Chapter 15

Patient Resources in a Cancer Center

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Introduction

Treatment of cancer is complex and requires clinical expertise, close surveillance, and supportive therapies, among others, to help manage untoward side effects resulting from antineoplastic regimens. These therapies expose patients to adverse consequences such as increased organ toxicity that could adversely affect overall quality of life. For instance, childhood cancer survivors are at a higher risk of being unable to work or missing work because of poor health; they also report difficulties with obtaining insurance coverage, hence posing a challenge to adherence to optimal care [1]. A childhood cancer survivorship study showed that, in fact, survivors of childhood cancer spend a higher percentage of their income on medical expenses, adversely influencing their future health-seeking behavior and ultimately their treatment outcomes [2].

Novel targeted therapies with better toxicity profiles, vis-à-vis conventional chemotherapies, have become an integral part of treatment algorithms for various solid organ neoplasms and hematologic malignancies; they are already changing the treatment paradigm of various cancers [3–9]. However, these new therapies are expensive, especially when required to be taken for a long time [10, 11]. Unfortunately, patients with cancer are at high risk for substantial treatment-related costs owing to the high cost of these novel therapies. Apart from the high cost of therapies, availability of high-resolution genomic analysis of tumors, and other technologies, which are being used for more accurate diagnosis and prognostication have further added to the already elevated cost of treating cancer [12–14].

A recently published longitudinal study aimed at evaluating the impact of cancer on patient's debt in the United States found a substantial proportion incurring financial toxicity and asset depletion [15]. This is also the case for parents of children

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receiving anticancer therapies [1]. Below, we describe resources that are generally available to cancer patients to help cope with stressors associated with cancer care and to address their medical, financial, and spiritual needs, among others.

Available Resources

Education

Patient education is an essential requirement when developing a plan of cancer care. Education represents a continuum which is provided by several members of the treatment team, namely, hematologists/oncologists, advanced practice providers, nurses, nutritionists, and pharmacists, among others. Below, we describe available educational sources for patients, whether related to disease-specific, antineoplastic drugs and supportive therapy education.

Disease-Specific Education

Several cancer societies provide disease-specific education to patients with cancer. We summarize a small selected sample of societies and organizations:

- (a) AA-MDS International Foundation (www.aamds.org).
- (b) American Cancer Society (ACS) (www.cancer.org).
- (c) International Myeloma Foundation (www.myeloma.org).
- (d) Leukemia & Lymphoma Society (www.lls.org).
- (e) Melanoma Research Foundation (www.melanoma.org).
- (f) National Cancer Institute (NCI) (www.cancer.gov).
- (g) Susan G. Komen, originally known as The Susan G. Komen Breast Cancer Foundation (www5.komen.org).

Treatment Education

Below we summarize the most common types of antineoplastic therapies offered to patients apart from surgical tumor resection. We also highlight selected educational sources available to patients.

Conventional Chemotherapy

Conventional chemotherapy, alone or in combination with targeted therapies, remains an important treatment for various hematologic malignancies such as acute myeloid leukemia, acute lymphoblastic leukemia, lymphomas, breast, lung and

colorectal cancer, among many others. Side effects associated with chemotherapy vary according to each agent, but generally result in bone marrow toxicity which manifests as pancytopenia and could increase risk of infections, and organ toxicity manifesting as alopecia, mucositis, enteritis, cardiomyopathy, hemorrhagic cystitis, and others. When severe toxicity ensues, it can result in death. Therefore, it is important to empower the patient with the necessary knowledge about commonly occurring side effects associated with specific chemotherapies to ensure more successful outcomes. This information is generally available in the package inserts that is found online for each specific antineoplastic agent. Others sources of information include the drug manufacturer, the ACS (www.cancer.org), and the NCI (www.cancer.gov).

