

CANCER, TRAUMA AND PERSONAL GROWTH

Addressing subjective responses to cancer

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Top-line summary

An individual's subjective appraisal of the experiences of cancer and its treatment is an important factor in whether he or she develops a stress response syndrome or experiences posttraumatic growth. Posttraumatic stress disorder, broadly defined by the U.S. National Institute of Mental Health as "an anxiety disorder that can develop after exposure to a terrifying event or ordeal in which grave physical harm occurred or was threatened," is the most commonly described stress response, with acute stress disorder and subthreshold or partial posttraumatic stress disorder also occurring. This evidence-based review article addresses the definitions, prevalence, contributing factors, risk factors and protective factors, as well as the clinical management of stress response syndromes in cancer patients. The article also describes the posttraumatic growth experienced by many patients, and outlines some changes in care that have been promoted by the cancer survivorship movement. Clinical examples illustrate some typical presentations of people confronting the adaptive challenges associated with the cancer trajectory.

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Psychologic responses to a cancer diagnosis and treatment are contingent on the affected individual's subjective appraisal of the events. Responses to the illness and its treatment range from posttraumatic stress syndromes to posttraumatic growth, defined as "significant positive change arising from the struggle with a major life crisis."¹

A trauma model for cancer and its treatment as traumatogenic stressors has been the subject of research and clinical interest over the past 15 years.^{2,3} This has been formalized in the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition (DSM-IV)⁴ by including life-threatening illness as a potential traumatogenic stressor associated with posttraumatic stress disorder (PTSD) and other stress response syndromes. In many cases, however, increasingly effective and specific treatments have also allowed reframing of cancer as a chronic illness. In this regard, the survivorship movement emphasizes the resilience of those affected,⁵ and research provides evidence of the potential for posttraumatic growth.^{6,7} This article reviews the role of cancer as a traumatogenic stressor from a clinical perspective, as well as the potential for posttraumatic growth following the challenge of cancer and its treatment.

The DSM-IV introduced a shift in the trauma criteria of PTSD to emphasize the subjective experience of those affected by trauma and to allow greater inclusiveness in defining traumatogenic stressors.⁸ Trauma is defined as experiencing, witnessing or learning about an event that involves either actual or threatened death or severe injury (criterion A1). Trauma in this definition is not synonymous with a noxious event, in contrast to more broadly interpreted and less precise uses of the term.⁹ Further, DSM-IV added an important



modification to the stressor criteria for PTSD with the requirement that the subjective response to trauma is one of intense fear, helplessness or horror (criterion A2). Subjective responses at the time of trauma are considered to play an important etiologic role in stress response syndromes.¹⁰ One study reported that among people exposed to trauma, only 3% of those who do not meet criterion A2 go on to experience persistent traumatic memories.¹¹ Both criteria A1 and A2 must be met to consider a diagnosis of a stress response syndrome. In addition, re-experiencing, avoidance and hyperarousal constitute 3 categories of symptoms that occur on a continuum in stress response syndromes following exposure to a traumatogenic stressor. Cancer-related stress response syndromes including acute stress disorder,

PTSD and subthreshold or partial PTSD have been the subject of systematic literature reviews concerning adults with cancer^{2,3} and children with cancer and their parents.¹²

The variability in individual responses to traumatic events is tremendous. The developing literature on posttraumatic growth reports that cancer and its treatment may precipitate positive psychosocial sequelae, including improved interpersonal relationships, a greater sense of purpose in life, greater self-confidence and enhanced sense of spirituality.¹³ Overlapping concepts such as benefit finding (the positive effects that result from a traumatic event⁷) and resilience (an interactive concept whereby exposure to high-risk experiences is associated with a relatively positive psychologic outcome despite the experience¹⁴) are also postulated to account for psychologic change associated with enhanced well-being following such events. Such experiences have been described in relation to cancer in the empiric literature.^{6,7}

TRAUMATIC NATURE OF CANCER AND ITS TREATMENT

Cancer and its treatment present unique traumatogenic features that distinguish it from discrete trauma such as motor vehicle accidents. These include a lack of clarity as to what are the critical stressor(s), i.e. diagnosis, treatment, side effects, changing prognosis, the chronicity of the disease course, the associated uncertainty of its life-threatening nature with prolonged, repeated or multiple stressful life events, and the internal origin of the threat with associated inability to avoid the stressor.^{2,3} Little is known regarding the differential risk of the various cancer and treatment-related events towards the development of a posttraumatic stress response.

