded as the diagnostic criteria.

Nevertheless, there is still no adequate data regarding the validity of these models. Brief Symptoms Inventory (BSI) and Hospital Anxiety and Depression Scale (HADS) are used widely for detecting psychological distress. These tools were specifically designed to detect depressive symptoms in medically ill patients. In many studies CES-D (Centre for Epidemiological Studies –Depression) or the BDI (Beck Depression Inventory) showing acceptable sensitivities and specificities in sample of cancer patients were employed. More over patients with depressive symptoms may not fulfil the DSM 4 TR criteria for depressive disorder, and may be the cause of high rate of reported adjustment disorder.

Non-Western, especially Japanese patients still had difficulty with Western bio psychiatric concepts of depression. Sadness, worry, and stress, not depression were more commonly used terms, thus mental health providers need more euphemisms: worry, maybe sadness, stress, anxiety. These patients are reluctant to discuss with psychological issues, especially emotional disclosure to their physicians. They would like not to view their condition as an individual issue. Focusing on community and contextual factors, such as family, work, financial, and housing issues, was seen as more acceptable. The physicians might avoid the term depression during these discussions.

Depression in cancer patients should be distinguished from demoralization. The depressed person has lost the ability to experience pleasure generally, whereas a demoralized person may enjoy the present moment, if distracted from demoralizing thoughts. The demoralized person feels inhibited in action by not knowing what to do, feeling helpless and incompetent; the depressed person has lost motivation and drive, and is unable to act even when an appropriate direction of action is known. Diagnosing severity of depression simultaneously would be useful for moderate and severe major depression responding well to antidepressant pharmacotherapy.

iii. Assessing Risk factors of depression in cancer patients:

Comprehensive assessment of risk factors of depression in cancer patients leads to better prevention and early treatment. Table below describes the common risk factors of depression in cancer patients.

Table - Common Risk factors of depression in cancer patients

- Physical: pain, low performance status
- Metabolic: Abnormal electrolytes, Vitamin B12, folate, parathyroid and thyroid hormone, ACTH, cortisol, cachexia, Paraneoplastic syndrome

- Brain tumor, vascular vulnerability, Parkinsonism, Lewy body disease
- Drugs: corticosteroids, interferon, interleukin-2, vincristine, vinblastine, procarbazine, paclitaxel
- Psychiatric: History of depression and suicide, substance abuse
- Others: recent life events, recent loss of spouse or significant other, younger age, living alone, poor social support, economic difficulties

There are multiple mechanisms that can cause depression in cancer patients. Reactive depression to the diagnosis of cancer can be understood from a psychosocial perspective in that it is caused by distress regarding the diagnosis of cancer and the resulting implications on an individual's life. However, recently other mechanisms have also been elucidated. A *sickness syndrome* has been described in individuals with chronic illness which has signs and symptoms of depression like anhedonia, fatigue, loss of appetite, sleep and libido, lethargy, cognitive symptoms, psychomotor slowing and weight loss. These symptoms may be understood as stemming from the pathophysiologic alterations caused by cancer, due to para-neoplastic syndromes or by chemo/radiotherapy. These symptoms are also present in depression making differentiation difficult. However, more often than not, major depression in addition, is also accompanied by guilt, depressive cognitions and suicidality. Sickness syndrome can be caused by pro-inflammatory cytokines that are released after tissue damage and destruction.

Numerous approaches have been used to diagnose depression in patients with cancer. The inclusive approach advocates that neurovegetative symptoms be counted while assessing for depression, whereas in the exclusive approach, these symptoms are not considered. Some suggest a compromise wherein an amalgamation of both approaches can be used depending on the purpose for which depression is being assessed. The inclusive symptoms could be used for clinical purposes as treatment would not differ because often even neurovegetative symptoms of any cause

respond favourably to antidepressants. The exclusive approach can be used for research purposes to obtain more specificity in assessment of depression. Regardless of the approach, the general consensus is that treatment of even subsyndromal depression improves quality of life and hence clinicians should keep a low threshold for diagnosis of depression.

Treatment used for cancer such as IL-2 or IFN- α and a variety of other chemotherapeutic agents can also cause depressive symptoms. The prevalence of depression is higher in cancer survivors who have received intense chemotherapeutic exposure in childhood. Oncologic surgery may also increase chances of having depression. In breast cancer patients, patients who had a mastectomy had greater prevalence of depression than those who had breast-conserving surgery. Though the obvious reason for this might be related to more disfigurement caused by mastectomy and resulting body-image concerns, the underlying reason could also be that more radical surgery might induce activation of pro-inflammatory cytokines which are known to play a causative role in depression.

Table : Cancer medications that can cause depression
IL-2 IFN- α Amphotericin-B Cycloserine Glucocorticoids L-asparaginase Leuprolide Procarbazine Tamoxifen Vincristine Vinblastine

FACTORS INFLUENCING DEPRESSION

Disease related factors :

Recurrence

Site of cancer – More in Pancreatic, oropharyngeal, breast carcinomas

Chronic pain

Severe disease

Disability

Metabolic factors : deranged electrolytes, paraneoplastic syndromes

Patient related factors

Depressive coping style

Less social support

Younger age

Living alone

Economic difficulties

Past psychiatric illness or h/o suicide attempt

Recent losses

Tendency towards pessimism

Iatrogenic causes

Chemotherapy

Disfiguring surgery : e.g Mastectomy > Breast conservation

Colostomies

Diagnostic criteria used

Inclusive >Exclusive

Depression interferes with adherence to medical treatment for cancer and ability to care for oneself and thus might have an effect on disease progression. Depressive symptoms are associated with an increased risk of dying. A depressive coping style has been found to predict decreased survival.

Depression by cancer type:

Cancer types highly associated with depression include oropharyngeal (22%–57%), pancreatic (33%–50%), breast (1.5%–46%) and lung (11%–44%).

A less high prevalence of depression is reported in patients with other cancers such as - colon (13%–25%), gynecological (12%–23%) and lymphoma (8%–19%).

Breast cancer is the most frequently studied one with a prevalence of depression of 1.5%-46%. Oropharyngeal and lung cancer were associated with high rates of alcohol and nicotine dependence.

Under-recognition of depression in cancer

The reasons for under recognition of depression in cancer are similar to those as for under identification of distress in cancer. Patients are reluctant to voice their emotional complaints for fear of seeming weak or ungrateful; it is also due to stigma of being diagnosed as having a mental health problem. Professionals are reluctant to inquire about feelings and asking about depression, reportedly due to lack of time, and lack of skill [one may say it is a lack of will].

It is also due to emotional self-protection and attributing physical symptoms to physical [medical] illness, thus not considering an emotional problem. Lastly, patients, families and health professionals assume that emotional and psychological distress is inevitable and untreatable.

Cancer in terminally ill patients & children:

Prevalence of depression has been reported in the range of 12% -26% in cancer patients with advanced disease. Depression and hopelessness each independently are significant predictors for desire for hastened death in terminally ill patients, social support and physical functioning added a significant but smaller contribution to the desire for hastened death. Pain and decreased performance status are more consistently related to depression than stage of the cancer. Children and adolescents with cancer were no more anxious or depressed than the control adolescent population. Only 16% reported that they knew they had cancer; 62% could define (or point to) the location of the tumor. The children who stated they had cancer had higher depression scores.

Depression due to Treatments of cancer :

There was no significant difference with respect to psychiatric morbidity, marital adjustment, fear of recurrence in patients underwent mastectomy and those who undergone conservative surgery followed by radiation, though the latter had better body image. Another study found that 15 % of the tamoxifen treated group had depression on the basis of clinical interview as compared to 3 % of those not taking tamoxifen in a study of 257 women with lymph node negative breast cancer. Whereas another study on women at high risk for developing breast cancer and those who were on tamoxifen showed a prevalence of depression of 16.9% as compared to those on placebo of 21.4%.

Cancer Pain and depression:

Pain in patients with cancer causes substantial depression and anxiety, which reduces these patients' capacities to cope with pain and other aspects of the illness. They found that depressed patients had more pain and metastasis than non-depressed patients. Causative role of pain for

depression is also supported by the fact that patients in high pain group had a significantly lower previous history of major depression, but the development of pain produced significantly more prevalence of depression in a sample otherwise less prone to experience major depression.

Depression and cancer progression:

A review found 6 major recent studies in which depression were found to predict cancer incidence, progression or mortality, 5 studies in which no association with depression and disease progression could be found and 3 other studies with ambiguous results. Stronger evidence links sustained depression after diagnosis to faster cancer progression or short survival. Current evidence does not strongly support a link between depression and cancer incidence though methodological differences may have obscured the results, taking into consideration the fact that many studies have only looked at cross sectional depression

Depression related to Recurrence of cancer:

Fear of recurrence is common in cancer patients and almost half the women had an episode of depression, anxiety, or both in the three months after diagnosis of recurrence compared with 36% in the three months after initial diagnosis.

Depression & Demoralization:

Demoralization factors identified commonly are lack of control over one's life, feelings that life was a burden rather than a gift, life has been worthless, life lacks meaning and purpose, feeling anger/bitterness about cancer diagnosis, without their health life is empty future holds no meaning. Demoralization as defined by these 7 symptoms was found to be distinct from depression. About 15 % of patients diagnosed as syndromal demoralization met criteria for MDD as per DSM 4 TR and about 29% diagnosed as syndromal MDD met criteria for demoralization.

iv. Management & Prognosis:

Clinical practice guidelines for the psychosocial care of cancer patients are available in some countries. The National Institute for Clinical Evidence (NICE) guidelines for the management of depression in adults with a chronic physical health problem in the UK propose that screening for depression should be undertaken in primary-care and general hospital settings for high-risk groups, which include those with significant physical illnesses.

When beginning treatment with cancer patients with depression and their families, information and support are provided, a time for appropriate decision and informed consent, support for families and carers, being respectful of, and sensitive to, diverse familial, cultural, ethnic and religious backgrounds, coordination of cancer care and choosing depression treatments.

After carefully assessing symptoms, risk factors, and functional impairment, moderate/severe major depression or mild/less major depression (minor depression, adjustment disorders with depressive mood, 'reactive depression') should be evaluated in the next. For mild/less major depression, in principle, low-intensive psycho-social interventions should be provided, such as a peer support group, supportive psychotherapy, problem-solving technique, and/or anxiolytics and hypnotics.

For moderate/severe major depression, intensive-psychosocial interventions should be provided, such as more formal cognitive-behavioral psychotherapy or pharmacotherapy. Before choosing antidepressants, consider administration route of antidepressants (e.g. bowel obstruction, stomatitis), adverse effect profiles (nausea, constipation, erectile dysfunction, urinary retention, etc.), estimated prognosis and time enough for responding to antidepressants (at least 4 weeks, physical status,

especially, liver and renal dysfunction, drug interactions, and patient's preferences for avoidable adverse effects. Selective serotonin reuptake inhibitors (SSRI) with safety and less adverse effect profiles, such as citalopram and sertraline, are the starting drugs. The newer agents, such as, mirtazapine, duloxetine, venlafaxine, are also considered especially for patients with cancer pain.

Although SSRIs and SNRIs have been shown to be effective in treating hot flushes in women with a history of breast cancer, paroxetine (an irreversible inhibitor of CYP2D6) use during tamoxifen treatment is recently reported to be associated with an increased risk of death from breast cancer. It should be cautious to use SSRIs and SNRIs, which can reduce or abolish the benefit of tamoxifen in women with breast cancer by inhibiting its bioactivation by CYP2D6.

The older agents, such as tricyclic antidepressants, are usually avoided except for patients with neuropathic cancer pain because of the drugs' anticholinergic and anti-alpha-adrenergic properties. Amitriptyline as well as mirtazapine are listed in the essential drugs for palliative care endorsed by the International Association of Hospice and Palliative Care (IAHPC). Vulnerable and elderly patients should be started at low doses with careful dose escalation and be monitored every 1-2 week for adverse effects and response. When facing death, antipsychotics rather than antidepressants should be considered for reducing and sedating some of the distressing symptoms caused by terminally ill depression.

Newer antidepressants have an excellent risk-benefit ratio and can be used for isolated symptoms in the absence of a depressive syndrome as well. Also, these isolated symptoms can be fore-runners for a full blown depressive episode, amount to significant morbidity and respond to antidepressant treatment. Therefore, their treatment can also prevent an episode and improve quality of life in cancer patients. Imipramine, Fluoxetine, Paroxetine, Amitriptyline, Mianserin, Mirtazapine and Desipramine have been found to be effective in treating depression in

various studies. Pain can be treated with tricyclics or SNRIs. Mirtazapine has been found to be useful for insomnia and nausea associated with chemotherapy. Fluoxetine, Paroxetine and Venlafaxine are also useful in decreasing hot flashes in patients with cancer.

Guidelines for use of antidepressants in cancer patients

- Start the treatment at low doses followed by a period of dose titration to achieve an optimum individualized response (low doses may help to avoid unwanted initial side effects, particularly in patients in poor physical conditions).
- Inform and reassure patients of latency period and possible side effects, in order to avoid premature drop-out, especially if patients are receiving other medications.
- Treat the patient for 4-6 months in order to avoid relapses or new episodes of depression after remission.
- Regularly monitor the patient's physical variables and concomitant use of medications for cancer (e.g., steroids, antiemetics, antibiotics, antiestrogen and chemotherapy agents).
- Discontinue medications by tapering the dose by 50% over a couple of weeks to reduce the risk of withdrawal symptoms that can be distressing and may be mistaken for symptoms of cancer illness or relapse into depression.
- Reassurance and education of the patients are extremely important in oncology settings.

Electroconvulsive therapy can be considered for cancer patients with severe, life threatening depression, those with a history of good response to ECT in the past, and for those who are unable to tolerate the side effects of antidepressants or are nonresponsive to antidepressants. Psychotropic

medications can also be safely and effectively used in palliative care of the terminally ill cancer patients.

Psychological treatments :

Supportive psychotherapy or cognitive behaviour therapy can be employed to facilitate ventilation, enhance coping skills and to correct cognitive errors and maladaptive schemas.

Recent evidence suggests the use of combined pharmacotherapy and psychological therapies for depressive disorders, with no clear benefit of one over the other.

Complementary and Alternative Medicine (CAM) Treatment:

Allopathic or Modern medicine clinicians commonly forget or neglect enquiring about usage of CAM therapies by patients. But it is well known that CAM treatment is commonly used by most of the patients. Data regarding treatment of depression in cancer using CAM modalities like Ayurveda, Chinese medicine and homeopathy is currently lacking and it needs further research before being advised to the patients.

Preventing and reducing depression through cancer treatments

This can be achieved by a number of strategies through the use of following methods:

- Helping the patient make a choice between radical and conservative surgery,
- the use of prosthetic techniques.
- care of colostomies
- reducing myths about RT
- reduce toxicity like, nausea, vomiting, alopecia.
- reduce financial burden and hospitalisation through social support
- through pain relief and symptom control

In conclusion, a more sensitive, collaborative and comprehensive approach to the diagnosis and treatment of depression, including clinical education, enhanced role of nurses, and integrating oncology and specialty care, is required in the clinical oncology setting

Chapter 5: Delirium

Momentary delirium states in cancer patients may easily be missed.

Delirium (sometimes called 'acute confusional state' or 'acute brain failure') is a common clinical syndrome characterized by disturbed consciousness, cognitive function or perception, which has an acute onset and fluctuating course. It usually develops over a few hours to days. However, it can be prevented and treated if dealt with urgently.

