

Emotional turmoil in oncology patients

Abstract

Emotional turmoil is a negative mental state involving feelings of panic, confusion and agitation. People experiencing emotional turmoil feel physically and mentally unwell which results in difficulty making decisions cancer diagnosis is hard to take and having cancer is not easy. As the patient face their own mortality and cope with the many demands of cancer, often patient and their families look at their religious beliefs, personal and family values. Literature has shown that at least 70-75% of the oncology patients will be exposed to some sort of psychological or emotional shut down mainly depression during their journey from diagnosis to follow up. The main reason is anxiety, fear of the unknown, pain, suffering and fear of death. In the literature it seems most oncological patients do not have clarity about their disease or what is sequel of their disease or treatment offered. Clinical practice guidelines established by the National Comprehensive Cancer Network (NCCN) recommend that all oncological patients should undergo routine screening for distress when they report first time and at important points in their disease or treatment process. Recommendations highlights that oncology team adopts approved distress assessment tools available today for screenings and scientifically proven clinical pathways upon assessment results.

Keywords: emotional turmoil, confusion, panic, agitation, diagnosis, cancer, depression, clinical practice, treatment, emotional, psychological, mortality, oncology, influence

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Rashmi Koul,¹ Arbind Dubey,¹ Reem Al Omran,² Patricia Taj³

¹Department of Radiation Oncology, Canada

²Radiation Oncology Resident PGY 2, Canada

³Department of Radiation Oncology, Canada

Correspondence: Rashmi Koul, Department of Radiation Oncology, CancerCare Manitoba, 675 McDermot Ave, Winnipeg, MB. R3E0V9, Canada, Email rkoul@cancercare.mb.ca

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Abbreviations: POMS, profile of mood states; RFS, rhoten fatigue scale; FSCL, fatigue symptom checklist; PFS, piper fatigue self-report scale; NCCN, national comprehensive cancer network

Introduction

In the medical literature psychosocial distress is immersing as a significant clinical issue in oncology patients.¹ Studies have shown that majority of patients with cancer report significant levels of psychosocial distress; however this emotional turmoil or social disruption during their oncological journey is highly underestimated.² The news of cancer diagnosis often affects internal and external coping abilities which eventually influence their decision making, compliance and overall quality of life.³

Methods

A search of English Literature from 1970 onwards was performed by RAO with the term emotional turmoil. Results are summarized below.

Results

In modern medical literature about 70-75% of the oncology patients will experience some sort of psychological or emotional shut down mainly depression during their journey from diagnosis to follow up.⁴ The main reason is anxiety, fear of the unknown, pain, suffering and fear of death. In the literature it seems most oncological patients do not have clarity about the full diagnosis of their disease or what will happen to them during or after treatment.⁵ For the majority of patients, these reactions resolve in few days after their first appointment with oncologist when they receive detailed information on diagnosis, stage of disease and treatment plan. Other patients will keep on experiencing these debilitating depressive symptoms during the course of treatment

and even after treatment affecting their long-term physical and mental well-being.⁶ This has profound lasting effect on their families and loved ones. If patients are well informed they tend to cope with their emotions better especially if they have strong social support.⁷ In oncological patients treatment often is tedious, tiring and long. Even after completion of their treatments, the fear of recurrence lurks in their mind which in itself is very disruptive. So success depends on support from health care professional team, family and friends which essentially helps to maintain positive attitude and boost their morale.⁸

Assessment of emotional distress correctly is a big challenge in modern medicine. This clinical entity is very complex and often hard to diagnose, primarily because signs and symptoms often imitate disease symptoms and treatment related side effects. Insomnia, fatigue, difficulty concentrating and changes in appetite are all indicators of psychosocial distress but can be seen in a variety of diseases as well. Patients also struggle with pain, insomnia, nausea and other debilitating conditions.⁹ Decision on end-of-life (requirement of health care proxies, decision on comfort measures only and or do-not-resuscitate) foster severe anxiety in many patients and their loved ones.¹⁰ Cherney and colleagues defined suffering as “an aversive emotional experience characterized by the perception of personal distress that is generated by adverse factors undermining the quality of life”.

Fatigue

Fatigue is a common symptom encountered in oncology patient's either due to disease process itself or sequel of the cancer treatment offered.¹¹ In literature there are either single or multiple item tools available for use for proper fatigue assessment. The single item assessment scales are very simple but have strong issues with reliability and validity.¹² Multiple item assessments carry 3-7 items so that chances of error are reduced. These tools have reasonable validity,

but may be redundant.¹³ It is a well-established fact that fatigue should be viewed as a continuous dimension. Not only emphasis should be on biochemical or pathophysiological causes but also on spiritual and psychological, aspects as well.¹⁴ Fatigue, like any other human experience, has three components: physiological response, behavioral response and verbal description.⁹ Fatigue so far has been measured by checklists such as the Symptom Profile,¹⁵ the Rotterdam Symptom Checklist¹⁶ or by the Profile of Mood States (POMS).¹⁷ In modern medicine more specific instruments are available to assess fatigue in oncological patient population. They are one dimensional or multidimensional instrument depending on scale. The simplest measure of tiredness is the Rhoten Fatigue Scale (RFS). In this scale a visual analogue scale is combined with a numerical ten points rating scale, ranging from 'not tired, full of energy' to 'total exhaustion'.¹⁸ The Fatigue Symptom Checklist (FSCL) is a multidimensional questionnaire; aiming to assess fatigue in a work situation.¹⁹ The original FSCL contained 30 symptoms, divided into three subscales based on a factor analysis

- i. General feelings of sleepiness, with items like 'feel tired in the legs' and 'want to lie down',
- ii. Mental feelings of fatigue, with items like 'difficulty in thinking' and 'become nervous' and
- iii. Specific bodily sensations, with items like 'headache' and 'dizziness'.