Although a key feature of a posttraumatic stress response is the linkage of symptoms to the traumatic stressor, the chronicity of cancer-related stressors may repeatedly reintroduce threats to life or bodily integrity. Nevertheless, chronicity is not unique to cancer, as it is also a feature of

war, domestic violence and incest. The chronic nature of the threat to life and to bodily integrity posed by cancer follows from the initial diagnosis to diagnostic and treatment interventions, and on through recurrences and the fear of recurrence. In regard to the latter, the affected person can perceive cancer recurrence as an immediate threat, and the fear of recurrence could be described as a sense of serious current threat.¹⁵ Indeed, a preliminary study of people with hematologic cancers found that those with high levels of recurrence fears have higher levels of traumatic stress response symptoms than those with low to moderate recurrence fears.¹⁵

DIAGNOSIS AND PREVALENCE OF POSTTRAUMATIC STRESS RESPONSES

Acute stress disorder (ASD) was first introduced in DSM-IV and describes trauma responses that range from 2 days to 4 weeks in the initial month following a traumatic event, after which PTSD must be considered. ASD differs from PTSD by its greater preponderance of dissociative symptoms. In addition to experiencing or witnessing the life-threatening nature of cancer and responding to it with intense helplessness, hopelessness or horror, 3 dissociative symptoms must be identified, including emotional numbing, reduced awareness of one's surroundings, derealization, depersonalization and dissociative amnesia.

PTSD is diagnosed 1 or more months after the diagnosis of cancer. PTSD symptoms include:

- 1 or more re-experiencing symptoms: nightmares, flashbacks, intrusive thoughts, emotions or images that may include future-oriented fears about one's health
- 3 or more avoidance symptoms: detachment, restricted affect, withdrawal from others, inability to recall aspects of the trauma, and avoidance of thoughts, activities and reminders of the trauma
- 2 or more arousal symptoms: hypervigilance, decreased concentration, increased startle response, insomnia and irritability
- evidence of significant distress or impairment of functioning.

PREVALENCE OF PTSD IN PEOPLE WITH CANCER

The reported prevalence of cancer-related PTSD ranges from 0% to 35%, depending on methodology and demographic characteristics of participants.^{2,3} Rates of 3% to 4% have been reported among those with early-stage cancer, and of up to 35% following cancer treatment. Based on DSM-III-R criteria, lifetime prevalence of PTSD among the general population was assessed to be 5% to 6% among men and 10% to 14% among women — rates thought to be higher using DSM-IV criteria.⁸ However, many view posttraumatic stress responses on a continuum.^{2,3,12,16,17} Subclinical PTSD has been reported among 5% to 13% of those with cancer.

The parents of children with cancer are at great risk of traumatic stress response syndromes, given their role in witnessing and responding to their child's potentially life-threatening illness. In a community sample, the subjective components of intense fear, helplessness and horror were most commonly reported in response to the traumatic

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events of rape and to a child's life-threatening illness.¹⁸ A systematic review of traumatic stress response syndromes among childhood cancer survivors and their parents reported prevalence ranging from 0% to 21% among the children and 9.8% to 44% among parents — rates that were significantly higher than among the general child and adult populations.¹² There is some evidence that posttraumatic stress may also develop among siblings of children with cancer¹⁹ and among the spouses of those with cancer.²⁰ The most consistent predictor of posttraumatic stress symptoms among partners of women with metastatic or recurrent breast cancer was the anticipated impact of the loss.²⁰ The following example illustrates how the partner of a woman with cancer presented with symptoms of posttraumatic stress disorder several years after her diagnosis:

A husband of a woman diagnosed with a brain tumour 3 years earlier presents with high levels of anxiety, a desire to avoid the cancer care centre (as it reminded him of his wife's diagnosis and treatment), intrusive memories of the time surrounding her diagnosis and hypochondriacal concerns with fears of his own death. He fears the responsibility of raising his 3 daughters and is hypervigilant to safety concerns for them. Treatment with an SSRI was instrumental in reducing anxiety and intrusive symptoms.

Many patients presenting with PTSD have comorbid psychological disturbances⁸ that must be considered in those with cancer-related PTSD, including depression, grief, substance abuse, being suicidal and other anxiety and adjustment disorders. Further, illness and treatment-related symptoms of cancer are frequently similar to PTSD symptoms, and may lead to overdiagnosis or misdiagnosis of PTSD. In this regard, clinical assessments can disentangle such symptoms and clarify their etiology.