Delirium is a serious condition that is associated with poor health outcomes (pneumonia, longer hospital stays, death). It is a distressed experience for family and medical ward staff as well as for patients, caused by delusion, facing memory loss, and nearing death. Delirium also interferes with appropriate assessment of physical symptoms, such as pain, and communication with family and friends. Delirious patients sometimes are not competent to consent to medical treatment, and exhibit impulsive behaviors caused by disinhibition, resulting in suicidal behaviors.

i. Prevalence:

The prevalence of delirium in people in the general adult population is 0.7 % (95% CI 0.4–1.1) among those 55 years over, and that on medical wards in hospital is about 14% to 24%. Up to 51% of postsurgical people and up to 88% of people having terminally ill cancer develop delirium.

Although delirium is common and treatable (but many irreversible in the last 24-48 hours of life, very few cancer patients receive beneficial pharmacological and non-pharmacological treatments. One of the barriers that interfere with appropriate treatment may be associated with 'hypoactive subtype of delirium', characterized by people who become withdrawn, quiet and sleepy and who do not express discomfort and

distress. Patients with hypoactive delirium were definitely as distressed as those with hyperactive delirium. Hyperactive delirium showing restlessness, agitation and aggressiveness can be easily recognized. Moreover, it is often unrecognized in part because of its fluctuating nature, its overlap with dementia, lack of formal cognitive assessment, underappreciation of its clinical consequences, and failure to keep on thinking of delirium.

ii. Diagnosis, Signs & Symptoms, and Risk factors:

If delirium is suspected, it is essential to carry out a clinical assessment based on the clinical and diagnostic criteria. The Short Confusion Assessment Method (CAM) can be useful to for rapid assessment and diagnosis in a short time.

According to CAM the features of delirium are –

- acute onset and fluctuating course,
- inattention,
- disorganized thinking,
- altered level of consciousness.

The risk factors for delirium are presented in Table 1 and the common causes of delirium in cancer patients in Table 2. After diagnosing, carry out the assessment of risk and of cause for delirium.

Table 1. Common Risk factors for delirium

Age of 65 years or older
History of delirium, dementia, cognitive impairment
Low performance status, immobility, low level of activity
Visual or hearing impairment
Dehydration, malnutrition

Many psychoactive and non-psychoactive drugs
Alcohol abuse
Advanced illness and coexisting medical conditions

Table 2. Common Causes of delirium in cancer patients

Cancer disease-related

Brain tumor and metastasis,
Paraneoplastic syndrome,
Ectopic hormone-producing tumor (ACTH, ADH, insulin-like,
parathyroid hormone)

Cancer treatment

Chemotherapy,
Corticosteroids,
Brain irradiation

Cancer pain drugs

Opioid analgesics,
Antidepressants,
Psychostimulants

Other Drugs

Benzodiazepines,
Anti-cholinergic drugs,
Alcohol

Infection

Metabolic disturbance

Hypoxia,
hypercapnia,

Hypo- or hyper-glycemia,
Vitamins (B12, folate),
Electrolyte imbalance (Na, K, Ca),
Anemia,
dehydration,
poor nutritional status,
liver or renal dysfunction

Environmental

Admission to hospital,
Physical restraints,
Bladder catheter

Delirium is currently proposed for the diagnostic category termed Neurocognitive Disorders. This category contains diagnoses that were listed in current classifications as Delirium, Dementia, Amnestic, and Other Cognitive Disorders. New category is proposed to be divided into three broad syndromes: Delirium, Major Neurocognitive Disorder, and Mild Neurocognitive Disorder. The Neurocognitive Disorders Work Group discussed that visuospatial impairment and impairment in executive function are key symptoms of delirium; the group has also added a clarification that a preexisting neurocognitive disorder does not account for the cognitive changes. Nothing is mentioned in the current criteria about accompanying symptoms. Though not necessary or sufficient in themselves to make the diagnosis, they should be recognized as frequent symptoms of delirium. Evidence is questionable for a subcategory for chronic delirium or subsyndromal delirium in parallel with minor neurocognitive disorder.

iii. Prevention, Management & Prognosis:

Multi-component approaches to reduce risk factors for delirium should be ideally provided for all newly admitted elderly patients, which are proven to

prevent delirium resulting from orientation and therapeutic interventions for cognitive impairment, minimizing of the use of psychoactive drugs, and so on.

When delirium develops, identify and manage the possible underlying cause or combination of causes. Ensure effective communication and reorientation (for example, explaining where the person is, who they are, and what your role is) and provide reassurance for people diagnosed with delirium. Consider involving family, friends and carers to help with this. Provide a suitable and safe care environment. Family members feel more distressed about facing delirious patients, therefore, information, education, and reassurance about the nature of delirium and its meaning are critically important management as well. Information for patients with delirium and their family are offered which: explains that delirium is common and usually temporally, describe people's experience of delirium, encourages people at risk and their families to tell their healthcare team about any sudden changes of fluctuations in usual behavior, encourages the person who has had delirium to share their experience of delirium with the healthcare professional during recovery, and advises the person of any support groups. Ensure information meets cultural, cognitive and language needs.

In terminal delirium, over half of the bereaved families reported to experience high levels of emotional distress and felt some need for improvement of the specialized palliative care service. Control of agitation symptoms with careful consideration of ambivalent family wishes, providing information about the pathology of delirium, being present with the family, respecting the patient's subjective world, explaining the expected course with daily changes, and relieving family care burden can be useful care strategies.

If delirium is significantly distressing for the patients, or the person with delirium is considered a risk to themselves or others, consider pharmacological interventions; short-term antipsychotic medication and implement safety precautions and procedures. All four guidelines (USA,

Australian, Canadian, and UK) recommend low dose use of haloperidol (0.25-0.5mg). Start at the lowest clinically appropriate dose and titrate cautiously according to symptoms. Some of the guidelines recommend atypical antipsychotics like olanzapine, risperidone, and quetiapine. Open-label prospective studies revealed that aripiprazole, perospirone, mianserin, and trazodone might be effective for delirium, whereas melatonin was effective in a randomized placebo-controlled study. If there is difficulty distinguishing between the diagnoses of delirium, dementia or delirium superimposed on dementia, treat for delirium first.

The recommended management of delirium is quick and aggressive, giving the appropriate medication in the early stages of the disorder. Low dose benzodiazepines and antipsychotics are the drugs of choice. Intravenous route is preferred because it works faster and avoids the need for repeated intramuscular injections.

In conclusion, there is still a need to improve the understanding of pathophysiology of delirium and the efficacy of specific drug and/or non-drug therapy in delirium subtypes and subgroups based on the large, multicenter trials in this field.

Chapter 6: Somatization & abnormal illness behaviors

Cancer patients can have physical distress not always due to the disease but also psychological and emotional factors.

There is a common belief among health professionals that physical or somatic symptoms occur only in medical, physical or “organic” disorders, and that psychiatric disorders present mainly with emotional, psychological or cognitive symptoms. Similarly, when physical or somatic symptoms occur in a person with a diagnosed medical disease, these symptoms are suspected or believed to be due to the underlying medical disease, its complication or its treatment. Somatic symptoms and somatization in depressive disorders and anxiety disorders are common clinical and research observations. Thus, it is likely that the depressive, anxiety or other psychiatric disorders in cancer may manifest with physical or somatic symptoms. Psychological factors affecting medical conditions is a category in DSM 5, could be useful in documenting illness behaviours in cancer patients as the factors that influence the course of the malignancy as shown by a close temporal association between the psychological factors and the development or exacerbation of, or delayed recovery from, the malignancy, factors (e.g. poor adherence) interfere with the treatment of the malignancy, the factors constitute additional well-established health risks for the individual and factors influence the underlying pathophysiology to precipitate or exacerbate symptoms or to necessitate medical attention.

Somatic symptoms in cancer are frequent and contribute to illness behaviour. Somatic symptoms could be in the form of pain, fatigue, anorexia, weight loss, reduced energy, lethargy and tremor. They pose a

challenge in the diagnosis of depression in cancer patients as they overlap with symptoms of depression.

Somatic symptoms in cancer could be due to emotional disturbances which lower the pain threshold, or they could be due to the underlying pathology itself. It is difficult to determine the exact cause of somatic symptoms when they occur as it could be multifactorial, viz. due to physical, psychological causes, cancer chemotherapy, radiotherapy, a combination of these or idiopathic. Persistence of somatic complaints after recovery from cancer could also be a part of abnormal illness behaviour and trying to maintain the sick role. Somatic complaints that have a clear correlation with life events or stress are more likely to be psychogenic in origin, whereas those that are aggravated by disease progression or treatment are likely to have physical causation.

Chronic fatigue has been associated with a poor quality of life (QOL) in cancer patients. Somatic symptoms also associated with poor QOL, more morbidity and complicate treatment decisions. Aggravation of somatic symptoms that are psychological in origin can wrongly lead to more aggressive treatment of cancer and hence, a careful assessment is warranted.

i. Prevalence:

Residual or persistent fatigue in survivors of childhood cancer, survivors of Hodgkin's disease and cancer patients referred for psychiatric consultation have been noticed. In a prospective study of patients with Hodgkin's disease and non-Hodgkin's lymphoma nearly a fifth of patients, who were disease free and off treatment, continued to exhibit illness behaviour like complaints of feeling tired, poor concentration and irritability, probably due to psychological factors. Somatization is common in patients referred for psychiatric consultation with about 28% demonstrating prominent somatic presentation with multiple somatic symptoms. There is an association between somatization, depression, and cancer. Common somatic complaints observed in cancer

patients are pain, fatigue, sensory symptoms, anorexia, weight loss, tiredness, exhaustion, weakness, reduced energy, tremors, lethargy and mixed symptoms. A study reported high prevalence of psychological distress in cancer patients (37%) and among patients with psychological distress somatisation was more frequent followed by depression and anxiety.

An important issue related to somatic symptoms in cancer is the difficulty in deciding whether certain physical symptoms are due to cancer, treatment by cytotoxic drugs, radiotherapy, psychiatric disorder, or a combination of these, because somatic symptoms of depression overlap those of cancer. However, they present a challenge since the management of cancer pain and fatigue due to chemotherapy would be managed differently from pain and fatigue as somatoform symptoms.

The somatic symptoms in cancer are not life threatening, rather these fluctuate in course. They have important implications in the management and prognosis of cancer due to the associated disability and poor outcome with reduced quality of life. Somatic symptoms magnify disability resulting from cancer, interfere with treatment adherence and decisions, cause delay in recovery, result in poor outcome and recurrence, reduce overall well-being and quality of life.

ii. Diagnosis of Somatization:

Cancer related somatic symptoms have cognitive, psychological, and physiological causes each of which is amenable to treatment. The occurrence of somatoform disorders in cancer patients is likely to complicate the treatment and outcome of cancer. In advanced cancer, depression and somatic symptoms have been known to be due to endocrine and metabolic brain syndromes, cerebral metastasis, neurological infections, nutrition deficits, and anti-tumor therapies. Breathlessness, muscle pain, dizziness, and palpitation are common

symptoms of anxiety and panic attack which have been noted in cancer patients.

Somatization in disease free cancer patients is perhaps related to anxiety and depression. Cancer patients with somatization also have excessive somatic concern and preoccupation, but whether this is the cause or effect of suffering from persistent somatic symptoms is difficult to conclude. It could be the effect of persistent somatization since most subjects had no previous evidence of somatization. Depressive symptoms and depressive disorders were encountered commonly in these patients, and this association between depression and somatization is similar to that documented in psychiatric populations.

Assessment of somatic symptoms and differentiating their etiology needs careful evaluation of association with stress and psychological factors. When somatic symptoms arise or are aggravated after stress, psychological or emotional factors, they are likely to be psychological somatic symptoms. Those related to progression of disease or treatments are probably more physical. Some somatic symptoms may have both physical and psychological factors implicated. Lastly, there may be somatic symptoms which may not be clearly physical or psychological in origin and may be idiopathic.

iii. Diagnosis of Abnormal Illness Behaviour in Cancer patients:

The occurrence of unexplained somatic symptoms, persistent fatigue and tiredness in disease free cancer patients has raised doubts of the occurrence of abnormal illness behaviour in cancer patients. One study confirmed the association between psychological disorders and abnormal illness behaviour in cancer and pointed out a role for personality variables (external locus of control) and low social support in favoring maladaptive responses to cancer. In another study, different forms of abnormal illness behaviours such as denial, irritability, dysphoria, measured using the

Illness Behaviour Questionnaire, were noted in cancer patients in association with depression.

iv. Management & prognosis

The management of somatization would include a combination of psychosocial and pharmacological methods. Psychotherapy, counseling, reassurance and reattribution of the somatic symptoms can be useful. Low dose antidepressants, both tricyclics and SSRIs can also be effective, though one needs to be cautious of drug side effects which may be further misinterpreted as worsening of the disease or new somatic symptoms. Fatigue in terminally ill cancer patients is determined by both physical and psychological factors; hence it may be important to include psychological intervention in the multidimensional management of fatigue in addition to physical and nursing interventions.

Chapter 7 Other Psychiatric and related disorders

Good sleep is an indication of relaxed body and mind.

Other psychosocial disorders encountered in cancer patients are sleep disorders, psychosis, psycho sexual dysfunctions, and anticipatory nausea and vomiting, alcoholism and substance use disorders.

i. Sleep disorders:

Sleep disturbances are common in cancer patients, but there are few specific data on their prevalence. Sleep problems may be a symptom of cancer itself, part of the stress reaction to having cancer, as sequelae to some other cancer symptom such as pain, or a side effect of cancer treatment. Insomnia is the more common sleep problem, although hypersomnia also occurs. Most insomnias are related either to pain or to psychophysiological factors.

A few studies undertaken in this area have found that sleep disturbance as a symptom is common in cancer patients and the prevalence of sleep disturbances in patients with advanced pancreatic cancer was found to be as high as 54%. In our experience with cancer patients, we have also found that a significant number of patients had insomnia as a major problem, both in the presence and absence of other emotional problems. A few patients with insomnia reported that they were disturbed emotionally because of the sleep problems. It has been found, in a study that patients with lung cancer, rarely complained of sleep disturbance though most of them had a sleep architecture similar to that of insomniacs.

Management: Treatment of sleep disturbances should start with the identification of a specific cause of the problem and one should do a thorough medical and psychological evaluation of the patient; after that

behavioural interventions, medications, or psychotherapy may be helpful. When using medications, keep in mind possible complications such as daytime sedation, tolerance, and rebound insomnia.

Patients avoid to fall asleep, out of a fear that if they sleep off, they may not get up again! Others would like to pass away during sleep to avoid any distress and upset during the last minutes of life. The choices are very personal and subjective, hence these views cannot be generalised to everyone.

ii. Psychosis:

Schizophrenia and other functional psychoses are comparatively less frequent than the other above mentioned disorders but contrary to the earlier beliefs cancer is not rare in patients with schizophrenia as compared to the general population. Recently the impact of cancer in patients with severe mental illness has been the object of discussion among mental health professionals. The different organization in mental health care systems in different countries is making an attempt to understand if and how people with severe psychiatric disorders are in fact looked after in terms of screening of cancer, prevention and treatment. Problems can emerge in using drugs that could worsen psychotic symptoms. Vinca alkaloids can produce hallucinations. Opioid treatment also could create problems in psychiatrically ill patients who develop cancer.

It has been reported that severe mental illness is associated with behaviours that predispose an individual to an increased risk of some cancers, including lung and breast cancer, although lower rates of other cancers are reported in this population. Severe mental illness is also associated with disparities in screening for cancer and with higher case-fatality rates. This higher rate is partly due to the specific challenges of treating these patients, including medical co morbidity, drug interactions, lack of capacity, and difficulties in coping with the treatment regimen as a result of psychiatric symptoms. To ensure that patients with severe mental

illness receive effective treatment, inequalities in care need to be addressed by all health-care professionals involved, including those from mental health services and the surgical and oncology teams.

