A Lifetime Voyage With Cancer

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Abstract

Cancer is a group of disease caused by the proliferation of abnormal cells in the body which can form into a malignant tumor. The location and the migration of these abnormal cells from one part of the body to another determines the stage of illness and the treatment line that has to be decided based on its severity. There are four major types under which cancer can be divided- Carcinoma, Sarcoma, Leukemia and Lymphoma. Childhood cancer is like any other cancer that is mainly diagnosed among children and is caused due to mutation or change in genetic material. Adults who are later in life diagnosed with cancer also carry mutated genes from the childhood but, the environmental carcinogens later triggers the growth of cells in the body. Though the cancers diagnosed in childhood is found to be aggressive in nature, the rate of remission among them is also found to be high. Family plays a major role during the course of treatment especially in children diagnosed with cancer. They go through situations like caregiver’s burnout and difficulties with physical and mental well-being. The difficulties that the caregiver goes through also needs to addressed. The role of spirituality has also been emphasized during the course of treatment. Children diagnosed with cancer face difficulties in terms of their physical, emotional and social aspects. Government schemes have also been provided for the families of patients diagnosed with such chronic illnesses. Finally, the importance and the need for palliative care for patients diagnosed with terminal illness like cancer have been addressed. As palliative care aims at providing a better quality of life during their final stages of life and therefore, its necessary to help the patient during such a phase of their life.

Keywords: Childhood cancer, parental role, role of government, continuous treatment, palliative care, psychological interventions.

Introduction

“You can beat cancer by how you live, why you live and in the manner in which you live”- Stuart Scott. (Cancer survivor, STAFF, 2018)

Cancer is not a single disease. It is a group of diseases marked by an uncontrollable rapid growth of abnormal cells which might lead to the formation of a malignant tumor or neoplasm. (Holland, J. C., 2010).

Malignant tumors are the ones that are cancerous in nature. It increases to an extent that the number of abnormal cells present in the body will be more than the normal cells. In some cases, these tumors can migrate from the primary source of origin to secondary sources which further spreads to the nearby healthy tissues resulting in damage of the organ and its functions. This is referred to as Metastases. For example, cancer spreading from lung to brain (Holland, J. C., 2010).

Cancer is a generic disease diagnosed in people of all age groups, irrespective of their age, gender or family background. Cancer can be broadly divided into four types: Carcinomas are malignant tumors that develop in different organs of the body, such as adenocarcinoma, squamous cell carcinoma; Sarcomas are the type of malignant tumors that develop on muscles and connective tissues such as bone sarcoma, angiosarcoma; Leukemia is the cancer of blood forming organs; and Lymphoma are the cancer that develop in the lymph nodes or lymphatic systems of the body, such as Burkitt lymphoma and Follicular lymphoma. Cancer can be found in any part of the body. Most commonly
found cancers are those of breast, brain, colon, lung, bladder, prostate and rectum. Depending on the severity and stage of the cancer, appropriate treatment is given for the patients. Most commonly used methods for cancer are surgery, chemotherapy, radiation therapy and hormonal therapy (Sarafino, 1998).

Childhood cancer just like any cancer that occurs in adults is caused by mutation or change in the genetic material. Adults who are later in life diagnosed with cancer also carry mutated genes from the childhood but, the environmental carcinogens later triggers the growth of cells in the body. Cancers diagnosed at a young age tends to be more aggressive than those diagnosed at older ages. Therefore, the chances of proliferation are double than that of adults, wherein the rate at which the cancer cells multiply tend to slow down. With biology and recent researches, the scope of treatment especially in pediatrics have also increased. The rate of remission among childhood cancers are also found to be high (Holland, J. C., 2010).

One of the reasons can be because of resilience among children. Adults, tend to have uncertainties about themselves and their future and are found to be quite apprehensive. Since children are not much aware about their illness, their family members and other caregivers helps them to fight against the disease and encourage them to be strong and courageous throughout. Having a positive outlook helps to instill hope and enhance the immune system of the individual. Most commonly diagnosed childhood cancers are leukemia (blood cancer), neuroblastoma (cancer found in certain types of nervous tissues), retinoblastoma (cancer of eye), rhabdomyosarcoma (cancer of soft tissue) and bone cancers. Studies have shown that survivors of childhood cancer suffer from chronic illnesses which begins by early or middle adult years. Similarly, cognitive impairments as well that are associated with the treatment of especially head and neck cancers are found both in children and adult cancer survivors. These cognitive impairments affect their development as a whole (Adler, N. E., 1970).

Journey together

Cancer not just affects the patient alone but the family as well. The equilibrium in the family in terms of functioning patterns gets disrupted and affected as a result they have to come up with new and effective solutions to manage the challenging situations. Many researches have shown that role of family plays a vital role in the success of the treatment undergone and has also shown high rates of effectiveness in the treatment (University Hospital Brno, 2006). The family’s perception about the illness, preparing themselves, relationship with the child and the medical support staffs, emotional support, all aids to a complete well-being of the child.