RISK AND PROTECTIVE FACTORS

Cross-sectional and retrospective studies on the predictive value of both demographic and medical variables for the development of cancer-related PTSD are limited and often provide mixed evidence regarding the predictive values of specific variables.^{2,3} A recent review of both childhood cancer survivors and their parents determined that traumatic stress responses were more common among females than males,¹² consistent with the general trauma literature among civilians.⁸ Although several reports have not found cancer stage to be predictive of stress response syndromes, the spectrum of disease stages is often not represented in the studies. Stress response symptoms have been found to be more directly related to disease stage than have anxiety and depression.²¹ Among trauma survivors presenting to an emergency room, however, while major depression and PTSD were independent sequelae with similar prognoses, interaction between the syndromes increased distress and dysfunction.²² More recent diagnosis and treatment, greater treatment intensity and recurrences have been associated with more frequent or greater severity of stress response syndromes.³

A prospective study of lung cancer and ear, nose and throat cancer patients that evaluated features of stress

responses as predictor variables found that having heightened dissociative responses at the time of cancer diagnosis was a strong predictor of cancer-related PTSD at 6 months' followup, and the sole predictor of the severity of PTSD at 6 months.²³ Elevated emotional distress within the initial month following a cancer diagnosis was also a key determinant of PTSD at 6 months, whereas cancer-related variables were not predictive of subsequent PTSD. Similarly, a meta-analysis of 68 studies of non-cancer related PTSD found peritraumatic dissociative responses to be the strongest predictor.²⁴ Kangas and colleagues found a strong trend toward a predictive relationship between cancer-related ASD and subsequent PTSD.²⁵

Ozer and colleagues' comprehensive review of non-cancer related PTSD²⁴ found that predictors included a history of prior trauma, previous psychologic adjustment, family history of psychiatric disorders, perceived life threat during the trauma, posttrauma social support and peritraumatic emotional responses. Reviews of cancer-related PTSD similarly find that prior trauma may have a priming effect and that a history of recent multiple life stressors predicts distress after cancer.^{2,3} In this regard, prior exposure to traumatic and recent life events was significantly associated with PTSD symptoms among those with cancer and among parents of children with cancer.^{12,26} Second-generation female Holocaust survivors are reported to have greater stress response symptoms at 8 months to 8 years following a diagnosis of breast cancer than women whose parents were not Holocaust survivors.²⁷

Emotional and instrumental support provided by family, friends and health professionals can positively affect the mental health of those with cancer. In this regard, greater perceived social support was reported to be protective against traumatic stress responses in women with breast cancer.²⁶ In people with advanced cancer, criticism by one's spouse is reported to increase intrusive thoughts.²⁸ Problematic communication by parents when one of them has cancer predicts posttraumatic symptoms among sons and daughters.²⁹ Similarly, one of the reported predictors of PTSD among women with cancer is problems in communicating with health professionals.³⁰

An example of the positive impact of clear, optimistic communication by health professionals in a case of early-stage cancer is as follows:

A professional woman presented with renewed feistiness and desire to address difficult personal decisions following surgical management of early-stage endometrial cancer. She had a 3-year history of PTSD subsequent to intimate partner violence. In contrast to the perceived mixed messages she previously experienced from health and legal professionals in response to her domestic situation, she reported that the gynecologist helpfully communicated with clarity, certainty and optimism regarding her cancer management.

MANAGING CANCER-RELATED STRESS RESPONSE SYNDROMES

Increased awareness of the risk and presence of traumatic stress response syndromes among people with cancer may

lead to earlier identification and appropriately timed interventions. The importance of monitoring emotional distress as a core indicator of the cancer patient's well-being is now well recognized.³¹ If distress is identified, the differential diagnoses must include posttraumatic stress responses. It is also necessary to disentangle intrusive and hyperarousal symptoms of traumatic stress syndromes from recurrent thoughts about the illness and insomnia due to illness or its treatment. Persons with cancer and their caregivers should be actively encouraged to rely on existing support networks.