The management is the same as in schizophrenia with any medical disorder, with a caution of drug interactions between anti cancer treatment and anti psychotics.

iii. Psychosexual dysfunctions:

Conversations about sex, sexuality and sexual activity are avoided with cancer patients, though these are quite important for their overall quality of life. Patients are embarrassed to talk about sex, and spouses/partners are shy to talk about it and afraid that this might be misconstrued as being insensitive.

Sexual concerns can occur with cancer of any organ system involvement, but it is much more common in the involvement of reproductive organs or those involved in intimacy and sexual activity.

Psychosexual dysfunctions can occur in patients who have a malignancy of sexual organs or related body parts like testis, prostate, cervical cancers, uterus or ovary or breast. The dysfunction could be due to direct effect of the disease, hormonal derangements, chemotherapy, radiation treatment or hormonal treatment.

Sexuality and intimacy are altered following mastectomy. One study found that approximately 36% husbands reported that mastectomy had a 'bad' or 'somewhat bad' influence on their sexual relationships. Maguire et al.(36) found that one year after the wives' mastectomy 29% husbands reported moderate to severe sexual difficulties.

A review of sexual functioning morbidity estimates for major organ sites, indicates that a large number of cancer patients have problems in sexual functioning. The highest rates are in those patients where the

cancer is at a sexual or reproductive body site. The exact prevalence of psychosexual problems is not known among cancer patients, but it is thought to be much more prevalent than expected. Cancer survivors experience rates of sexual dysfunction ranging up to 90%; actual rates may be even higher than reported rates due to widespread reluctance of patients to discuss sexual problems with staff.

Sexual problems among cancer patients usually start acutely, after diagnosis, or treatment. In some cases, such as in prostate cancer or cervical cancers, sexual problems may be the earliest sign of disease. Problems in sexual excitement and arousal are common, orgasmic problems are also quite frequent while in some there may be pain during intercourse(. Sexual activity and satisfaction is affected by the malignancy, its effect on the health, changes in body image, foul smelling or blood stained discharges from the tumour site, chemotherapy, radiotherapy or surgery. Loss of libido could be due to the above factors, but it could at times be a manifestation of depression associated with cancer. General weakness and cachexia could also contribute to the sexual weakness, and disinclination. Fatigue after the treatment can be very severe and interfere with sexual activity.

Management : General Guidelines include treatment medical cause if any, treatment of depression, allaying anxieties and fears related to contagion, pain or , bleeding, and dispelling myths and misconceptions. It is useful to include partner in the treatment. Treatment of specific phase problems include decreasing anxiety and performance fears by discussion and clarification of doubts, non performance touching should be encouraged to increase intimacy without fears of having sexual contact. Sensate focus exercises which involve non genital touch and increase arousal and re-sexualizing the relationship is an important part of treatment. Many couples would have terminated sexual contact and resuming the sexual nature of the relationship plays an important role

The management would include sexual and marital counseling besides any medications for underlying medical or psychiatric causes of the dysfunction

or difficulty. Also, regarding this important area, cultural implications are important, given the role of social habits, religious and traditions in modulating the expression of sexuality and sexual disorders secondary to cancer.

Sexual preferences and orientation are also important to consider, and these may change due to the cancer or its treatment.

Vaginal lubricant or oestrogen cream can also be useful. Sexual alternatives to intercourse such as non penetrative sex or mutual masturbation may be encouraged whenever there are fears of pain

Partner support is an important part of treatment as partners are very often unaware of sexual issues. They may also feel left out and isolated during the course of treatment and feel distant from their spouse.

Use of Prosthesis and Dilators : Vaginal Synechiae and stenosis are common problems associated with radiation therapy among woman with uterine cancers which leads to sexual dysfunction and dyspareunia. At the Tata Memorial Hospital, Occupational therapy department, soft washable and reusable vaginal dilators have been used which significantly reduce problems related to sexual intercourse. Women found these self dilators very useful specially if used early. Penile prosthesis in prostatic cancers and cancer of the penis are increasingly being used and have been reported to be quite effective and useful. These are still not popular and not easily available in the Indian context.

A review noted effectiveness and feasibility of psychological interventions targeting sexual dysfunction following cancer but attrition rates were high, placebo response was notable, and there were often barriers impeding survivors from seeking out psychological interventions for sexual concerns. Despite the prevalence of sexual difficulties following cancer treatment, psychological interventions are a viable, but not often sought after option to help improve sexual functioning, intimacy, and quality of life for cancer survivors and their partners.

iv. Anticipatory Nausea & Vomiting [ANV, Conditioned response to chemotherapy]:

The conditioned side effects are thought to develop through a classical conditioning. These conditioned responses can occur before, during or after chemotherapy. The anticipatory nausea and vomiting are found to be associated with a higher anxiety level, post-chemotherapy nausea and vomiting are also reliable predictors of anticipatory side effect.

Patients report these feelings before and during travel to the hospital to receive their dose of chemotherapy.

The management of the anticipatory nausea and vomiting is gradual desensitization, counseling or low dose benzodiazepines.

Management: Behavioural techniques may be designed to :

- 1) Reduce autonomic arousal and thereby produce a physical state incompatible with the concomitant of nausea and vomiting.
- 2) Control the cues: Internal cues can be controlled by the autonomic arousal while external cues can be controlled by changing pairing chemotherapy with environmental stimuli.
- 3) Reduce post chemotherapy nausea or vomiting, thereby reducing a reliable predictor of anticipatory symptoms.
- 4) Change cognition or perception concerning chemotherapy, as well as teach self control and coping strategies.
- 5) Control anxiety – Low dose benzodiazepines can be used for the same over the short term.

Relaxation techniques like muscle relaxation, relaxing imagery and hypnosis may also be useful in the treatment of conditioned response to chemotherapy.

Nonpharmacologic approaches, which include behavioral interventions, may provide the greatest promise in relieving symptoms. Little evidence

supports the use of complementary and alternative methods, such as acupuncture and acupressure, in relieving ANV. Behavioral interventions, especially progressive muscle relaxation training and systematic desensitization, should be considered important methods for preventing and treating ANV.

v. Alcoholism and Substance Use Disorders:

Alcoholism may co exist in many cancer patients, as a risk factor for many malignancies especially involving the gastro intestinal system, head and neck and hepatic systems. Similarly, nicotine use, both smoke and smokeless is associated with pulmonary and head and neck cancers. Patients with dependence on alcohol, nicotine or other substances may need additional help to manage these drug dependencies.

Similarly, there can be evidence of cannabis and opiate abuse or dependence, which would need appropriate management. One has to be cautious not to under medicate for cancer pain in a patient who has a substance use disorder. Misconceptions that treatment of cancer pain with morphine would necessarily lead to addiction also need to be dispelled. It is important to differentiate addiction from 'pseudo addiction' in patients with cancer pain.

vi. Fear of cancer recurrence :

Most cancer survivors live in a constant dread about cancer recurrence. This anxiety may be intensified especially during the chemo/radiotherapy termination as the protective cover of chemo/radiotherapy is no longer available and the patient feels exposed to the risk of disease progression.

Any bodily symptom or distress or a sore may be misinterpreted as a sign of recurrence!

vii. Personality :

Galen observed that women with breast cancer frequently tended to be melancholic. Much has been discussed and written about the 'Cancer prone' personality. Type C personality traits characterised by suppression of emotions, high conformity and tendency to avoid emotional outbursts has been often associated with cancer. Certain personality traits have been found to predispose individuals to cancer, or, when present, are associated with faster progression. These are :

- 1) Difficulty in expressing emotions
- 2) Attitude of helplessness/hopelessness

In a study done on medical students, those who had a tendency of emotional expression/acting out were less likely to develop cancer later whereas a group characterised as "Loners" who had difficulties with emotional expression were 16 times more likely to develop cancer (46). However, there is inconclusive evidence to support these theories and positive findings in this area have not been consistently replicated.

Chapter 8: Psychiatric disorders related to disease & treatments

All cancer treatments affect the mind to some extent or more.

It is important to discuss the psychosocial and psychiatric problems, which may be directly related to the cancer or its treatment. These are not exclusive from the discussions in earlier chapters, and will have overlaps with topics mentioned in previous chapters.

(a) Effect of the cancer:

Psychiatric symptoms sometimes occur due to the direct effect of the disease process. Psychiatric symptoms are seen in almost all patients with supratentorial tumours and are the presenting symptoms in 25 percent of cases. A common presentation of carcinoma of pancreas is with depression. Physiologically active tumours of endocrine glands like thyroid, pituitary and parathyroid can also manifest as psychiatric syndromes. In the advanced stage, cancer can produce psychiatric symptoms by metastasis, and other modes as in paraneoplastic syndrome.

(b) Morbidity associated with treatment modalities:-

Differentiation of psychiatric morbidity related to the cancer as such or from treatment is rarely clear. The three forms of treatment available- surgery, chemotherapy and radiotherapy are associated with psychiatric morbidity. Psychiatric morbidity associated with cancer therapies range from 18 to 40%.

Due to Surgery:

Surgery often generates fear of the procedure and grief over the lost body parts. Mastectomy is the surgical treatment which has been studied extensively. Anxiety, depression and sexual problems were found in a 'substantial minority' of patients who had undergone this treatment. In the study conducted by Peter Maguire and colleagues women with breast cancer were followed up for one year after the surgery. The anxiety symptoms noted were persistent tension, inability to relax, palpitations and panic attacks. Roughly one third of the patients had sexual problems. They had either stopped intercourse or ceased to enjoy it. Husbands of mastectomy patients also reported sexuality and intimacy as the severely affected areas following the surgery.

Other problems reported in this area were disturbances in the body-image and a feeling of personal inadequacy. Studies have reported the persistence of concerns regarding disfigurement for several years after the surgery. Subsequent studies except one confirmed these findings. Though the initial reports blamed mastectomy as the sole cause of the psychiatric morbidity, later studies comparing the psychiatric morbidity of mastectomy patients with patients who had breast conservative surgery revealed that breast conservation did not categorically eliminate psychiatric problems. Anxiety levels, in fact, were found to be a little higher among patients who underwent conservative surgery in the recovery phase. Mastectomy group was different only in the negative body image and experienced more intense and persistent negative feelings about their bodies. Colostomy, laryngectomy and hysterectomy are the other surgical treatments studied in this respect. Colostomy patients have significantly more depression, sexual dysfunctions and other social problems than patients undergoing bowel resection without colostomy. Depression, anxiety and disturbances in familial and social relationships have been noted as main problems in laryngectomy patients. In a comparison of pre operative and post operative laryngeal and oral cancers in India, concerns about disease and treatment significantly reduced following laryngectomy, but the concerns about speech and

communication were reported by 76% of laryngectomees following surgery. These were then attended to by the speech therapist. Mastectomy, permanent colostomy, maxillofacial surgery and hysterectomy have also been studied well and reported to produce immense psychological impact on patients, like depressive illness, psychosexual problems and social problems (isolation, loneliness, decreased social visits), drinking, and occasionally suicide.

Due to Radiotherapy:

Radiation treatment [RT] is associated with highly unpleasant side effects. The side effects include nausea, vomiting and increasing fatigue. A prospective study of patients receiving radiotherapy had shown significant psychiatric problems in first three months. Different authors have tried to correlate the psychiatric problems to the common side effects of Radiotherapy. The unpleasant fatigue usually seen in radiotherapy patients had a high correlation with psychiatric morbidity. Radiotherapy has also been reported to cause nausea, a peculiar denervating kind of fatigue, poor psychosocial adjustment, unrealistic expectation about the outcome and non-engagement with the physician. In an prospective study on levels of anxiety and depression in patients receiving radiation treatment in a cancer hospital in India, anxiety and depressive disorders were detected frequently both prior to treatment and later during follow-up. Frequency of anxiety increased significantly after initiating RT, but later reduced during follow-up assessments after a few months.

Due to Chemotherapy:

In some of the neoplastic disorders like Wilm's tumour or Hodgkin's disease chemotherapy produces dramatic improvement. But, most often prolongation of life is achieved at the cost of quality of life [QOL]. Most of the studies in this area, which judge outcome solely on the basis of survival ignore QOL and psychiatric morbidity. This is reflected in the result of study which reported the quality of lives of patients receiving

multiple chemotherapeutic drugs as unsatisfactory (60). The psychiatric morbidity related to chemotherapy has been studied extensively in patients with breast cancer. Adjuvant chemotherapy in mastectomy patients was found to be associated with a significant increase in the incidence of depression, anxiety and sexual problems. This study found that chemotherapy in patients with breast cancer was associated with greater psychiatric morbidity than radiotherapy. However, in another study, the overall level of psychological distress did not significantly correlate with the physical side effects of treatment. In a study on two groups of patients with small cell carcinoma of lung receiving different chemo-therapeutic agents and found that patients receiving vinca alkaloids had a higher incidence of psychiatric problems. All chemotherapeutic agents can produce organic mental syndromes.

Chemotherapy can produce nausea and vomiting as immediate effects. Though various chemotherapeutic agents vary in this emetogenic potency, almost all have side effects. After an initial episode of nausea and vomiting 15 to 65% of patients develop anticipatory nausea and vomiting. Sometimes, it becomes so severe that they cannot continue treatment. Patients may also develop a conditioned response when exposed to sights and smells reminiscent of chemotherapy experience. Lung cancer patients receiving palliative chemotherapy were found to have fewer depression and communication problems than those receiving no treatment at all. In this case chemotherapy may promote a feeling of optimism. Chemotherapy is also known to cause fatigue, nausea and irritability along with adverse effects on the family and/or sexual life. Vinca alkaloids are especially known to cause depression.

Chapter 9 Psychiatric Emergencies

Psychiatric emergencies can arise in medical settings and require immediate attention and intervention.

Psychiatric emergencies warrant immediate attention in similar to other oncologic emergencies. Early diagnosis and treatment can result in effective management of these psychiatric emergencies. The most common psychiatric emergencies are delirium, depression, suicidal behaviors, and severe anxiety in cancer patients. There are, however, some difficulties to carry out the psychiatric and psychosocial assessment of the cancer patients without a history of psychiatric disorders encountered in the emergent setting. When the patients are agitated, confused, self-harmful and leave the hospital against medical advices, these disorders require as urgent and aggressive attention as do other distressing physical symptoms.

When emergent, carry out the assessment of risk and cause for agitated and suicidal behaviors (see Table below). Suicidal statements are commonly thought, and when asked, expressed by cancer patients, often resulting from their frustration or wish to share or end their distressed situation. However, it could be dangerous when they have actual plans with suicidal attempts, especially if juxtaposed with delirium, depression, or substance abuse. So, it is important to ask if they have a suicidal plan as well as psychiatric and psychosocial disorders.

Table . Psychiatric Emergencies - Assessment of agitated, confused, suicidal, or treatment refusal in cancer patients

1. Oncology emergencies (spinal cord compression, superior vena cava syndrome, hypocalcaemia, acute dyspnea, seizures, acute urinary and

bowel obstructions, massive hemorrhage, cardiac tamponade, and acute embolic phenomenon)

2. Excited, agitated, restlessness, anxious

- Major depression, adjustment disorders with anxious mood
- acute exacerbation of major psychosis, alcohol and substance abuser, dementia and other organic brain disorders, panic disorder, generalized anxiety disorder, personality disorders
- uncontrolled pain, anticipated painful images of medical procedures, surgery, or advanced illness
- akathisia due to dopamine-2 receptor antagonist; prochlorperazine, metoclopramide, haloperidol, chlorpromazine
- Steroid psychosis
- Grief reaction

3. Confused, somnolent

- Delirium
- Encephalitis, brain tumor, brain hemorrhage, hepatic encephalopathy, dementia with delirium, alcohol and substance withdrawal, epileptic seizure, and other organic brain disorders
- Drug intoxication

4. Suicidal

- Depression, adjustment disorders with anxious mood
- Delirium, drug intoxication

5. Refusal against medical advice

- Cognitive impairment, dementia, delirium
- Major depression, adjustment disorders with anxious mood

The emergencies need to be identified timely and require immediate intervention. Psychiatric emergencies are an indication for referral to a psychiatrist or other specialists.