A “family survivorship model” was created by Northouse et al. (2006) which highlights the impact of cancer on the family members and the concerns they experience. It consists of three main variables that is constant fear in the minds of the caregivers regarding recurrence of the illness, burden on the family and physical well-being both for caregivers and patients (especially important for the patient).

One of the noticeable concerns was the length of hospital stays that also contributed to many of the difficulties faced by the caregivers and the patients in terms of financial expense and factors like low self-image, extreme boredom and feelings of helplessness and worthlessness in patients. Due to all these factors, the atmosphere within the family becomes monotonous. Mothers spend most of their time with the ill child, taking care of them and the fathers take care of the household, other members of the family in the absence of the mother and the expenses to be met. To tackle such issues, informal caregivers are also introduced to look after the ill child at home. By increasing the family care givers self confidence in dealing with cancer pain, it will thus improve the quality of life of both the patient and caregiver. Thus, trying to bring back the stability that was disturbed and the new roles that the caregivers were forced to adopt (Pellegrino R, 2018).

According to Matthews et al. (2004), spirituality plays a predominant role in the lives of caregivers and patients who are diagnosed with a chronic illness and is also the most highly ranked component in cancer survivor caregivers. It can be equally seen in families with patients who are still
undergoing the treatment (Vad'urová, 2007). This dimension includes spiritual well-being, feeling of spiritual support, effectiveness, hope, feeling of sense and overall satisfaction with life.

The care givers and other people associated with working with cancer patients like oncologists, psychologists, nurses and social workers needs to be mentally and physically strong to help the patient fight the disease. Family burden and ‘burn out' among caregivers is a widely noted phenomenon experienced by people working in areas related to trauma and chronic illnesses. It is a situation wherein the individual is unable to experience joy and also face difficulties in areas like planning, decision making etc. due to excessive physical, mental and emotional exhaustion. It is an equally common phenomenon observed among medics as well working in areas related to oncology and trauma.

Role of communication is another important area especially in the field of pediatric oncology. Inadequate information can cause anguish and miscommunication further causing emotional distress for the healthcare providers and family members. Studies have showed that parents show protective attitude towards their children. Therefore, communication patterns and strategies should be taught to the health care providers in terms of eliciting information (Singh, Raj, Paschal & Hussain, 2015).

Post-traumatic stress disorder and post-traumatic stress symptoms are some of the common phenomenon that overshadows the family soon after the diagnosis of any terminal illness like cancer (Aaron, 1999). The symptoms can be prominent during the course of treatment or after the treatment. The experience of traumatic stressful symptoms are not only because of the diagnosis but also due to the distressful, intrusive thoughts that comes to one’s mind. This can be usually seen in families with children suffering from cancer or individuals themselves suffering from cancer (Kazak, 2004). To overcome the stress and difficulties faced by the individual and the caregivers, methods like relaxation techniques, psychotherapies such as Trauma focused Cognitive Behavior Therapy, Eye Movement Desensitization and Reprocessing etc. can be used. Along with the above mentioned therapies, mindfulness practices can be integrated for maintaining the life peacefully for the childhood cancer survivors and for their parents (Sathiaseelan & Balasundaram, 2014)

**Challenges faced by the Child**

Children diagnosed with cancer go through a traumatic experience in terms of acceptance, undergoing invasive treatment procedures, facing difficulty to attend school regularly due to therapy cycles, to face new people and in some cases develop poor self-image. The dreadful disease affects the physical and emotional aspects of the child’s life thus making the child’s quality of life poor. In researches done in the field of psycho oncology or the branch dealing with psychological aspects in patients suffering from cancer, especially children, results have shown that children go through psychological problems like behavioral disturbances and adjustment issues (Noll Ret. al., 1999). It refers to the constant problem in the child’s behavior which disrupts the interpersonal relationships of the child further affecting their relationship with the family, life and society.

The social and emotional problems in children who undergo treatment have reported to have experienced increased levels of distress which is more influenced by the psychosocial aspects than the physical facets of the illness. (Earle EA, Eiser C., 2007). It is important to know about the child’s feelings and emotions and evaluate the difficulties they go through during the time of treatment in order to help them and bring effective changes in the interventions which will further aid to the treatment and yield a constructive outcome. Understanding the child and what he or she is going through can help in building trust and support the patient through his/her journey. The problems faced by the patients are not just limited to the period of treatment rather some life changing side effects persists for years and may vary from person to person. The side effects experienced by the person depends on the medicines given and the susceptibility of the body condition. Some might experience side effects such as nausea, changes in taste, difficulty in swallowing, complaints of constipation mild rashes etc., whereas some might experience shivering, extreme vomiting, severe body pain (which cannot be controlled without medication) and other such symptoms (Marina, 1997).
Researches have shown that come children who underwent intensive chemotherapy have chances of developing cognitive problems ("Children with cancer also face challenges as survivors", 2017). In some of the case studies it is shown that as a result of intensive chemotherapies for cancers like leukemia etc., children tend to show some kinds of cognitive problems which was earlier not present such as taking longer than usual to do a certain task. Issues like cognitive problems occur because in some cases where the cancer is aggressive, the doctors might give interthecal therapy wherein the chemotherapy is passed through the blood brain barrier by injecting it directly into the spine. The range of side effects may vary from individual to individual. Some children might have seizures because of this form of therapy whereas some might have difficulty processing information.