Given the paucity of treatment literature specific to the cancer population, treatment interventions currently provided for those with cancer-related PTSD are primarily informed by the general PTSD literature. Goals include reducing the severity of symptoms, preventing or treating comorbid psychiatric illnesses, improving adaptive function and restoring a psychological sense of trust and safety.³² Both pharmacotherapy and psychological treatments have been successfully used separately or together in the treatment of PTSD.³²⁻³⁴ Treatment choice may depend on the patient's current point in the trajectory of cancer and treatment, accessibility of and motivation for psychological interventions, and urgency of treatment. Among those who develop ASD, PTSD or subclinical PTSD, empirically supported psychological treatments include exposure therapy, cognitive behavioural therapy, eye movement desensitization and reprocessing (EMDR) and psychoeducation³⁵ — ideally instituted within 2–3 weeks. Educational materials may assist by describing the expected physiologic and emotional responses to trauma, encouraging self-care tasks, outlining the importance of remaining mentally active and describing stress-reduction techniques such as breathing exercises and physical exercise. Multi-session interventions provided by highly trained therapists were most useful in mitigating posttraumatic symptoms in medical patients.³⁶ A standard psychoeducational support group for women with breast cancer was found to reduce PTSD symptoms.³⁷

Selective serotonin reuptake inhibitors (SSRIs) are the first-line psychopharmacologic treatment for both men and women with PTSD and are also used for ASD.^{32,34} Fluoxetine, sertraline and paroxetine have all been shown to reduce symptoms of intrusion, avoidance, numbing and arousal.

POSTTRAUMATIC GROWTH

Some individuals report that the experience of cancer and its treatment elicits personal growth. The concept of posttraumatic growth encompasses such components as increased investment in and satisfaction with relationships, greater compassion, changed philosophy of life, living more in the here and now, willingness to try new things, greater capacity to cope and increased self-reliance.¹³

Benefit-finding allows positive reappraisal of a traumatic event. It is a cognitive coping strategy used to reduce distress that women are more likely to use than men. When measured some time after the event, benefit-finding reflects the individual's perceived change or posttraumatic growth.⁷ Among people with hematologic cancer, a greater sense of coherence or seeing the world in ways that facilitate successful coping was found to be associated with lower recur-

rence fears and lower levels of posttraumatic symptoms.¹⁵


Posttraumatic growth is complicated, non-linear, multifaceted and moderated by many factors. Growth may include instituting change to better one's life following a traumatic event, although the change itself could be experienced as disruptive, contributing to distress. Although perceived growth has been linked to optimism, people with cancer who report both positive and negative life changes in response to their illness are found to have the best adjustment. The empiric literature suggests that posttraumatic growth is most evident 2 or more years following the event.⁷

The case of a man treated for advanced prostate cancer illustrates the mixed nature of the experience of posttraumatic growth:

A male in his mid-50s in his third marriage states matter-of-factly that he does not expect to live another full year. He was sorely disappointed that his lowered energy required that he discontinue working, reducing his ability to provide financially for his family. However, he now spends a few hours each day pursuing valued hobbies and has reconciled with estranged adult children, and takes great pleasure in spending time with grandchildren.

RECONCILING POSTTRAUMATIC STRESS SYNDROMES AND POSTTRAUMATIC GROWTH FOLLOWING CANCER

Parallel to the growing literature that provides empiric support for the utility of a trauma model in cancer,³ a survivorship model of cancer care has been endorsed.³⁸ The founding members of the National Coalition for Cancer Survivorship, the oldest survivor-led cancer advocacy organization in the U.S., adopted a survivorship model emphasizing that most people with cancer survive years beyond diagnosis and treatment. This group aims to foster hope and to alter doctor-patient communication, promoting early dialogue regarding the long-term or late effects of cancer that may affect choices in cancer care. To reconcile research evidence indicating that cancer may contribute to posttraumatic stress responses in some people and be followed by positive outcomes in others, thus recognizing that cancer may be associated with both positive and/or negative psychosocial consequences, it has been suggested that cancer be seen as a psychosocial transition.¹³

Overall, cancer is recognized as an adaptive challenge to the majority of those affected. Some individuals with cancer and/or their loved ones develop a full or subclinical traumatic stress response syndrome if they respond with intense fear or helplessness to the traumatogenic stress of cancer and its treatment. Prospective research is required to identify the elements of cancer and its treatment that contribute to a traumatic stress response, the trajectory of PTSD and subclinical forms, and ways to prevent such responses from occurring. Prevention and treatment must also consider the family members of those with cancer. 

Disclosure

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