Chapter 10: Psychiatric morbidity in Advanced Cancer and Palliative Care

Care is as important as cure.

As the disease progresses, there is more distress and emotional and psychological disturbance both in the patient and the caregiver. Advanced cancer is associated with increased psychiatric morbidity for mainly three reasons:

- 1) Physical symptoms like pain, nausea, vomiting, and weakness cause emotional distress.
- 2) Fear of death produces severe emotional distress.
- 3) Disease process or its spread and metastasis may directly produce psychiatric problems.

In active and advancing disease physical problems become more significant. Depression is associated with increasing levels of physical disability. Cancer pain which becomes severe in advanced stage has concomitant psychiatric morbidity. In the advanced stage of disease the patient is usually aware of the progressive and irreversible nature of cancer. Fear is a common reaction during this stage. Patients are preoccupied with fear of abandonment by doctors, fear of loss of composure, bodily function and dignity and above all fear of death. In addition, the disease process also produces psychiatric problems directly. Brain metastasis can cause clinical symptoms in 10 to 15 % of cases. Lung, breast, kidney and testis are the common primary sites. Non-metastatic neurological complications are also not uncommon. Cancer related medical problems like metabolic encephalopathy, infection,

electrolyte imbalances can also produce psychiatric problems like delirium and other organic mental syndromes.

Palliative and End-of-life care

In terminally ill patients, confronting the fear of death and death itself is a challenge. And guiding people through this process is a challenge in itself that psycho-oncologists face. It is not just about addressing physical, medical and mental health concerns, but going beyond that and addressing larger issues such as existential concerns, spiritual and religious issues at the end of life.

The word palliation has its roots in the latin word '*palliare*' which means 'to conceal'. This implies that though a dying patient cannot be cured, his suffering can be concealed. According to WHO, palliation is best done in an interdisciplinary team approach and should aim at pain relief, affirmation of dying as a normal process, offering support to patients and families to cope and enhancing quality of life. Answering questions about life and death, coping with grief and spiritual issues also acquire a whole new dimension towards the end-of-life.

Physicians are faced with a lot of ethical and moral dilemmas as patients make requests and even demands for assisted suicide or euthanasia. Psycho-oncologists, at the outset need to be aware of the fact that this could be a manifestation of untreated depression, which should be treated promptly in such cases. A syndrome of demoralization is distinct from depression and consists of a triad of loss of meaning, hopelessness and desire for death. The desire for hastened death (DHD) also arises because of loss of dignity, autonomy and a sense of powerlessness.

The entire topic is fraught with controversies between the medical fraternity and legal system as well as within the fraternity. Some countries have legalised euthanasia. However, regardless of one's moral or ethical stance or laws of the land, a desire for death should be explored from various vantage points, depression and demoralization should be assessed for and

ameliorative measures like pain relief, attempts to enhance quality of life should be instituted.

Pharmacotherapy :

Haloperidol has emerged as the most effective medication for managing delirium towards the end-of-life. Pain relief and management acquire a lot of importance in palliative care settings as the focus is on symptom relief. Depression and anxiety can be treated symptomatically by a rational use of antidepressants and anti-anxiety agents.

Psychotherapy :

Existential therapies help the patient try to make sense of and find meaning in their adverse experiences. Viktor Frankl's logotherapy is one such approach. Another kind of existential therapy is the use of life narrative. In this method, past coping skills and strengths are highlighted and the physical illness is understood as a part of the larger canvas of life. Life review is a similar method which uses various techniques like story-telling, constructing family tree, reminiscing to promote a dignified acceptance of death. Meaning centred therapy and dignity therapy has also been used in this group. Dignity therapy, a brief empirically based structured psychotherapy that addresses pride, maintaining dignity and continuity can also be used to address end-of-life concerns.

Chapter 11 Psychiatric aspects of paediatric malignancy

Cancer in children devastates their parents.

Paediatric malignancies often pose special problems. Children often exhibit behaviour problems in response to the illness and treatment. In clinical practice, psychological problems in children with cancer are mild, superficial and easy to understand. Initially, these emotional problems may be related to missing school, studies, friends and play time. It is parents who are totally shattered. Many parents react to the diagnosis with shock. Anxiety, grief, hostility, anger, guilt and disbelief are other responses which may be observed in parents. Despite the improvement in medical outlook, most parents display practically identical responses to the diagnosis of cancer, implying that for most parents a diagnosis of cancer in their child is still inextricably connected with death.

For parents, learning the diagnosis is the first serious confrontation with the potential death of their child. The initial parental reactions to the diagnosis have a striking resemblance with the emotional and behavioural effects of normal grief at or after the death of a loved one. The term 'anticipatory mourning' is introduced to refer to parental reactions of mourning and grief prior to the final loss. Viewed from the parental perspective, it is generally assumed that anticipatory mourning serves as an adaptive function in case the child dies because the parent relinquishes the attachment to the dying child over time. Parents who had difficulties in accepting the fatal prognosis and as a consequence failed to mourn in anticipation found no relief after the death of the child. From the child's perspective the parental anticipatory mourning can be destructive for the relationship between parents and child. This has been noted in those instances in which the child who was

realistically mourned for, lived on. When the child is clinically doing well, the immediate threat of loss becomes remote and parents move from a state of anticipatory mourning to an increased hope for cure. With continued remission, affirmation of life becomes stronger, and most parents whose child was in remission expressed few difficulties and returned to normal life. However, when the child relapses the threat of loss becomes real and the process of anticipatory mourning is relived. Parents find the first relapse worse than the initial diagnosis. Although parents continue to hope, their hope narrows with the progression of disease, finally converging in living on a day-to-day basis.

Chapter 12 General Principles of Management

A good assessment is therapeutic.

It is important to measure the severity of psychological symptoms before initiating the management of the psychological problems, like depression and anxiety and other related conditions.

Instruments used to assess for psychiatric comorbidity in cancer

1. Confusion Assessment Method - can be used for assessment of delirium in cancer patients
2. Beck Depression Inventory - Stresses more on mood and cognitive symptoms of depression
3. Montgomery-Asberg Depression Rating Scale - useful to assess depression in the context of medical illness
4. Hospital Anxiety and Depression Scale - is probably the most popular scale used for detection of anxiety and depression in persons with medical disorders like cancer, especially since the scale excludes somatic or physical symptoms of the depressive illness, which could be due to the medical disease or depression.
5. State-trait anxiety inventory - Useful as a screening instrument
6. General Health Questionnaire – Excludes somatic symptoms of the illness and also useful for screening
7. Edinburgh Depression Scale – has been validated to assess for depression in palliative care settings
8. The coping and concerns checklist – has been used to detect common physical and psychosocial problems in patients with cancer.

Medications:

Medications are the main method of management of psychiatric problems in cancer patients. Psychotropic medications are used with caution. It is very important to take into account potential drug-drug interactions while prescribing psychotropic medications. Prescribing psychotropics is complicated by a plethora of factors such as multiple medications these patients are on including anti-cancer, hypoglycaemic agents, analgesics and drugs for comorbid cardiac, hepatic or renal conditions. It is also prudent to keep in mind factors such as cancer cachexia, extremes of age, varied nutritional states, differences in drug metabolism, comorbid substance abuse, debilitation and malnutrition. A temporal correlation between the starting of a particular drug and the beginning of an adverse effect guards a clinician against a possible drug-drug interaction. Some strategies to lessen interactions include choosing a psychotropic with a profile that is least likely to interfere with concurrent medications, reducing the dose of the offending agent, therapeutic drug monitoring and monitoring for adverse effects.

Psychotherapy :

Having a life changing diagnosis is not something one is prepared for by life. Being diagnosed with cancer can lead to intense disease and death related dysphoria and anxiety, so much so that a person can feel punished, estranged and isolated. Faced with the ultimate existential concern of death, cancer patients are in the throes of a spiritual and existential crisis right from the time of diagnosis. However, most of the current oncology practice does not focus on helping a person find meaning of the experience, resolve existential concerns, enhance social support and process their emotions. Finding meaning in the experience, making the most of life that is left and relinquishing control over things that cannot be controlled are some positive coping strategies that can be employed.

Suppression of emotional expression and avoidance are found to hinder coping with cancer.

Psychological interventions with its emphasis on fostering a positive attitude, helping the patients to comply and cope with the treatment and reducing emotional distress, can in fact compliment the traditional medical treatment. Many of the patients who suffer from cancer related psychiatric problems do not receive any professional help because physicians rarely ask patients about their emotional well-being, and patients are reluctant to disclose their distress.

The types of psychological interventions used in cancer patients are many and diverse, like behaviour therapy, cognitive therapy and supportive therapy.

The aims of the psychological interventions are:

- 1) To reduce anxiety, depression and other emotional distresses.
- 2) To improve the mental adjustment to cancer by imparting a positive attitude.
- 3) To promote a sense of personal control over cancer and its treatment.
- 4) To improve patients communications with the spouse or other family members.
- 5) To encourage the open expression of emotions.

During psychological intervention for cancer related problems, it should be acknowledged that a cancer patient, after all, is a psychologically normal individual under severe stress. Hence, the therapy should be brief and directed towards current problems. There should be also be an active attempt to identify and make use of the personal strengths.

Supportive Therapy: Supportive therapy can be done in individual as well as group setting.

Individual supportive therapy: Here one to one setting helps to develop a relationship of trust so that patient can talk freely. Efforts should be made to reduce denial but maintain hope. Meaningful activities should be encouraged for as long as possible. Simply listening, understanding and sometimes just sitting quietly with the patient were also described as elements of therapy.

Group Supportive Therapy: Support groups are frequently employed in psychosocial intervention to provide emotional support. Groups of cancer patients, recovered cancer patients, those who have undergone surgery, chemotherapy or radiotherapy, spouses, or family members can be very effective in alleviating distress among participants. Obviously, groups are not the answer for every cancer patient, at the same time there is some evidence to suggest that support groups are associated with better psychosocial adjustment to cancer in some.

The two main functions of supportive therapy are emotional support and provision of information regarding the disease and its treatment. The stress of having cancer and the mode of its treatment create the need for emotional support. The patients also need clear, unambiguous information about the disease and its treatment which should be imparted sensitively.

Both group and individual psychotherapy have been found to have positive effects on depression and anxiety and have also been found in some studies to prolong survival. SEGT (Supportive-expressive group therapy) improved QOL in women with breast cancer, though it did not prolong survival over long-term follow-ups.

Counseling: During counseling the cancer patient, the therapist should be on a look out for 'cues' of emotional distress which are likely to be given out by the patient. The aim is to optimize patient to disclose his distress or facilitate emotional expression.

The counselling sessions may achieve three levels.

- First, in which the patient will give a lot of information about the physical condition, physical symptoms, family or other issues, but not anything about emotions.
- Second, in which the patient besides giving information about physical aspects may talk about emotional distress, but would not express or show the feelings.
- The third level, would have not only information about physical and psychological aspects, but it would also have the expression of emotional distress. The therapist should attempt to achieve this third level to be effective in his role.

In patients who have difficulty in expressing the emotions visual imagery or role play may be useful. Ventilation is an effective way of relief when the emotion is elicited. If the emotional expression is maladaptive, it should either be channelised to a positive action or the patient should be taught a safe way of expressing it.

Effectiveness of Psychological Intervention: Patients with early or treatable cancers are different from those with terminal disease and hence it is convenient to discuss the effectiveness of these two groups of patients separately. Regarding patients with early cancer, patients who received psychological treatment had a better outcome than the untreated control subjects. Both kinds of psychological treatment, the consultation therapy and cognitive skills training were found to be equally effective.

The assumption that all cancer patients need therapy and that any type of therapy is better than no therapy is unjustified. Some patients may actually do worse with such treatment than they would have without psychotherapeutic intervention. Three approaches that have been used in this regard.

- The first advocates providing treatment for every one.
- The second suggests waiting to see who gets into serious emotional difficulties before treatment is offered, where as the

- third attempts to identify those at high risk and implement preventive measures.

High risk patients can be identified by mood, vulnerability, concerns about self and others and problem is coping.

Role of confiding ties:

Having close confiding ties, with friends or relatives have been reported to be useful in the prognosis and outcome of psychosocial distress related to cancer.

Role of Cultural factors & Cultural implications

Sociocultural and traditional factors have an important role in the etiopathogenesis, manifestation, presentation and management of psychosocial disorders related to cancer. The implications of the cultural aspects are important in view of current globalization and immigration. It is crucial for health care providers to recognize the influence of cultural factors and be able to provide culturally sensitive care for their patients. The knowledge about a person's cultural background can improve psychosocial care. Hence, there is a need for cultural sensitivity and respect for cultural norms, preferences, taboos and traditions of the patient. Promoting cultural awareness and cultural competence among healthcare professionals should improve their confidence and skills in providing comprehensive care for cancer patients and families from different backgrounds. Cultural competence is effective when based on knowledge of a culture, on appreciation of cultural differences, on awareness of biases and prejudices, and on attitudes of humility, empathy, curiosity, respect, and sensitivity.

Principles of Psychological Management

There is a significant role of psychological management of psychosocial problems in cancer patients.

Some broad steps include

- Sensitive breaking of bad news
- Providing information in accord with person's wishes
- Permitting expression of emotion
- Clarification of concerns and problems
- Encouraging confiding tie
- Involve patient in decisions about treatment
- Setting realistic goals
- Appropriate package of medical, psychological, spiritual and social care
- Effective communication skills
- Handling difficult questions – how long will I live, will I get well
- Handling treatment refusal
- Dealing with depression, anxiety
- Dealing with anger
- Dealing with 'why me'
- Spirituality issues
- Blocking behaviours of professionals

Effective communication skills can help provide ways for the above situations. There are many ways of preventing and reducing psychosocial problems through cancer treatments. These include helping patients and families make the choice between radical and conservative surgery, the use of prosthetic techniques and care of colostomies, if any, reducing myths about radiotherapy and steps to reduce toxicity like, nausea, vomiting, alopecia and reduce financial burden and hospitalization through social support and providing pain relief and symptom control also can be helpful in preventing or reducing depression in cancer patients.

Chapter 13: Communication Skills

There is no perfect communication – every communication has its own impact.

It is like a drug; it can cause good effects, side effects, adverse effects and complications.

Communicating is a key part of cancer care services, whether it is with the patients, their caregivers, colleagues or administrators. Most studies have found the oncologists' ability to detect psychological distress far from satisfactory. This could be due to various reasons.

- First, the current medical undergraduate and postgraduate training in India does not focus on communication skills and does not equip one to probe into psychological issues when patients express concerns.
- Second, most of the patient's concerns are taken as a natural reaction to the diagnosis of cancer, which might not always be true.
- Thirdly, the oncologists themselves work in a very stressful, difficult and physically and emotionally taxing environment where too less doctors see too many patients. This makes it difficult for them to do an in-depth assessment when they encounter psychological issues.
- Fourthly, neurovegetative symptoms of depression are most often, present due to cancer, and hence missed.

Identification of psychiatric problems, therefore, is a very necessary prerequisite to their management. Nursing staff in oncology can therefore play a key role in identification of mental health problems, and can then refer patients for further management.