Targeted Antineoplastic Therapies

Treatment of cancer has evolved over the past three decades. Nowadays, the backbone of anticancer treatments relies more heavily on targeted therapies, also known as precision medicine. It is a type of cancer treatment characterized by a more specific mode of action than conventional chemotherapy, through targeting specific genes and proteins involved in the growth and survival of cancer cells. It can either affect the tissue environment of cancer cells, or disrupt other key mechanisms essential for cancer growth and proliferation. Targeted therapies may be used as monotherapy; for example, in chronic lymphocytic leukemia and chronic myeloid leukemia; or in combination with other cancer treatments, namely, chemotherapy, surgery, or radiation in the case of solid tumors like lung, breast, and colorectal cancer. Below, we summarize several available online sources, apart from drug manufacturers, to educate patients about targeted therapies:

- (a) The American College of Physicians (ACP) offers a library of patient education materials accessible through the following hyperlink: <https://www.acponline.org/practice-resources/patient-and-interprofessional-education>. ACP is currently replacing its online library with a new Patient and Interprofessional Partnership initiative, delivering high-quality, patient-centered, interprofessional education resources for internists, patients, and their clinical teams.
- (b) UpToDate is another platform offering patient education through two levels of content: “The Basics,” which are short overviews in easy-to-understand language aimed at answering important questions a patient may have about a medical topic; and “Beyond the Basics”, which are extensive, more detailed reviews with some medical terminology. Information about targeted therapies is included within each type of cancer (<https://www.uptodate.com/contents/table-of-contents/patient-education/cancer>).

Following is a list of other selected resources for patient education on cancer-targeted therapies:

- (a) The NCI: <https://www.cancer.gov/about-cancer/treatment/types/targeted-therapies/targeted-therapies-fact-sheet>

- (b) My Cancer Genome: <https://www.mycancergenome.org/content/page/overview-of-targeted-therapies-for-cancer/>
- (c) The ACS: <https://www.cancer.org/treatment/treatments-and-side-effects/treatment-types/targeted-therapy.html>
- (d) The National Comprehensive Cancer Network (NCCN): https://www.nccn.org/patients/resources/life_with_cancer/treatment/targeted_therapy.aspx

Radiation Therapy

Since its discovery in the nineteenth century, radiation has been used in medicine through several applications [16]. In the field of cancer therapeutics, radiation therapy is one of the primary treatment modalities, exerting its action by directly killing cancer cells or causing DNA damage leading to tumor cell death [17]. Cancer patients also benefit from the option of radiation therapy in the palliative care setting, for example, to relieve pain caused by bone metastasis or cytreducing large tumor masses obstructing the airway in head and neck cancers [18]. Constant advancements in this area enhanced the accuracy and quality of radiation delivery, increasing the survival rates for many patients [19]. Damage to healthy tissue near the treatment area results in multiple side effects, commonly skin problems (dryness, itching, blistering, or peeling), and fatigue [20]. Other side effects are site-specific: for instance, radiation therapy aimed at head and neck tumors causes dry mouth, difficulty swallowing, mouth sores, nausea, hair loss, and tooth decay [21]. Chest radiation may result in lung fibrosis, radiation pneumonitis, cough, fever, shortness of breath, and cardiovascular side effects [22]. Radiation therapy for solid malignancies is also associated with higher risk of acute leukemias and non-Hodgkin lymphomas [23].

Multiple educational resources for patients on radiation therapy benefits and side effects are available on the American Society for Radiation Oncology (ASTRO) website (<https://www.astro.org/Patient-Care-and-Research/Patient-Education>), including brief videos, patient brochures, and radiation therapy presentations. With the emergence of modern virtual environments, radiation therapy patient education has witnessed the rise of two recent educational tools, namely, the Virtual Environment for Radiotherapy Training (VERT) and the Patient Education And Radiotherapy Learning (PEARL). The VERT system relies on a three-dimensional interactive radiotherapy treatment room that replicates realistic movements, sounds and even a visible radiation beam, suitable for both patient education and residency training [24]. Similarly, the PEARL system uses common features including a virtual patient and treatment room environment, but with limited functionality as it was solely conceived for the purpose of patient education [25]. Such rich visual displays and virtual environments constitute an innovative approach in radiation therapy patient education; however, they should be tuned to every cancer center's budget and capacity [26]. Their roles in supporting psychological and health-related patient outcomes are still under investigation.