Factor analysis on the Dutch version of the FSCL resulted in a three-factor solution with an item distribution, which differed from the original subscales. A physical fatigue scale, a mental fatigue scale and a malaise scale were distinguished.²⁰ Piper and colleagues set out to develop an instrument to measure the experience of fatigue of patients, the Piper Fatigue Self-report Scale (PFS).¹⁴ The total fatigue score is calculated on the basis of the scores from four subscales representing the temporal, intensity, affective and sensory dimensions of fatigue. Based on the results in a sample of breast and lung cancer patients who started their first week of radiation, the authors concluded that the PFS shows excellent reliability and moderate construct validity. However, a large percentage of patients had troubles filling in the questionnaire. Also, no mention was made whether the assumed dimensions of fatigue were reflected in the actual data of the patient population. In conclusion, most measures of fatigue in cancer are incorporated in instruments that measure broader aspects of patient functioning.²¹

Insomnia

It is a known fact that insomnia also can affect one's quality of life.²² In oncology it has been found in literature that almost 50% of patients suffer from sort of sleep disturbances. Lack of sleep can often lead to fatigue causing severe impact on quality of life and disease course.²³ There are various causes of insomnia in cancer patients. The main goal of treatment should first be address underlying pathology.²⁴ Treatment should be multimodal including both non-pharmacological and pharmacological approaches.²⁵ A systematic plan should be laid out so that in addition to disease process, physician or oncology nurses should pay attention to other related psychosocial factors as well which have been found to precipitate lot of symptoms.²⁶ In oncology the prevalence of sleep disturbances vary by tumor type and stage at which they present. In literature so far the incidence of insomnia is highest in breast cancer patients. The reason elucidated by authors are gender, ovarian ablation due to treatment which causes decrease in estrogen level and hot flashes which precipitates sleep disturbances.²⁷ Other malignancies known to cause insomnia are melanoma, colorectal,

ovarian and lung cancers.²⁸ The likely reason may be the treatment modalities used in these neoplasm's. In early stage disease, insomnia is due to anxiety and distress caused by new diagnosis and related events such as treatment. In advanced stages tumor itself may be the causative factor for many debilitating symptoms such as an impinged nerve or a viscera stretched due to tumor mass effect causing pain eventually leading to insomnia.²⁹ Chemotherapy, hormonal therapy, immunotherapy and radiation as well as some adjuvant medications cause insomnia.³⁰ In oncology practice often steroids are prescribed for a variety of indications most commonly as anti-inflammatory, antinauseant or to increase appetite and steroids are known to cause insomnia.³¹ Biological modifiers such as interferon and interleukin used for melanoma and renal cell carcinoma can cause disruption of sleep cycle. In literature it has been reported that high cortisol levels in breast cancer patients with sleep disturbances had higher mortality rate due to immune suppression caused by decreased natural killer cell activity. The stress can increase serum cortisol and precipitate insomnia. This is supported by many authors in the literature.³²

Another common symptom we find in oncology outpatient clinic is distress. Simple stress measurement tools can help oncology nurses to differentiate distress from disease effects. The Distress Thermometer, a thermometer-like diagram on which patients are asked to rate their level of distress on a 0-to-10 scale and an accompanying short problem list helps patients identify practical areas of concern, such as child care, housing, or specific physical symptoms.³³ Distress levels are sometimes highest at the beginning of treatment, because of anticipatory anxiety, and can climb again at the end of treatment, when patients might feel more isolated as a result of fewer interactions with clinicians. Patients may have trouble concentrating, and their ability to carry out usual daily activities may be impaired.³⁴ Most patients will successfully adapt within a few days to a few weeks, with support from family and friends.

Studies have also reported a wide range of prevalence of depression in cancer patients, and this variation reflects lack of standard assessment tools and diverse disease sites and stage of disease.³⁵ Lansky and colleagues surveyed ambulatory patients with gynecologic cancer and found a 5% rate of depression.³⁶ Dugan and colleagues recorded clinically significant depressive symptoms at a prevalence of 35.9% in a large group (N=1109) of ambulatory patients with varied sites and stages of disease.³⁷ Depression is highly associated with oropharyngeal (22%–57%), pancreatic (33%–50%), breast (1.5%–46%), and lung (11%–44%) cancers. 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%).³⁸ A study by Craig et al.³⁹ reported an overall prevalence of 53% for hospitalized cancer patients with varying primary sites and stages. Overall, it is estimated that 25% of cancer patients have clinically significant depressive symptoms or major depression. Most patients still try their best to enjoy pleasures of life and perhaps engage the activities that they enjoy. There is nothing inherent to the cancer that any patient loses capacity to be happy or not experience pleasure in life such as quality time spent with family or friends, knowing that these experiences may be among the last they are allowed to have. The knowledge that death is near can increase the poignancy and emotion of such contacts.^{40,41} Pain has been strongly correlated with depression and suicide.⁴² Patients whose pain remains unrelieved may believe that the pain signifies disease progression. This belief is often accompanied by agitation, anger, and hopelessness, especially if patients do not see efforts being made to control or relieve the pain.⁴³

Conclusion

Clinical practice guidelines established by the National Comprehensive Cancer Network (NCCN) recommend routine screening for distress upon admission and at any time where major changes are anticipated in the disease process. They recommend adopt approved distress assessment tools for screenings, and use of established clinical pathways based upon assessment results.⁴⁴ Unfortunately, these guidelines are not consistently implemented, partly because nurses have not been given the time, education, resources, or organizational support to meet their patients' needs.

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Conflict of interest

Author declares that there is no conflict of interest.

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