The first and foremost kind of communication skills that medical and paramedical professionals in the field should be armed with is Listening. There is a difference between hearing and listening; the latter should also be an active listening, and not a mere presence in front of the person you are communicating with. Most often, communication is considered to speaking or telling or talking to another person. In fact, active listening can be therapeutic and satisfying both to the speaker and the listener. Active listening involves maintaining a good warm empathetic eye contact, and a number of non verbal cues which indicate active listening, like leaning forward [rather than leaning back and being laid back in posture], nodding and gesturing that the person who is speaking is being understood. Paraphrasing, reflecting back and summarising, asking probing questions and encouraging the person to speak out are other techniques which indicate active listening with genuine interest.

In clinical practice, one of important skill needed is the skill of breaking bad news in a manner that is sensitive, conveys the appropriate information, and imparts a sense of hope in a realistic manner. Similarly, answering difficult questions, in an honest and sensitive way, need to be adequately learnt and practices.

Barriers to effective communication:

Some of the common reasons given by professionals regarding difficulty in communication are as follows:

- Lack of time in busy clinical practice
- Inadequate training during their undergraduate and postgraduate training
- Misconceptions like persons from rural areas or those uneducated may not understand
- Pressure from the caregivers and family members about what and how much to inform
- Focus on curative treatment, investigations and care, rather than communication

In practice and communication skills training programmes, it is observed that, effective communication does not take extraordinary excess time, in fact it saves time, as the communication issues which are not handled with keep recurring in future interactions.

Guidelines for breaking bad news

Breaking bad news or discussing diagnosis or prognosis is perhaps the most difficult task in cancer care and is an important part of psycho oncology practice and services.

The common steps in a clinical situation can be as follows. These can be varied and are flexible depending on the situation.

- Get all necessary information and prepare the place for the interaction. There should be privacy, and if the person wants a relative to be present.
- Check if the person wants to know
- Check what he/she already knows
- If the information is correct or partial, you can confirm or complete it. If the person does not know –
- Give a warning shot or a hint that something serious needs to be discussed
- Give a pause after the warning shot, to allow for any shock
- Tell about the diagnosis in simple words and terms, and wait for a moment for the person to understand it
- Provide realistic hope and plan for further care.
- Check what the person has understood and how he/she is feeling; also check if he/she wants to continue further interaction.
- Check immediate concerns and worries

- Provide necessary support
- Check feelings and encourage if the person has any questions.
There may be many questions, some difficult, which can be handled as discussed above
- End with summarizing and extending full support of the team.

These can also be summarised as in the following box.

Guidelines for breaking bad news
<ol style="list-style-type: none"> 1. Breaking bad news starts with asking questions and assessing the patient's and family's readiness to grasp the information that is being conveyed. 2. An appropriate setting and privacy needs to be ensured. 3. Next, one should find out how much the patient already knows and whether they want any or more information. 4. After making sure that the patient is ready, the session should progress in a way that patient and family have a sense of control over the quantity of new information that is being received. 5. A 'warning shot' or an indication needs to be given at this stage, that something serious has happened, after which information is provided in steps. 6. After informing the diagnosis, it is important to pause, and acknowledge that the news could have shocked or distressed the person. 7. Further concerns or queries are explored and discussed and ventilation is facilitated. 8. Session is summarised and availability for a further session is emphasised.

Collusion

Collusion in health care refers to withholding or not sharing important information on certain aspects of medical diagnosis/investigations with patients/relatives. Collusion may be two-sided. It may be manifested as family members not wanting the health care professional to share some information with the patient, or also they may themselves not share information with the health care team. It may be partial or complete. The 'recovery plot' that is often followed by patients and relatives involves focusing mainly on treatment and recovery, while ignoring issues such as risk of relapses and recurrences, long term prognosis, pain, disability and death. Physicians also unwittingly find themselves becoming a part of this, when it is referred to as 'medical activism. Collusion is also affected by gender and age of the patient and cultural factors. Most western cultures respect autonomy and independence as opposed to Indian culture which is paternalistic and frequent demands from relatives to protect the patient are common. Therefore, collusion manifests differently depending on the socio-cultural milieu.

Handling collusion:

1. Acknowledge that collusion exists
2. Identify the same
3. Explore and validate the reasons for collusion, most common one being wanting to protect the patient from distress.
4. Establish the potential emotional and psychological cost of collusion. Once detected, it can lead to mistrust, anger, distress and a sense of having been betrayed. Patient might find it difficult to trust family and treating team further as they may become unsure of what else is being hidden from them. It thus also hinders a healthy therapeutic alliance.
5. The next step is to establish a contract with the relatives that there is no intention of disclosing anything to the patient without the relatives' explicit consent.

6. Explore patient's awareness of the seriousness of his/her medical condition, which is usually underestimated by relatives. In fact, most of the times patients are well aware of their health condition.
7. Assess patient's and relatives' feelings periodically.
8. Pace of handling collusion should be acceptable and tolerable and health professionals should make themselves available whenever needed.
9. Assess for grief, distress and depression and handle them.

Treatment refusal or Non-adherence

Many times, patients may refuse treatment or become non-adherent to treatment. Non-adherence maybe prevented by giving periodic information to the patient in a clear manner and also by explaining the side effects and dosing. Following the information, it is important to check whether the patient has understood what you have told him. After this, you should check if he has any doubts about the treatment. Finally, offer to give him a note explaining the dose and timings of the medicines. These methods may often help in preventing non-adherence.

If it cannot be prevented, non-adherence should be detected early and appropriate steps need to be taken to prevent it from becoming a problem. In order to handle non-adherence, firstly, we should identify the factors leading to it. Is it due to the attitude towards the disease or is it related to depression; or due to fear of drug related side effects, or due to lack of information. These can be managed by providing adequate information and taking steps to reduce side effects. Family education and counseling has an important role to play in preventing non-adherence.

Quiet and Withdrawn patient

A withdrawn patient becomes a challenge as there is no verbal communication. It is important to acknowledge that the person is quiet and not talking. The professional has to be observant about the non-verbal signs of fear, depression or anxiety. A series of educative guesses need to be made and observe for any non-verbal response to these possibilities. These can be further pursued. An assurance of necessary help can be useful.

A common reason can be depression. If other features of depression are noted, like feelings of sadness or weeping spells, poor sleep, or indication of depressive behaviours, management of depression by counselling or medications need to be started. Withdrawal may also be due to fear or anger, which can also be appropriately dealt with.

Denial

In many situations, denial is a protective and good defense mechanism. It needs to be handled only when it interferes with treatment or clinical care. While denial may be adaptive by reducing distress, it may be maladaptive in cases where because of the lack of anxiety regarding their treatment, patients do not seek help. Patients use denial when the truth is too painful to bear. Hence, denial should not be challenged unless it is creating serious problems for the patient or relative. It is important to deal with denial gently so that fragile defences are not disrupted but firmly enough so that any awareness can be explored and developed. Maguire and Faulkner have suggested strategies such as-

- restating the course of problems,
- looking for inconsistencies between the patient's experiences and perceptions, or
- look for other cues, which may help him acknowledge that he has a serious illness.

These methods may help the patient shift from denial into relative or full awareness of the illness or prognosis. In individuals with good emotional resources, denial, if present is usually seen only transiently. It helps them 'buy time' for painful realization without getting overwhelmed. In less resistant individuals, extreme and persistent denial may be evident, to the degree of interfering with recognition of seriousness of symptoms or implications of condition. In itself, denial is neither good nor bad. The way in which it may assist or impede an individual's adjustment to terminal illness should be the central concern for the people involved in palliative care.

Angry patient or relative

Anger is a common emotion that health professionals face among patients and their relatives in palliative care. Anger is usually a response to helplessness, loss of control over one's life or related to fears of abandonment. It may also be a product of poor communication between health professionals and patients or relatives.

Anger of patients is often misdirected. For example, the patient may be angry at his relatives for not visiting him, but shout at the nurse for a trivial reason. Similarly, relatives may get angry when a patient is in pain or is dying. This might be related to their guilt or helplessness. The health professional has three goals when handling anger in a palliative care setting-

- Defusing the anger
- Finding the reason for anger by listening and acknowledging the reasons for anger
- Dealing with the cause of the anger.

When a patient or relative is angry, the first step is to defuse the anger, because challenging it will not help, in fact if anything, it can escalate the anger. It is important to acknowledge the anger by using statements such as- I can see that you are very upset. Would you like to talk about it? Let me sit with you in a quiet place and understand what make you feel this way. Just talking to a patient or relative in a calm manner, without admonishing

them about their anger and offering to listen to their concerns, helps in defusing anger.

The professional should determine if the anger is justifiable or unreasonable. If it is justifiable appropriate steps should be taken; however, if the anger is unreasonable, this should be communicated to the patient or the relative.

Many a times, anger may be a side effect of a medication, unrelieved pain and symptoms, reaction to a psychological situation, or a feature of anxiety or depression or grief reaction. In such situations, the underlying cause should be treated.

Communicating with children and others with special needs

Depending on their age, information and communication with children can be done using simple language and terms, use of pictures and toys to explain to them. The parents of children needing palliative care are more traumatised and emotionally affected than the children themselves.

Similarly, persons with intellectual disability need to be provided information using as simple terms as possible, and use of toys and play therapy.

Situations needing effective communication skills

Effective communication skills are needed for the following common situations in cancer care and oncology practice.

- Handling difficult questions – how long will I live, will I get well
- Handling treatment refusal
- Dealing with depression, anxiety
- Dealing with anger
- Dealing with ‘why me’
- Spirituality issues

- Blocking behaviours of professionals

The general strategy for dealing with these are as follows:

- Question asked
- Acknowledge/ Ask more/ clarify
- What does the person already know?
- Provide information
- Check understanding
- Check feelings
- Encourage next question

Chapter 14 Caregiver stress and burden

Caregiving can provide a meaning and purpose to one's life.

A diagnosis of cancer and its subsequent course is a significant stressful life event not only for the patient, but also close relatives of the person.

This causes caregiver stress and burden. One can identify stages in the caregiving process.

Initially, caregivers are quite enthusiastic and energetic to look after the person with cancer and give all their attention and compassion in the looking after process. They do not complain about this role and responsibility and do it to the best of their abilities. As these progresses, the stress starts building up and the role of caregiving becomes an effort. This leads to fatigue and being fed up with the process of caregiving. This ends with burnout, when the caregiver, does not care for the cancer patient, and does the service without any feelings, in a mechanical and impersonal method. The caregivers may also develop psychiatric disorders like adjustment disorders or depressive or anxiety disorders.

There is recent mounting evidence that highlights the importance of specific psychosocial interventions not only for the patients, but carers as well in order to cope with burden, end-of-life issues and anxiety. Religion, spiritual practices like having faith and trying to find meaning in the caregiving experience, religious and community support are factors that help in coping and positive psychological adjustment among caregivers. Cognitive behaviour group therapy and caregiver sleep intervention (CASI) are some specific forms of psychotherapeutic intervention that have been found useful in caregivers.

The caregivers should involve other relatives or friends or volunteers to share the caregiving and even explore some respite care for their patient. If

needed, professional help in the form of counseling or medications can be sought and will prove to be useful.

Caregiver support groups may prove to be very useful and supportive. Caregivers can learn from each other's experiences and give tips of managing their stressful situations. They can provide simple practical solutions which are missing from textbooks and journal articles.

It is important for caregivers to take care of their own health and well being, in order to take appropriate care of their cancer patient.

Chapter 15 Ethical aspects

There is no black or white in ethics, it's all shades of grey.

Modern palliative care movement in developing countries is just about a decade or so old. The World Health Organisation (WHO) considers palliative care as the active, compassionate care of patients at a time when the goals of cure and prolongation of life are no longer possible. According to a WHO document, palliative care comprises of

- relief from pain and other distressing symptoms;
- psychological and spiritual care of the patient with the aim of improving morale and emotional status despite poor physical prognosis;
- work with family, friend and caregivers to establish a support system to help patient to cope, to remain self-determining, and to live as joyfully and actively as possible until death;
- a support system to help family during the patient's illness and in bereavement.

Developing countries are economically impoverished, with low education and resources, but with well ingrained cultural, traditional and family values, with a religious or spiritual lifestyle. Practice of palliative care in such situations is bound to be rife with debatable ethical issues. Principles of ethics in health care in the developed world are based on the four principles of autonomy, beneficence, non-maleficence and justice, however, in a traditional and developing society the dilemmas in ethical practice of palliative care may be quite different and diverse. Since these four principles are well known among those interested in ethics, this essay has partly examined the ethical dilemmas in relation to these principles to examine if such an approach would be suitable to the developing and traditional societies. A practical and functional approach towards ethics has

been applied where ever possible. Discussions on ethics in palliative care often concentrate on issues like patient autonomy or euthanasia, however, the reality in the developing world seeks discussion on an entirely different set of problems. Adoption of the dominant ideology from the West in the developing world raises problems related to cultural incompatibility. Effective models of palliative care delivery that have been tested in developed countries seldom apply to the developing world where poverty, extended families, and insufficient health infrastructure require the adaptation of such care to local cultures and circumstances. It is said that, individuals who have experience in palliative care in wealthier countries with well-structured health systems see the palliative care needs of developing countries as forbiddingly huge. Considering that majority of the suffering in cancer patients in the world is in poorer countries, the ethical issues pertaining to palliative care in these countries, need to be addressed. With the rapidly changing world, there may be ethical dilemmas which are applicable to most countries irrespective of their development, and those which are unique to developing or low resource countries. There may also be certain issues which are unique to the Indian setting and some in common with the South East Asian countries.

Traditional palliative care in India has been practiced since ancient times, through home based spiritual and religious care of the dying according to traditional customs and rituals. Such a practice was considered as the ethical and moral practice. With the advent of modern medicine, palliative care is being reformed. A majority of newly diagnosed cancer patients in India (and other developing countries) have advanced disease. These patients are usually neglected or often receive futile, expensive anticancer treatments, whereas what they really need is maximum medical management in the form of palliative care and psychosocial support. The extent of problems relating to the lack of palliative care, and its implications, is not well described for cancer or non-malignant diseases. This article discusses the ethical issues related to palliative care in a traditional and developing society. There is hardly any robust evidence from randomized controlled studies from palliative care settings from

developing countries, though there are quite a few essays, commentaries and viewpoints on emerging themes in this area. The ethical issues discussed here relate to the themes identified in the WHO's definition of palliative care in terms of cancer pain and pain relief, home or hospice care, role of families in personal autonomy and confidentiality, and role of spiritual care, mainly in the Indian setting, though some literature from other south-east Asian countries and developing countries has also been reviewed.

Pain Relief and Symptom Control:

In developing countries, availability of oral morphine is often restricted for pain relief because of excessive regulations imposed to prevent their misuse and diversion¹¹. Thus on one hand, opioid availability is seriously limited; on the other hand, there are differing public opinions and attitudes about use of opiates. Many myths of pain and opiates are as prevalent, if not more, as in other countries. Hence, due to restrictions and legal hurdles in the opiate availability and dispensing, cancer pain patients end up suffering. Non-compliance of patients to take adequate medications and the resistance from relatives makes it difficult to achieve optimum symptom control. There is no literature to suggest that this is a caste issue, though availability is probably a bit easier or affordable for those in upper class of socio economic ladder and higher education. Lack of awareness among patients, doctors, nurses and paramedical personnel causes unrelieved pain in cancer and other terminal diseases.

Symptom control, the essence of palliative care is not without problems, especially in the difficult socio-economic conditions of a developing country. Indian society is known for its traditional use of raw opium in the form of *amal or doda*, due to its climate and difficult living conditions. The ethnographic information suggests that opium use is in many ways integrated into the socio-cultural fabric of the local community. Raw opium is used for recreation and within settings which facilitate social bonding. The traditional roles ascribed to the use of opium raises dilemmas in its

use as a regular medication for cancer pain relief. A recent study, however, confirmed that diversion of medical morphine towards recreational use is not really an issue. Many inexpensive analgesic drugs are not readily available and some very expensive drugs are often prescribed, adding to the patients' burden. Attempts have been made to increase morphine availability through the courts in India, which have issued directives to improve morphine availability, yet a majority of Indian cancer patients have poor access to the drug.