Supportive Therapies

Availability of effective supportive therapies have facilitated timely administration of chemotherapy, chemoimmunotherapy, other targeted therapies, and radiation therapy. These supportive therapies include but are not limited to:

- (a) Antiemetics to prevent nausea and vomiting.
- (b) Antimicrobials (antibacterials, antifungals, and antivirals).
- (c) Bisphosphonates or equivalents.
- (d) Granulocyte-Colony stimulating factor (G-CSF) that stimulates the bone marrow to produce granulocytes.
- (e) Intravenous fluids and electrolytes.
- (f) Transfusion of blood products (red blood cell and platelets). In certain cases, patients may need infusions of fresh frozen plasma and cryoprecipitate.

Education about the side effects of these therapies are generally provided by treating hematologists/oncologists, nurses, and pharmacists. More detailed information is available at the manufacturer website or online drug package insert.

Supporting Services

Financial

Receiving a diagnosis of cancer not only imposes health-related challenges on the patient, but also results in “financial toxicity,” a term coined to describe the financial hardships associated with the cost of cancer treatments. Patients experiencing financial burden elect to alter care to defray out-of-pocket expenses [27]. Moreover, high treatment expenditures have been associated with nonadherence and poor clinical outcomes in several studies [28–30]. Accordingly, the NCI recommends offering financial counselling services at cancer treatment centers to help patients and their families understand the scope of the problem and plan better on how to manage their anticipated expenses. In the absence of proper counselling, financial toxicity bears material and psychological consequences [31]. Material consequences are mainly monetary owing to reduction or loss of income, time away from work, depletion of savings, and ultimately bankruptcy [32]. Interestingly, cancer patients are twice more likely to file for bankruptcy as compared to people without cancer [33]. On the other hand, psychological consequences translate into increased stress, worry, and decreased quality of life [34]. As a result, cancer patients develop maladaptive coping behaviors to lower their cost of care, such as not showing up to scheduled visits, medication noncompliance, omitting doses, and neglecting refills [35].

Apart from financial counselling, patients are encouraged to seek financial help starting from oncology social workers, case managers, physicians, and oncology nurses who can provide referrals to financial resources and support services, in addition to contacts with national, regional, and local organizations for financial

support. The ACS website also offers a list of programs and resources dedicated to help with cancer-related expenses like housing, transportation, caregiver expenses and food costs, accessible through the following hyperlink: <https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-financial-and-legal-matters/managing-costs/programs-and-resources-to-help-with-cancer-related-expenses.html>.

Palliative Care

Integration of palliative care into standard oncology management at the time of cancer diagnosis is essential for optimal quality care, based on evidence from clinical trials [36]. Palliative care services focus on approaching the patient as whole, communicating about goals of care while accounting for patient preferences [37]. This comprehensive approach addresses the quality of life, physical, psychological, emotional, religious, spiritual, and family concerns, as well as future care plans [38]. As such, offering palliative care to the patient and family caregivers confers additional emotional and psychological benefits by lowering levels of depression, caregiving burden, and psychological distress and anxiety [36].

Current professional guidelines recommend the integration of palliative care early in the disease course, and all throughout the treatment [39–41]. Palliative care is provided by specialists who work as part of a multidisciplinary care team that may include nurses, registered dietitians, pharmacists, chaplains, psychologists, and social workers, in conjunction with the oncology treatment team [38]. The American Society of Clinical Oncology (ASCO) offers a palliative care booklet (https://www.cancer.net/sites/cancer.net/files/palliative_care.pdf) to help cancer patients, their families, and caregivers understand options, find support, and ease the disease challenges. The NCI website also offers a wide platform to explain all about palliative care for patients and their families (<https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/palliative-care-fact-sheet>). Resources for program managers include the palliative care guide published by the World Health Organization that suggests steps for planning and implementing palliative care services at cancer treatment centers (<https://apps.who.int/iris/bitstream/handle/10665/250584/9789241565417-eng.pdf;jsessionid=45331C2A5976BE5888179C10E4737A95?sequence=1>).

While palliative care is provided at every step of treatment and at any stage of cancer, hospice care is a specific facet of palliative care only given to patients with advanced stages of cancer with a life expectancy of 6 months or less [42]. It shifts the focus from direct anticancer treatment to symptomatic relief. Consequently, the patient elects to stop chemotherapy, for example, and receive additional support in all other areas. Hospice is associated with less hospital-based end-of-life medical care, better quality of life, and improved caregiver outcomes [43–46], as well as better symptom relief and patient-goal attainment [47]. Therefore, encouraging earlier hospice enrollment may improve the end-of-life experiences for cancer patients and their families.