Support from the Government

There have been many schemes and provisions provided by the government for patients and family members of patients suffering from chronic illnesses. Government has come up with various welfare schemes and funds such as Ministry of Health & Family Welfare and Health Minister’s Cancer Patient Fund (HMCPCF), in order to help patients from below poverty line and provide assistance to other poor patients who cannot afford the expenses of the treatment. Some other schemes that mainly focus on welfare of the cancer patients are Central Government Health Scheme (CGHS) which is valid only for retired Central Government employees and dependent relatives. This scheme can be used at any hospitals or health care set ups apart from the ones registered under Central Government Health Scheme and offers coverage for treatment of cancer at appropriate rates.

Similarly, reservation facilities are provided for patients with cancer and certain amount of concessions for the attenders of the patient. Certain state specific schemes are also available for cancer patients such as Rajiv Aarogyasri Heath Insurance Scheme which started in the year 2007 mainly for the people falling in the category of Below Poverty Line, to provide them with quality health care services. Cancer Suraksha Scheme is an initiative started by the government of Kerala on 1st November 2008, for the families of children below the age of 18 years who cannot afford the expenses of the treatment. This scheme covers the cost of drugs, implants and procedures involved in the treatment and not the treatment procedure as a whole. Mahatma Jyoti bha Phule Jan Aarogya Yojana is a health insurance scheme which is offered by certain states like Telangana, Kerala and Maharashtra. The main advantage of such scheme is to help patients from poor socio economic background who are diagnosed with cancer and who deny seeking help because of the expensive treatment procedures involved.

In the article “Food Service Provisions for the Cancer Patient” by A. Millard in the year 1991, Health related provisions such as food service provisions are also given for cancer patients in some parts of the world. Food related provisions are not very common as not much attention is paid to the nutritional difficulties faced by the patient. In most of the hospitals, regimented meals are provided to the patients as decided by the hospital staffs and not according to the patient’s needs. Commonly seen side effects of therapies include symptoms of nausea, vomiting, difficulty swallowing.

Due to all these symptoms, patient’s appetite is lost, making the body more vulnerable to other diseases and not strong enough to accept the high dosage of medications. Therefore, nutritious food should be given to the patient based on their needs and requirements. Similarly, more importance is to be given for provisions related to health and well-being of the patient.

Palliative care and Support

Palliative care is given for patients who are diagnosed with chronic life threatening illness like cancer. It does not aim at curing the patient instead improving the quality of life of the patient throughout the treatment and helping them cope with the symptoms. It is also called as comfort care, supportive care and system management (‘Palliative care in Cancer”, 2017).

In patients where medications or therapies will not work anymore in killing the cancer cells or when the cancer is in advanced stages, palliative care is the only focus. During the palliative care, the
A person is helped to cope with his or her emotions. Anxiety problems, depression regarding illness, financial difficulties related to it are also addressed with the help of counselling during palliative care. Just like how cancer not only affects the individual but the family members and the care givers as well, similarly emotional difficulties can be experienced both by the patient and the care givers. Therefore, the caregivers can also seek palliative care to cope with their emotions and other worries related to the illness (Zahm & Devesa, 1995).

Posttraumatic Growth is a term devised by Tedeschi and Calhoun (2004) which refers to the positive adaptive changes that occurs in an individual after a traumatic event or experience in their life. It is widely used especially in the field of psycho oncology wherein the patients are asked to find meaning and benefits from their traumatic experience such as diagnosis of a chronic illness. Most of the people have been seen to ruminate over the unwanted happenings in their life. At the same time, posttraumatic growth helps the individual to create a positive outlook about their life and therefore having a better psychosocial wellbeing (Ahuja, R & Sathiyaseelan A, 2018).

Researches have shown that palliative care has been very effective and its components have helped both the patients and the care givers as their symptoms have been controlled and can also communicate about their emotional needs effectively which in turn has shown improvement in the quality of life (“Palliative care in Cancer”, 2017). This care therefore aims at helping the patient spend their time with less of rumination and more of thoughts that would soothe their mind.

“When it rains, look for rainbows. When it’s dark, look for stars.”– Oscar Wilde (“A quote by Oscar Wilde”, 2018)

References