Primary concerns related to palliative care are cultural, socio-economic and educational in many other developing countries. Increasing poverty, patients and families receiving inadequate information about their diagnosis or prognosis, drug availability and costs, and insufficient knowledge by health care providers are obstacles to palliative care. Other barriers to development include the rural setting, limited professional workforce, competing demands, need for coordination across distinct organizations, and the need to address the dying process in a culturally proficient manner.

In terms of ethics, patients in low-resource countries, have a limited choice with regard to achieving pain relief, due to governmental reasons like its non availability and deficiency in healthcare delivery methods; societal reasons like attitudes of the family towards pain, addiction due to morphine, and myths; and attitudes of health professionals, arising out of lack of adequate knowledge and a negative perception about opiates. It is thus partly an issue of global inequality and partly socio-cultural issue. Prescription practices by many professionals are also influenced by the pharmaceutical industry; as inexpensive formulations like oral morphine are abandoned in favor of expensive ones, like buprenorphine, adding to the economic burden of the individual; a moral and ethical dilemma would be to suggest to the patient in pain or the relatives that they can easily obtain illicit crude opium, cannabis or other such street drugs in the neighbourhood, but wouldn't that be illegal !

Care: home or hospice.

A common moral and ethical dilemma is the wish of the patient to die at home or at a hospice; on one hand caring at home means 'giving up' by the doctors, on the other hand this implies preparing for peaceful death in a familiar environment. Preferences of patients, relatives or doctors may differ. However, failure to achieve preferred place of care or death is a universal issue, and not unique to developing countries. It is difficult to make a choice of either remaining in the hospice for optimal symptom control or returning home, where the medical care may not be available.

Though it is known that attention to palliative care needs could result in good treatment outcome and high level of patients' and doctors' satisfaction, most medical institutions and cancer centers in developing countries lack a specialist palliative care set-up. The lack of palliative care services is due to multiple factors – lack of specialized and trained professionals, inequitable fund allocation (more to curative and high tech treatments), besides lower allocations to health (and education) than to defence ! A system based on outpatient care has proven cost-effective, empowering families to care for patients at home. Wherever possible, inpatient facility and home visits are available for those who need them concurrent with growth of the palliative care movement.

The home based palliative care services deliver care to the patients who are unable to reach the hospital, enables patients to care for themselves and empowers the family to care for patients. In some cases, visits for home care were found to help change the attitude of families towards the patients - for example, allaying fear of contagion. In other instances, the visits changed the attitude of the neighbours towards the patient for the better.

A number of volunteers and community workers participate in the home care palliative services. This raises an ethical dilemma. A palliative care voluntary agency leader questions if one can overlook the specifics of the

dying patient's deepest needs and whether the interests of this sick person are best served by amorphous interventions extended by well-meaning people, perhaps even neighbours, or by trained professionals comprising doctors, nurses, and counselors?

Ideally, the patient should be allowed to make an independent, informed choice, to exercise his preference, on where, how and by whom, he / she would like to be cared, and where he/ she would like to meet the end of life. This is often influenced (interfered) by the relatives in the traditional joint family systems. Doctors in palliative care settings often face this ethical conflict of interests, and are persuaded by the family to decide on their behalf.

The volunteers do much of the needed nursing care such as wound care, cleaning out of maggots, doing bed sore prophylaxis, promoting and maintaining good hygiene, and nutrition, supervising the taking of prescribed medications, and supporting and the family members in their care. With respect to the question of how ethical is it to allow lay volunteers to perform medical and nursing tasks, Stjernsward argues that there is no way to compare 'quality' without objective numerators such as numbers covered or ratio of professional caregivers to caretakers. According to him, in developing countries, human resources have been mobilized for palliative care and broad capacity building for home care done, based on ethical principles and equity for all. He points out the negative attitudes by specialists who do not realize the importance of coverage and are unwilling to accept that it is not a question of either-or, but of two interdependent but complementary approaches - *everything for a few versus something for all needing it* - each with advantages and disadvantages. An approach that provides valuable support and care to the terminally ill for all in need of it in a community would ethically take priority over the presently favored approach of using a multidisciplinary team of palliative medicine experts to care for a lucky few. There is an ethical problem of injustice and equity here when we know the multidisciplinary team doing the palliative care never will achieve sufficient coverage.

However, the issues of autonomy need to be considered in the context of what is available and the barriers to accessing the palliative care services.

Role of Family:

There are two types of dilemmas faced by health professionals regarding communication due to cultural constraints - how to break bad news and whom to inform - patient or the relatives. The issue of informing versus not informing becomes a challenge at times, due to the unique doctor patient relationship, with both the doctor and patient expecting a paternalistic approach. Besides, it is often difficult to decide how much to tell. The few supporters of the "do not tell" policy believe that hope is lost once the truth is out, the "will to live" wanes, and the patient is depressed. However, when such patients come to know the truth, they may lose trust and, it is common to see them manifest feelings of fear, depression, and anger. In due course of time, it would emerge if the cultural constraints in an Indian society continue to prevent truth disclosures to patients.

In a traditional and developing society, the family plays a significant role in each stage of diagnosis and management. In the Indian family scenario, a responsible family member (patriarch) is the decision maker, who would discuss most treatment related matters, and invariably, there is collusion with the treating team. This paternalistic approach pervades throughout the medical practice is not confined to end of life care. This practice comes in the way of an individual's autonomy, and deprives him of the benefits of health services and care. On the positive side, it defends the person from any potential maleficence, and minimizes concerns about the future for the patient. Relatives want to protect their loved ones. It is common to see that most women with cervical cancer hide their diagnosis from their husbands and family members.

Moreover, there is hardly any place for privacy and confidentiality. Cancer affects the family, and is not the individual's problem alone. Hence, information is shared with relatives, irrespective of whether the person

involved desires this or not. Cancer is considered by many families to be due to *past sins or karma*. There is great amount of stigmatization associated with cancer, with consequent isolation and even social discard of the family making the issue of confidentiality even more important. Ideally, personal consent needs to be voluntary, informed and by a competent person. At times, terminally ill patients may not be totally competent due to physical factors and depression, and may give consent without fully understanding the situation. The patient's wishes must be respected and consent sought with care and sensitivity, but this should include the family, whenever possible or feasible. To illustrate this with an example, palliative home care volunteers have mentioned how they are constantly asked by a number of their patients to park their vehicle at a distance, away from the curious eyes of neighbors. It is a request the volunteers abide by, as they are aware that not only is it a matter of preserving confidentiality but that in a traditional society cancer carries a stigma that can impact negatively on the patient and on the family. This may be one reason why people tend to hide the diagnosis even from those closest to them. The role of family poses a challenge to the use of the four principles of ethics approach. As the traditional patriarchal system is still predominant in most facets of life, it is unrealistic to have a different and competing system of decision-making in healthcare?

It is a difficult ethical and moral dilemma when patients reach health services with advanced disease and in all probability would have to undergo expensive investigations and treatment. Many relatives of the patient and even health professionals are unable to decide how to make appropriate use of their limited funds - for children's education or marriage or for the patient's palliative care! There are no easy answers, as justice to one would be injustice to someone else. The individual and the family usually feel forced to take into account the good of the family, their community, society, and at times even the country. A palliative care doctor in Malaysia wondered whether it was right to operate on these patients when there was no continuity of care - so much effort and expense resulted

in such short-term benefits followed by frustration and suffering for patients and families when the disease recurred.

Euthanasia, like elsewhere in the world, poses a big question in developing countries. Due to poor pain relief, the patient at times requests euthanasia. This desire disappears with adequate analgesia, even raising hopes of a cure!. The support to euthanasia is little due to religious, spiritual and traditional factors, and the fact that such thoughts and acts are considered sinful, and illegal. The practice of palliative care is an alternative for those who are fed up with suffering. Irrespective of the decisions to prolong life or stopping life supports, patients' wishes need to be respected and the person must be allowed to die with dignity and in peace. However, this does not always happen and the elders in the family make the decision or persuade the doctor to decide 'whatever is best'!

Ethics and Spiritual Care :

Spiritual care is an essential component of palliative care. It is especially important in the developing world where medical and comfort resources are limited. It is known that patients, at their end of life, are vulnerable to suggestions and counselors need to desist from imposing their own beliefs. In most instances a sympathetic hearing to spiritual concerns is needed, helping individuals to come to their own conclusions.

Most hospices in India provide nursing care through Christian missionaries, who do a tremendous selfless service, but this creates a conflict with the predominant religious groups of Hindus and Muslims. Though such services by Christian voluntary agencies are provided in many developed countries as well, which are predominantly Christian, they may not encounter the conflicts with patients from other religions. A Christian nurse helping a palliative care center in south India was denied a reentry into the country, fearing religious conversions, under the guise of palliative care! The socio-political atmosphere determines some actions irrespective of the ethical *locus standi*. Closely linked to the ecumenical spirituality is the complex issue of multiple religions in a secular society. This gains significance given

the importance of religion in death and pre death and post death ceremonies. Among Hindus, certain customs and rituals for a dying person include putting the person on the ground (and not the bed), pouring holy water (of Ganges or any other holy river), in the persons mouth, besides chanting hymns. The risk of aspiration and interference with ventilatory efforts are overlooked at such a time. In our clinical experience, we have come across patients seeking religious conversions during their last days of life, creating conflict within the family and community. On the other hand, religious groups have successfully participated in community palliative care programmes. Is religious ethics equivalent to medical ethics, one may debate?

India has many systems of alternate and unorthodox medicine, with some link with spirituality. Hospice professionals recommend that these are best tried outside the hospice unless they are in fully-studied clinical trials. The availability of numerous systems of alternative medicine and a hope for cure even at a late stage of the disease means that many patients depend on these as their main form of treatment. Complementary and alternative medicines play a key role in palliative care and improve the quality of life, to some extent, due to some overlap or admixture with spirituality. Very little scientific research on these complementary or alternative methods casts doubts on their effectiveness. These methods with unproven results however attract the gullible patients with advanced diseases. To encourage research in these systems of medicines a substantial sum of federal funding is diverted, with the hope that such research may settle the matter to a certain extent, whether these systems need to be propagated.

The ethical issues in the use of these systems, which lack stringent modern evidence base, are tricky. Public faith in these relatively inexpensive systems is tremendous, and the inadequacy of the expensive modern medical systems only strengthens the resolve of the affected patients and their families to use these unproven systems. Rampant advertising by these systems, with unrealistic claims of cure, are undoubtedly an unethical practice.

Ethics committees in palliative care settings

Is there a need for palliative care centers to have their own ethics committees, to resolve some of the above discussed conflicts? Such committees could help the centers in decision making by the individual, family and even the health professionals. Often there are no absolutely right or wrong answers to such dilemmas, and one may need to have a casuistry approach. An adequate knowledge of relevant laws and legal guidelines can be helpful in having a framework of ethical decision making. The functions of such a committee may include education of patients, caregivers and staff on relevant ethical principles and resources, establishment of ethical guidelines, resolution of disagreements between staff and relatives, and any other ethical issues. Such a committee should be an advisory group to provide ethical solace to palliative care professionals who may have to encounter difficult and disturbing decisions. This committee may help the professional team to take decisions about terminally ill persons who are unable to express their wishes, or may be legally not competent. Or help decision making when the family's and patient's wishes are contradictory. For example, not every patient will read or understand written explanations of the informed consent and it is essential that this be followed up verbal explanation and any questions answered. It is perhaps, unethical to introduce any kind of new service in palliative care without carrying out research to find out if it does good or harm. Even so, this is a sensitive area in which there is danger that researchers may cause distress and may even do harm. It should also be noted that individuals at the end of life and their families are vulnerable. Strong emotions can impair their judgment, their confidence and their ability to concentrate and appraise risks. Some are so desperate for help that they will accept any person who approaches them in a friendly way; others are deeply hurt and unduly suspicious, since services are so scarce in a developing country. The subjects need to be protected from unscrupulous or potentially harmful intervention. This can be achieved by a properly constituted ethics committee attached to a reputable organization,

which can reduce these risks and constitute a source of reassurance to clients.

There is a justification to research and examine the scope, role and benefits of having such ethics committees. Till such time one probably needs to be cautious of the role of such ethics committees.

Ethics of palliative care training & trainers

Palliative care education and training has made a beginning in almost all countries across the world. In low resource countries the palliative care training raises some debatable ethical points. There needs to be a distinction between training of specialists and non-specialists in palliative medicine. It may be questioned whether it is good enough for the non-specialists to train other non-specialists in pain management, care of fungating wounds and fistulae, or the delirious patient with existential distress. What is the solution for shortage of experts and trainers or educators? In most developing countries, palliative care is still not recognized as a distinct specialty. In Singapore, the recent recognition of palliative medicine as a subspecialty of internal medicine, geriatric medicine and medical oncology is a setback to the development of the field. Continuing medical education offered only by the pharmaceutical industry instils bias into the minds of most medical professionals. Specific demonstrations, like the ones discussed above, can help build education programs that take account of local realities, and promote attitudes, knowledge and skills capable of gradually introducing a greater professional concern and a better prospect of effective care for the dying.

It can be surmised that palliative care services in developing countries are faced with numerous ethical dilemmas. This chapter draws attention to the challenges of using the four principles of ethics to the practice of palliative care in developing countries and traditional societies. The chapter also notes that certain ethical issues are similar to rest of the world, like the attitudes towards palliative care, use of religion based nursing, and some

which are particular to a developing country, like poverty, large number of patients, poor funding, inadequate health resources and infrastructure, few palliative care services and professionals, lack of palliative care education and training, lack of palliative care research and some which are specific to a traditional society, like the joint or extended family system, religious, societal, spiritual and issues related to unorthodox medical systems. The palliative care services need to be a mix of community services, home care, hospital based, and hospices, with a judicious use of available resources. A culturally sensitive, primary care program with help of volunteers, local physician and home health nurse should be developed and tried. In most of the Islamic world also, palliative care is in its infancy, and has similar ethical challenges as discussed here, mainly, undermedication of pain symptoms, which should be minimized in an ethical way. A recent report suggested that the synergistic effect of motivation and knowledge, coupled with the use of local resources, has made possible the development of a network of palliative care services, available for free to terminally ill patients. This approach of dialogical ethics in palliative care in developing countries, involving justice and fairness, may present a promising and relatively novel approach of case-based ethics. The provision of palliative care services in developing countries need to be based on determining goods within the traditional framework, through procedures enacted by all those involved. These could be dialogical in that the procedure is that of dialogue, involving both empathic critical discussion and negotiation, and overriding other ethical considerations, within the ethical dialogue. The approach of dialogical bioethics has proven fruitful for resolving bioethical problems such as that of medical futility, where approaches of substantive ethics have reached an impasse. The resolution of the ethical dilemmas need to be sought within the cultural and traditional framework of the society by blending cultural practices with contemporary palliative care medicine.

Chapter 16 Grief in oncology

A grief reaction to the diagnosis of cancer is common and understandable as the person copes with the loss of the previously healthy self, of a particular body part (breast, hair) and resulting disfigurement, of one's role in the society and family, work functioning or impending loss of life. The loss is missed causing an emotional pain and pining for the loss.

The sadness and depression of grief needs to be differentiated from the depressive disorder unrelated to the loss. In grief, there is a preoccupation with the loved object lost, where as in depression, depressive thoughts and cognitions are unrelated to the loss.

