

Psychological and behavioural considerations in young adult suffering from malignancy

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Late in the winter of my seventeenth year, my mother decided I was depressed, presumably because I rarely left the house, spent quite a lot of time in bed, read the same book over and over, ate infrequently, and devoted quite a bit of my abundant free time to thinking about death. This was the beginning of the book 'The fault in our stars', by John Green, which was made a successful movie. Indeed this sentence depicts the behavioural response after diagnosis of cancer in most individuals.

Psychological aspects of young adults and their responses to imminent doom are often left uncared by the attending oncologists.

Problems: The impact of diagnosis and treatment of cancer on their physical appearance, sexual development, and can lead to shame, social isolation, and regressive behaviour if not addressed promptly. Interruptions of school or work due to treatment will have negative consequences for their long-term career opportunities, financial status, and lifetime earnings.

Young patients with cancer may also engage in risky behaviours (tobacco, alcohol, or substance abuse) that may impair their health. Older age at cancer diagnosis, lower household income, less education, no pulmonary-related cancer treatment, and no brain RT were independently associated with a statistically significant relative risk of smoking initiation. The risk factors associated with heavy drinking included fair or poor self-assessed health, depression, anxiety, somatization, activity limitations, and cancer-related fears and uncertainty.

Younger patients (less than 50 years of age) may be more susceptible to anticipatory nausea and vomiting, because they generally receive more aggressive chemotherapy and have poorer emesis control than older patients. Young cancer patients 20 to 29 years of age are significantly less likely to use professional mental health services than teens and older patients 30 to 39 years of age.

Assessment: Young men and women go through developmental stages marked by rapid changes in cognitive and emotional growth, and these issues need to be considered while delivering developmentally appropriate psychosocial and supportive care to young patients with cancer. Palmer et al have recently developed a Young Adult Oncology Psychosocial Screening Tool to assist clinicians to support psychosocial coping during active treatment and promote healthy post-treatment survivorship in young patients with cancer. This screening tool has four main areas: the distress thermometer, the check list of "areas of concern," the tick box for information provision, and the signatures. Further validation of this tool and its use will help clinicians to improve psychosocial care for AYA

patients with cancer, regardless of treatment location.

What should be done: During the treatment period, *these patients should have the opportunity to live as normal a life as possible, continue their education and/or careers, and participate in the many milestones of their lives.* Young adult patients diagnosed with cancer should be recognized as a distinct age group that has unique medical and psychosocial needs.

Peer support programs assist these patients and survivors in establishing and maintaining relationships with their normal peers as well as with other young adult patients with cancer, offer opportunities to achieve age-related developmental tasks (building interpersonal and problem-solving skills), and promote positive psychosocial growth.

Communicating information to patients can be challenging, especially since there are several subgroups within the population with different levels of cognitive and emotional development. It is very important to establish direct communication with the patients on an individual basis, with sufficient sensitivity to each patient's needs and preferences. While some patients prefer not to receive direct communication about their cancer, others may desire to take a more prominent role in the management of their care. For the latter group, information should be provided directly to patients in an age-appropriate manner, allowing time to process the information and deliver information in a caring manner. Young adult patients prefer that information about their cancer and cancer-related risks be communicated to them in a manner that is positive, respectful, and non-judgmental.

The physician should **promote communication** between patients and family members (parents, spouse/partners, and siblings), provide information to family members and partners about psychosocial support and behavioural services to increase awareness of the possible psychosocial issues associated with diagnosis of cancer, consider family-based intervention models from paediatrics (eg, parent support groups, Impact of Traumatic Stressors Interview Schedule), establish direct communication with the individual patients, providing age-appropriate information about their cancer, treatment options, and potential side effects, thus reinforcing the importance of patient involvement in decision-making. Face-to-face meetings, camp and retreat programs, online support groups may be helpful. Some patients prefer not to share information about their cancer with their family in an effort to shield their family members from some of the things they themselves worry about. Therefore, obtain their permission to share information with other family members. Behavioural therapy has been used in patients with anticipatory nausea and vomiting.

End of life care: In one retrospective review, a significant number of adolescents dying of cancer felt that discussions about end-of-life occurred very close to death, thus allowing very little time to psychologically prepare for death. *It is imperative for healthcare professionals not to assume that young cancer patients may be less inclined to discuss death and other end-of-life issues.* Discussion about end-of-life preferences should begin early in treatment, but details should be individualized according to the preferences of the

patient and family. Many adolescents indicate a preference for dying at home, yet 80% die in hospitals. Physicians with experience in palliative care should facilitate discussion about end-of-life care issues such as nutrition/hydration, sedation treatment cessation, and place of death. An advance care planning document is necessary for terminally ill patients with metastatic cancer. Ongoing psychosocial support is extremely important during the transition to end-of-life care. For family and friends, grief from loss may begin before death.

At the end of the novel I began my discussion with, Hazel Grace, the central character suffering from recurrence of malignancy lives. She receives an e-mail from her boyfriend Augustus who was her chief motivator in the peer group, but himself dies from cancer. The mail included inspirational quotable: 'The real heroes are not the people doing things, the real heroes are people noticing things, paying attention. Almost everyone is obsessed with leaving a mark upon the world. Bequeathing a legacy. Outlasting to be remembered. I do, too. That's what bothers me most, is being another unremembered casualty in the ancient and inglorious war against disease'. That's the end.