Social Workers

Social workers are essential members of the cancer care team. They help address a variety of issues which include, among others:

- (a) Counseling for anxiety, depression, and other emotional aspects of cancer care.
- (b) Identifying resources for financial assistance, compassionate drug assistance programs, disease support groups, or spiritual counseling, etc.
- (c) Helping address and resolve transportation challenges.
- (d) Education of caregivers about the disease.

Case Managers

A case manager is a healthcare professional who has vast clinical disease knowledge and a good understanding of the healthcare industry and payers' dynamics. A case manager is usually a nurse or nurse specialist who oversees all aspects of cancer care and helps patients navigate complex health insurance coverage issues, whether related to specific prescribed drug(s) or supportive services such as rehabilitation and skilled nursing facilities or nursing home placement, if indicated. Their ultimate goal is to optimize quality and cost-effective care in both hospital and outpatient cancer care settings.

Nutritional Therapists

Both the cancer and its treatment(s) contribute to cachexia. Cancer patients are at increased risk of malnutrition due to decreased food intake, adverse effects of cancer therapies, and increase in metabolic waste products. A wide range of negative sequelae result from malnutrition, including prolonged hospitalization, reduced response to cancer treatment, increased susceptibility to treatment toxicity, decreased activity, and impaired quality of life, culminating in a worse overall prognosis [48]. Therefore, proper diet plans and clinical nutrition are paramount. Nutritional therapists are registered dietitians that constitute another component of a cancer patient's care team. They work closely with patients and their families to develop realistic and appropriate diet plans during and after cancer treatment. It is widely agreed that early consultation with a nutritional therapist is beneficial for cancer patients [49, 50], even in advanced stages of the disease [51]. Nutritional support prevents malnutrition, thus improving treatment tolerance and prognosis, while maintaining the patient's functional activity and quality of life [52, 53]. As such, cancer centers provide consultation services with nutritional therapists and registered dietitians who help patients manage their nutritional concerns through personalized diet plans, safe food handling practices, weight management, multivitamin supplements, among others. Patients who fail to achieve adequate energy intake with oral nutritional supplements are offered enteral nutrition options, or tube feeding, provided they have normal gut function. In the absence of proper gut

function or in case of patient refusal or intolerance due to nausea, vomiting or diarrhea, nutritional support is delivered through parenteral nutrition [52, 54–56].

Religious and Spiritual

In the context of patient-centered care, the holistic view of the patient should be addressed all along the cancer care continuum [57]. As such, support services must account for the patients religious and cultural beliefs, among others. Several tools have been developed to assess the religious and spiritual needs of cancer patients, among which are the Faith, Importance and Influence, Community, and Address (FICA) spiritual history tool [58, 59] and the Spiritual Needs Assessment for Patients (SNAP) questionnaire [60]. Once the specific needs are assessed, several interventions could be implemented. For instance, with the permission of the patient, a member of the patient's religious or spiritual community could be contacted [61]. The patient could be referred to hospital chaplaincy or psychosocial oncology providers, including oncology social workers, psychologists, or psychiatrists [61]. In other cases, members of the care team can intervene to address the religious and spiritual needs by offering narratives and psychotherapeutic interventions at bedside or during clinic visits [62]. Those interventions consist of a discussion of a short-term life review [63] and dignity talks [64] that enhance familial relationships with the patient and find purpose in the illness experience. Religious and spiritual support realizes particular prominence during end-of-life care, or once the patient resorts to hospice care.

Discussion

The field of cancer therapeutics has evolved dramatically over the past three decades bringing smarter therapies from the bench to the bedside. While novel therapies have revolutionized cancer care from the mechanistic standpoint, treatment remains complex requiring multiple players beyond hematologists/oncologists and nurses. Pharmacists, social workers, and case managers play an essential role in patient education about drugs and treatment complications, support needs, and financial aspects associated with care. The ultimate goal is to provide all needed support to help cancer patients with their fight against the disease.

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