Grief is the feeling resulting from the loss of a loved object or person, associated behaviours such as crying, anguish and searching. It is a process not a state characterized by changing affect over time. Grief is also considered as a reaction to the loss and accepting the reality of the loss and restoration of one's feelings, identity and self in the absence of the lost object.

Bereavement refers to the experience of loss of someone through death. Mourning is the social expressions in response to loss and grief. There are mourning rituals and behaviours specific to each culture and religion which help in accepting the reality of loss through an increase in social support which encourages expression of both positive and negative emotions.

Stages of grief:

The stages of grief can be described in many ways.

The common stages of grief as described by Elizabeth Kubler-Ross are denial, anger, bargaining, depression and acceptance.

Another way of discussing different stages of grief, which in fact serve a purpose during the process of grief towards acceptance and adjustment to the loss is -

Shock : Invariably, shock, denial and dismay is the first stage with the initial shock having feelings of numbness, disbelief. This helps in allowing the person to accept the reality of loss.

Pangs of grief follow the initial shock with multiple emotions like sadness, anger, guilt, searching, anxiety, and vulnerability. These help the person to experience the pain of grief.

Despair: This is followed by feelings of despair characterized by a loss of meaning and direction in life. The person attempts to understand what is going on and helps the individual to adjust to an environment in which the deceased is missing.

Lastly, the process leads to an **adjustment and acceptance** to the loss, develop new relationships and interests, and get used to the absence of the person and the loss. However, this may never go away totally, but the pain and distress associated with the loss is manageable. This helps the person to emotionally relocate the deceased to an important but not central place in the bereaved person's life and move on.

The stages of grief do not always follow a sequence and different individuals may respond differently. The stages appear and reappear during the process and some stages may not happen at all, or may be mitigated.

Impact of grief:

Increased psychological morbidity

Grief causes increased psychological morbidity in the form of depressive and anxiety or panic symptoms. These might manifest as major depression or anxiety and related disorders, alcohol and substance misuse or self harm behaviours. For a variable period there could be poor social functioning, poor academic performance and relationship problems.

Increased physical morbidity

Grief makes a person vulnerable to a variety of health problems, poor physical health and more visits to health professionals. This may be due to impaired immune function making a person vulnerable to infections or non communicable diseases. There could be increased risk of heart problem, elevated blood pressure or worsening of psychosomatic illnesses, worsening of arthritis and even increased relapses and recurrences in cancer. This has been discussed in an earlier chapter signifying the role of psycho-neuro-endocrino-immunology.

Increased mortality rates due to multiple factors has also been noted.

Factors related to severe grief state or reaction:

- Age of the individual
- Preexisting illness
- Duration of grief
- Sudden death or loss
- Those who are prone to anxiety or depression
- Unable to participate in the mourning rituals or funeral proceedings
- Inability to see the dead body or remains of the deceased.
- Multiple stresses

- Poor social or family support

Types of grief

- **Normal:** Grief following a loss or death of a loved one is a normal phenomenon as described in the above process or stages. Grief is considered to last up to 6 or 12 months, and does not cause any psychosocial impairment.

Grief may be abnormal, morbid or pathological or complicated as described below.

Abnormal grief may be

- **Non acceptance, denial:** person doesnot accept the death. Initial transient denial is normal, but when it persists for many days and interferes with day-to-day life, it is considered abnormal.
- **Avoidance of dead person:** the person avoids seeing the remains of the deceased, and avoids to talk about the deceased or touch the body.
- **Avoidance of funeral, burial:** the person avoids going to the burial ground, cemetery or avoids the funeral due to extreme anxiety, sadness, distress or feeling too upset or disturbed about the processes following death. There is some evidence of a conflict with the funerals and burials manifesting as excess versus no visit to grave
- **Hold on to belongings:** the family or relatives may hold on to the belongings of the deceased person, unable to part with these; clinging on to these as a memory or remembrance. The family may maintain their room as shrine, have excess versus no photographs.
- **Sense of presence, illusions, hallucinations:** these are varying manifestations of the phenomenon of denial. Continued searching for the existence of the deceased may be observed.

- **Domination by negative memories** is noted in the beginning and gradually get replaced by more fond and positive recollections of the dead person.

Morbid or Pathological Grief

Grief is considered morbid or pathological when there is excessive anxiety, sadness, excessive guilt, excessive anger – towards self, others, including doctors and even God and fate; and excessive religiosity.

Anniversary Reactions are experiencing features of grief on the anniversary day of the death, year after year. Remembering the deceased on the anniversary is normal, but if the experience becomes too distressing and disturbing, it indicates unresolved grief,

Complicated Grief

Grief is considered complicated if the psychological and emotional responses of grief have features of an identifiable psychiatric disorder like, dissociative disorder [fainting attacks], phobic disorder, obsessive compulsive disorder, reactive depression, reactive mania, acute psychotic episode or alcoholism & substance use.

- **Identification with the deceased**, may also be seen wherein the person acts and behaves like the dead one, and commonly, have similar symptoms as the person who expired.
- **Over idealization** of the dead person is seen commonly with the death of a celebrity or a famous person.

Another way to discuss types of grief is based on the course and trajectory of the grieving process.

Grief can be -

Normal : as described above.

Chronic or prolonged, when it lasts longer than one year, and shows no signs of abating or becoming less severe.

Exploding or hypertrophied, when it becomes very severe within a very short period, days and weeks following death.

Absent, when there are absolutely no features of grief which are expected to have occurred.

Oscillating grief is when the features of grief come and go in a short period of time, up and down, severe to absent to again severe and again absent.

Delayed grief starts a few days, weeks or months after the death,

Inhibited Grief is when the features appear to be present but being inhibited by the person

Anticipatory Grief can be seen in relatives of persons with cancer undergoing palliative care. This is in anticipation of death of the person; the features of anticipatory grief and similar to that of grief.

Grief based on loss can also be observed; loss of parents leads to thoughts of the past; the loss of spouse shows preoccupation with the present; loss of child shows preoccupation of future; loss of sibling has disturbances and thoughts related to past, present and future.

The loss may not always be due to death of a person, it may be loss of a body part, like mastectomy, loss of hair, amputation, resections, hysterectomy and similar loss of body part or function.

Assessment & Management

This includes careful enquiry about any death or loss which could have occurred in the person's life. The main presentation may be one of sadness and depression or anxiety or sleep disturbances.

It is important to differentiate grief reaction from depressive disorder.

A history of recent loss, temporally related to the onset of symptoms and a preoccupation with the loss, missing the lost person or object indicate a grief reaction. Person feels better when talking about the loss.

If there are abnormal presentations of grief, might indicate a conflict or disturbed relationship with the deceased.

Risk factors for severe grief, mentioned above, should be enquired.

Talking about the loss and grief symptoms itself relieves the distress.

At times, more intense grief therapy work may be needed, which includes re-grieving.

A group therapy session of persons recently bereaved can also prove beneficial.

Counselling and psychotherapy are indicated in cases of severe grief and where ever conflicts or interpersonal relationship problems are observed.

Chapter 17 Spirituality

The spirit will always be there.

Spiritual care is an essential component of palliative care. A World Health Organisation's Handbook on Palliative Care by Helmut Sell describes that Palliative care comprises of relief from pain and other distressing symptoms; psychological and **spiritual care** of the patient with the aim of improving morale and emotional status despite poor physical prognosis; work with family, friend and caregivers to establish a support system to help patient to cope, to remain self-determining, and to live as joyfully and actively as possible until death; a support system to help family during the patient's illness and in bereavement. All aspects of this definition including cancer pain, morale, family, and death and bereavement have a significant element of spirituality.

Spirituality plays an integral role in the care of the terminally ill. Hospice philosophy promotes patient and family centred care that is palliative, holistic and interdisciplinary. Spiritual care has been a major component of hospice care that is consistent with these values. Pertinent issues related to the role of spirituality in palliative care include the doctor-patient relationship, provision of spiritual care, and who provides this care and the difference between spirituality and religion. In today's medical practice, even a deeply concerned clinician can consider spiritual aspects of patient's care as a problem, viewing them as ethical problems or psychosocial ones. Spirituality includes two main components: faith/religious beliefs and meaning/spiritual well-being. These two constructs of spirituality have an important role in supportive care and end of life care.

Spirituality in end of life:

There is a close association between feelings of demoralization and spirituality as demoralization implies deprivation of spirit, courage and discipline. Demoralization, is experienced as a persistent inability to cope, together with associated feelings of helplessness, hopelessness, meaninglessness, subjective incompetence and diminished self-esteem. Demoralization has been commonly observed in the medically and psychiatrically ill and is experienced as existential despair, hopelessness, helplessness, and loss of meaning and purpose in life. Although sharing symptoms of distress, demoralization is distinguished from depression by subjective incompetence in the former and anhedonia in the latter. Demoralization can occur in people who are depressed, and cancer patients who are not depressed. Hopelessness, loss of meaning, and existential distress is proposed as the core features of the diagnostic category of demoralization syndrome. This syndrome can be differentiated from depression and is recognizable in palliative care settings. Thus, there is an apparent admixture of depression, loss of meaning and purpose, and existentialism in demoralization.

The doctor patient relationship and communication have spiritual hues which are less often recognized. In Indian settings, patients and families still view doctor as God or Godly, and often leave decision making to the doctor! Decision making on behalf of someone else, discussing diagnosis or other bad news situation is never easy since it goes beyond discussing medical facts and emotions. Patients and relatives raise questions like - Why me?; What will happen in future ?; Why did this happen to me ?; What will happen to me after I die ?; Will I be remembered ?; Will I be missed ?; and so on. Such questions assume importance at end-of-life period, as the uncertainty can potentially cause distress and restlessness of the mind. A large part of this distress is spiritual distress. Spiritual and religious factors also influence health dynamics – trust for clinicians, nurses, stigma, own

group dilemma and treatment adherence. Members of many religious groups may feel best understood by a professional who shares their own religious background. Spiritual and religious factors play a significant role in formation and maintenance of support groups.

Spiritual Distress & Coping:

Palliative care clinicians should be alert to symptoms of spiritual distress and intervene accordingly. Spiritual distress may be associated with negative religious coping. Negative religious coping like, punishment or abandonment by God, was reported to be positively associated with distress, confusion, depression, and negatively associated with physical and emotional well-being, as well as quality of life. The exact prevalence of spiritual distress in end of life in Indian settings is not known, though given the use of traditional, spiritual coping methods in different stages on cancer, one might speculate that spiritual distress could be relatively less or different from the Western world.

When faced with suffering and threats in life, patients frequently articulate spiritual concerns. Cancer patients use spiritual and religious coping methods naturally, when other coping methods do not provide solace. In a study of cancer patients in Bangalore, the commonest coping methods used were resort to religion and karma. Cultural and spiritual factors are invariably inter related and it may not be possible to segregate these.

Do spirituality & religiosity need to be distinguished in end-of-life care?

This is an important question in palliative care since both spirituality and religiosity increase as death approaches. Spirituality, religion and creativity may be inter-related and significant in their own right. One's spirituality or religious beliefs and practices may have a profound impact on how the individual copes with the suffering that accompanies advanced disease. People confuse between spirituality and religiosity and consider these synonymous. It is important to recognize that there are clear cut differences

between spirituality and religiosity. Spirituality is especially important in developing countries and traditional societies where medical and comfort resources may be limited.

Spiritual Pain:

Spiritual pain has been defined as "pain caused by extinction of the being and meaning of the self". The conceptual framework of spiritual pain based on a philosophical perspective consists of three dimensions of a human being - as a being founded on temporality, a being in relationship, and a being with autonomy. The attempts to assess these perspectives makes it easier to talk with the patients about their spiritual pain.

The large body of empirical research suggesting that patients' spiritual and existential experiences influence the disease process has raised the need for health care professionals to understand the complexity of patients' spiritual pain and distress. A study evaluated participants' intensity of spiritual pain, physical pain, depression, and intensity of illness, with a qualitative focus on the nature of patients' spiritual pain and the kinds of interventions patients believed would ameliorate their spiritual pain. It was noted that 96% of the patients reported experiencing spiritual pain, but they expressed it in different ways, as an intrapsychic conflict, as interpersonal loss or conflict, or in relation to the divine. Intensity of spiritual pain was correlated with depression, but not physical pain or severity of illness. The intensity of spiritual pain did not vary by age, gender, disease course or religious affiliation. Given both the universality of spiritual pain and the multifaceted nature of pain, it has been proposed that when patients report the experience of pain, more consideration be given to the complexity of the phenomena and that spiritual pain be considered a contributing factor. Spiritual pain left unaddressed both impedes recovery and contributes to the overall suffering of the patient.

Spiritual healing & treatment of spiritual distress:

Spiritual distress and spiritual pain would need a management plan directed towards spiritual healing. Invariably patients and families seek relief from different lay sources. It is known that patients, at their end of life, are vulnerable to suggestions and counselors need to desist from imposing their own beliefs. In most instances a sympathetic hearing to spiritual concerns is needed, helping individuals to come to their own conclusions. Guidelines for spiritual care giving include self-knowledge of one's own spiritual needs, authenticity and honesty and respect for the beliefs and practices of the patient and family. Existing psychotherapeutic interventions for spiritual suffering can be provided by a novel meaning-centered group psychotherapy for advanced cancer patients. The meaning-centered therapy is being used in a number of palliative care centers in the West, its applicability and usefulness in Indian settings is worth a try.

There are many systems of alternate and unorthodox medicine, most with some component of spirituality. Hospice professionals recommend that these are best tried outside the hospice unless they are in fully-studied clinical trials. The availability of numerous systems of alternative medicine and a hope for cure even at a late stage of the disease means that many patients depend on these as their main form of treatment and hope. Complementary and alternative medicines play a key role in palliative care and improve the quality of life, to some extent, perhaps, due to some overlap or admixture with faith and spirituality. Traditional therapies like pranic healing, yoga, pranayama, transcendental meditation, sudarshan kriya yoga (SKY), music therapy, tai chi and other complementary methods like reiki, aromatherapy, and alternative medicines like ayurveda, naturopathy etc. all have a variable spiritual element and are popular in traditional societies. Some studies have examined client use of spiritual and/or religious practices to cope with illness and adversity. One survey indicated significant relationships of spiritual practices such as yoga, prayer and meditation to working with palliative care clients. The total number of

these approaches was predicted by factors such as theoretical orientation and the social workers' own struggles with palliative care and other issues.

Inadequate scientific research on these complementary or alternative methods casts doubts on their effectiveness. These methods with unproven results, and misleading advertising, attract the gullible patients with advanced diseases. Public faith in these relatively inexpensive systems is tremendous, and the inadequacy of the expensive modern medical systems only strengthens the resolve of the affected patients and their families to use these unproven systems.

Clinical Implications:

Spirituality is complex and challenging to implement into clinical actions. Professionals have little or no training on how to deal with this aspect, especially in the end of life. Palliative care education programmes should have sufficient training inputs on spiritual aspects. Measurement of spirituality and spiritual care need to be important components of such a training.

Measurement of Spirituality

There are a few structured methods of assessing spiritual aspects like HOPE [Sources of **H**ope, **O**rganised religion, **P**ersonal spirituality and practices, **E**ffect on medical care and end of life issues], FICA [**F**aith, **I**mportance / influence, **C**ommunity, **A**ddress / apply], SPIRIT [**S**piritual belief system, **P**ersonal spirituality, **I**ntegration with a spiritual community, **R**itualized practices and restrictions, **I**mplications for medical care, **T**erminal events planning. There can be a semi structured interview consisting of different questions which can help assessing spiritual issues raised by serious illness, especially at the end of life.

A scale for assessment of Spiritual distress has been developed for use in Indian settings also.

Spiritual and existential well-being are major components of Health Related Quality of Life, especially at end of life. Overall, Quality of Life (QOL) is highly correlated with spiritual well-being among dying patients. There are also some standardised methods to assess spiritual well-being and spiritual quality of life, like the World Health Organisation Spiritual, Religious, and Personal Beliefs (WHOQOL SRPB) scale, Functional Assessment of Chronic Illness Therapies (FACIT Sp) Spiritual Well Being Scale and Holland's Brief Spiritual Beliefs Inventory for use in quality of life research in life-threatening illness. The simple way would, however, be listening to the person's spiritual concerns, thoughts and feelings, acknowledge these and reassure. Peace of mind and spiritual satisfaction were considered as more important than functional and psychological aspects in Indian cancer patients.

Spiritual Care:

Most hospices in India provide nursing care through Christian missionaries, who do a tremendous selfless service, but this may create a conflict with the predominant religious groups of Hindus and Muslims. Though such services by Christian voluntary agencies are provided in many developed countries as well, which are predominantly Christian, they may not encounter the conflicts with patients from the multiple religions in a secular society. This gains significance given the importance of religion in death and pre death and post death ceremonies. In clinical experience, one comes across patients seeking religious conversions during their last days of life, creating conflict within the family and community. On the other hand, religious groups have successfully participated in community palliative care programmes. Professionals working in palliative care settings employ diverse methods to improve quality of life of their patients by suggesting prayer, devotion, yoga, meditation or philosophical pursuits, whereas the patients themselves seek abode in holy or religious places, akin to hospice towns or cities, to obtain mental and spiritual solace awaiting death.

Spiritual Issues of Caregivers :

The spiritual issues in the caregivers of the terminally ill person are equally, if not more, important. The spiritual concerns and distress in the caregiver are likely to continue from period of anticipatory grief to the grieving period. The assessment and care of spiritual distress in caregivers could be similar to that in their patients.

Existential and spiritual issues are gaining clinical and research importance in palliative and supportive care of cancer patients. As concepts of adequate supportive care expand beyond a focus on pain and physical symptom control, existential and spiritual issues such as meaning, hope and spirituality in general have received increased attention from supportive care clinicians and clinical researchers. Spirituality cannot be imposed; it can only be shared. The objective of addressing spiritual issues at end of life is also to ensure a 'good death', which requires access to any spiritual support required by the patient or others involved in the care. Traditional palliative care in India has been practiced through the ages, with home based spiritual and religious care of the dying according to traditional customs and rituals, and hopefully this would continue with adequate support from modern palliative care.

Spiritual quotient:

The Spiritual Quotient, Sp Q may indicate a ratio of Spiritual strengths and spiritual distress or weaknesses. Thus, these might be involvement with spiritual activities and getting sufficient spiritual satisfaction and peace of mind versus spiritual pain and distress. In management of a person with advanced disease, attempts should be made to maintain a positive spiritual quotient, implying that there are more positive spiritual events as compared to spiritual distress.

Chapter 18 Staff Stress in oncology

Staff will be stressed unless you do something about it

Professionals involved in the management and care of cancer patients and their relatives are under continued stress due to the extensive morbidity and mortality related to the disease.

The common causes of staff stress can be due to different factors which could be listed as

- Personal and personality related: Persons with anxiety prone, neurotic personality or those who are too self-involved and self-abased are at a higher risk for developing staff stress earlier than others. The motivation to join oncology practice and palliative care is another key factor, is it to meet personal emotional needs or doing the 'in' thing, or to affiliate with a leader, or the need to prove oneself. The more the person invests emotionally into this activity, more are the chances of an early manifestation of staff stress and burnout.

Other personal factors are the amount of social and family support the person has and if there have been stressful life events. If these life events are health related or bereavements encountered, the stress may be intense. The professional may feel inadequate to deal with emotional needs or of not having enough knowledge about handling symptoms.

Staff members with higher death anxiety find difficulty in dealing with death in their patients.

- Work or job related are mainly noted to be more if there is excessive work load with poor support from colleagues or hospital administration. Those who are not able to afford a break in their work tend to get easily stressed out. Communication problems within the team and with other agencies are another source of stress. Lack of support for the dying patient/families can also be perceived to be stressful.
- Role in the care and management of the patient: Role stressors are an important unrecognized factor causing staff stress. These include the feeling that time is short for the interventions and the life of the patient; there is a dilemma between the efforts should be towards curing or caring for the person. The compassion and empathy can also cause a role diffusion and confusion between the role being both a professional and a friend to the patient or the family caregivers. This can lead to role ambiguity and role confusion, specially when the patient or caregivers press upon the doctor, nurse or professionals to make decisions on their behalf.
- Environmental factors: These are general stresses of life and living and may not be directly related to the disease or its treatment, like rising prices, political turmoil, overcrowding, financial difficulties or inter personal problems.
- Patient-related stressors: These are related to the morbidity and complications related to the disease, specially those which were unexpected or unwanted. Stress is also noted if there are patients who are having problems accepting death, patients who are angry and hostile, those who abuse alcohol or drugs. Young patients and children with cancer cause more emotional distress to the professionals. Negative responses in family members and their unrealistic demands are other sources of stress. Patients with whom the staff identifies or develops a personalized relationship can cause more psychological and emotional distress for the professionals.

- Administrative factors: These vary from poor infrastructure, lack of medications or equipment and poor staffing. Shortage of staff increases the burden on the existing staff. Poor pay / salary and facilities to the staff also increases the discontentment among the staff.

Staff stress among physicians is noted to be due to following reasons:

- Problems of communication & relationships
- Difficulty in taking conflicting decisions
- Feeling lack of competence in breaking or giving bad news
- Work overload
- Repeated confrontation with difficult & delicate situations

Staff stress among nurses is noted to be higher among those

- attending terminal patients
- on repeated or continuous night duties
- with high personal standards
- who are self-critical
- who face a lack of communication
- who receive little recognition of work well done
- who have had poor or scarce training

Staff stress in the team is observed in those teams which have

- Lack of communication
- Protagonism – causes mistrust, suspicion
- Poor administrative support for social support,
- Decision making, work involvement
- Unrealistic objectives
- Admission of dying patients

It has been noted that among the hospice caregivers' half the stress is contributed from work environment, one third from occupational role, one fifth from patient/family and <10% from illness related factors.

MANIFESTATIONS OF STAFF STRESS:

The manifestations of staff stress can be multiple and varied and are similar to some extent to features of any stress. These can be

- physical problems
- psychological problems
- behavioral problems

The common physical symptoms are:

- fatigue,
- sleeplessness,
- feeling nervous,
- tension pains/aches &
- low back ache
- lack of appetite

The common psychological symptoms are:

- depression and anxiety
- low self-esteem, decreased self-worth,
- self-criticism and cynicism
- somatization/ somatic concern
- irritability
- feelings of failure
- poor concentration
- grief, guilt,

The common behavioural symptoms are

- agitation
- restlessness
- withdrawal
- smoking
- drinking
- indulging in high risk behaviours

Other problems noted as a part of staff stress are -

- lack of organization
- loss of sense of priority
- problems with team members
- less-caring attitudes
- disenchantment
- lack of stimulus in work

BURNOUT: Continuous, moderate to severe staff stress leads to burnout.

This syndrome involves

- emotional exhaustion
- negative attitudes towards the recipients (depersonalization)
- a tendency to evaluate oneself negatively
- dissatisfaction with accomplishments
- amotivation and a lack of interest

Burnout is associated with

- work overload,
- role ambiguity,
- role conflict,
- time & staffing limitations,
- lack of advancement opportunities,

- poor work relations,
- lack of a leader or peer support,
- increased demands by patients and families
- frequent exposure to the death and dying.

Methods of coping with staff stress

Dealing with psychological problems has been found to be more stressful than dealing with physical problems. Some of the practical methods in dealing with staff stress and preventing burn out are -

- Effective teamwork
- Regular team meetings
- Team in-service education
- Staff support groups
- Grieving/memorial services/death rounds
- Maintaining records, journals, memory books

Methods of coping with staff stress: There are many methods available to cope with this stress of working with cancer patients. These include

- Sharing non-work-related social activities as a team
- Clear job descriptions with reasonable workloads and a stimulating work environment
- Taking time off for a change in the nature of work; vacation; posting to a less stressful of different work
- Support from family and friends
- Acquiring a sense of competence, control and pleasure
- Lifestyle management like walking, jogging, swimming or doing physical or mental exercises.

Other lifestyle management strategies include

- having outside activities
- physical activities and diversions

- non-job related interactions
 - taking time off/ Vacation
 - adequate nutrition and sleep
 - meditation and relaxation
 - keep a pet
- Developing a personal philosophy regarding illness, death, one's role in caring for a dying person.
 - Personal coping methods may vary from listening to music, doing creative activities, gardening, drawing, painting to doing yoga, meditation or relaxation exercises.
 - Developing self-control, using humour, learning from mistakes and sharing frustrations.
 - Maintaining self-esteem and valuing personal worth by evaluating gains achieved
 - Recognizing that you are here not to prevent death but to make dying easier
 - Acquiring a sense of competence, control& pleasure
 - seeing the patient obtain relief
 - positive feedbacks from the patient & family
 - empathic contact with patients
 - assisting patients and families to cope
 - witnessing the smooth termination of life

Preventive strategies in burnout:

Certain administrative measures can be useful in preventing burnout and reducing staff stress. These are organising training and courses on communication skills, team building and stress control. Conducting, organising or attending such courses, training programmes and continuing medical education activities or professional development activities can prove to be useful

Reorganising resources can be effective, like –

- Different duties according to capabilities
- Establish fair rotation system
- Stimulate goals in high quality of work
- System of 'breaks' during duties
- Creating protocols, codes, bioethic committees

Individual measures can also be useful. These could include

- Aiming at reaching one's innermost motivation
- Altruism but with goodwill, humor, respect
- Maintaining one's private life
- Developing a talent to listen carefully
- Accepting oneself as one is, and don't blame others
- Keeping a sense of priority, being organised and upto date in knowledge and developments
- Finding time to meditate, relax and rest
- Searching for spirituality and personal philosophy
- Trying to have an external support
- Accept the fact that life is maintained by different factors;

Professional caregivers need to recognize that it takes a 'total person' to respond day after day to the 'total needs' of other people. Caregivers should care for their welfare in order to serve better. The quality of life of the staff is important for providing good quality services and quality of life of their patients.

**REFERENCES,
RESOURCES
&
FURTHER READING**

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Appendix 1

Publications on Indian research on psycho oncology, year wise

SCIENTIFIC INDIAN PUBLICATIONS ON PSYCHIATRIC, PSYCHOLOGICAL & PSYCHOSOCIAL ASPECTS OF CANCER & PALLIATIVE CARE:

A list of Indian Publications on psychosocial aspects of cancer has been compiled here from the available sources and the Pubmed / Medline search. If people are aware of any more similar publications in the national or international journals those can be added to this list and made complete. These have been listed year wise.

Number of publications by years

Upto 1980	05
1981-1990	26
1991-1995	20
1996-2000	61
2001-2005	51
2006-2010	61
2011- 2015	37
2016-2020	94

1977-1980

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1981-1990

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15. Chaturvedi SK. Psychosocial intervention in cancer patients. *Journal of Rehabilitation of Asia*. 28, 1-4, 1987.
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Appendix 2

Publications on Indian research on psycho oncology, topic wise

Appendix 2 Publications on Indian research on psycho oncology, topic wise

INDIAN RESEARCH ON PSYCHOSOCIAL ASPECTS OF CANCER & RELATED TOPICS:

A list of Indian Publications on psychosocial aspects of cancer has been compiled here from the available sources and the Pubmed/Medline search. If people are aware of any more similar publications in the national or international journals those can be added to this list and made complete. These have been listed year wise.

Many articles reflect more than one area or topic; some are listed more than once, but many more can be considered relevant for different topics.

Publications by topics

• Breast cancer	34
• Head & Neck cancer	31
• Hematological /Pediatric Cancers	22
• Gynecological Malignancies	15
• Communication related	28
• Pain & Palliative Care	53
• Quality Of Life [QOL]	59
• Psychiatric Aspects /Psycho Oncology	71
• Overview of Psycho oncology in India	13
• Distress	23
• Yoga	10
• Caregivers	19
• Staff Stress	4
• Psychological aspects & personality	18
• Psychosocial & Psychological Interventions	13
• Others / Miscellaneous	16
• Books / Manuals	5

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Appendix 3

Publications of the author on PSYCHO ONCOLOGY & PALLIATIVE CARE up to December 2020

Appendix 3: Publications of the author on PSYCHO ONCOLOGY & PALLIATIVE CARE up to December 2020

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Epilogue

Psycho oncology can be considered as an important part of cancer care and oncology, including palliative care. For mental health professionals and psychiatrist's psycho oncology is a part of consultation liaison psychiatry. The general and basic psychosocial services can be provided by any professional who has had some training and experience in psycho oncology or psycho social oncology. Qualified experts are needed for special situations which need medications or cognitive behaviour therapy or other specialized interventions.

Psychosocial and psychiatric disorders are common in cancer patients at different stages of the disease, and may be related to the cancer treatments as well. Identification and appropriate management of these disorders is important for the holistic care of cancer patients. Adjustment disorders are common; however, there can be varied manifestations of depression, anxiety, panic, somatoform and illness behaviour disorders, or specific sleep, psychosexual or substance use disorders. Combination diagnoses are common; all types of depression and mood disorder are noted. The presence of psychosocial disorders may interfere with the adherence of the person for cancer treatment, but also aggravate their quality of life.

A recent meta analysis concluded that depression and anxiety is less common in patients with cancer than previously thought, although some combination of mood disorders occurs in 30-40% of patients in hospital settings without a significant difference between palliative-care and non-palliative-care settings. Clinicians should be cautious and vigilant for different mood complications, not just depression. Psychiatric emergencies occurring in cancer patients need prompt intervention.

The role of psychological treatments in the management of psychological problems is well acknowledged by physicians and other clinicians caring for patients in oncology.

In conclusion, psychiatric oncology has made numerous advances in the understanding of psychiatric disturbances, and care of cancer patients. There have been advances in psychoneuroimmunology, internet and phone based therapies for cancer patients and assessment and addressal of spirituality at the end-of-life. Medical education needs to be tailored to impart communication skills to medical graduates as well as post-graduates specialising in oncology. More randomised and controlled studies in the area are required, with longer follow-up periods and larger samples.

The bottom line of such care and interventions is improving the quality of life of not only the patients but also their relatives and caregivers. This may be through simple listening and communication skills, counseling or specialised interventions. Many a times, just assessment of quality of life, improves the quality of life!

Santosh K Chaturvedi
Editor

Author

The author of this book, Dr Santosh Kumar Chaturvedi, MD (Psychiatry) FRCPsych (UK), was previously associated with the National Institute of Mental Health & Neurosciences, NIMHANS, Bangalore as Dean, Behavioral Sciences, and Senior Professor and Head of Department of Psychiatry. He was also the Head of Department of Mental Health Education, and Head of Psychiatric Rehabilitation Services at NIMHANS, Bangalore.

The author has more than three decades of clinical and research experience and more than a hundred publications in the area of Psycho oncology and Palliative Care.

The author regularly conducts workshops on communication skills, psycho oncology, spirituality in palliative care.

This Book

This short handbook attempts to share the practice of psycho oncology from Indian perspective. This also provides a good reading list and shares list of publications on this theme, year wise and also topic wise and according to the organ system affected. The author shares his contributions and publications, many of which are available freely or can be obtained from common journals and books.

This book thus provides resource material on psycho oncology from Indian perspective and provides Indian researches and literature. This is not a textbook, but should help clinicians and researchers looking after cancer patients and their families.

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