

Rajiv Gandhi CANCER INSTITUTE & Research Centre

Newsletter

Price: 50 Paisa Issue: Aug. 2011

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EDITORIAL

From the Diary of a Cancer Patient!!!

Cancer patients are usually compulsive givers till depletion and exhaustion. Over and over again, I hear friends and relations say 'she was a saint, why she'. Generous people predominate among cancer patients because they put the needs of others ahead of their own. Cancer might be called the disease of nice people. They are "nice" by other people's standards. They are conditional lovers. They give love in order to receive love. If their giving is not rewarded, they are more vulnerable to illness than ever.

My job as a clinician is not only to find the right treatment but to help the patient find an inner reason for living, resolve conflicts and free healing energy. People who want to get well through the doctor alone or God alone are minimizing their chances. Here is the journey of one cancer patient who herself is a psychologist.

"Resilience is an individual's response to adversity by perseverance, optimism and utilization of external and internal resources. This was how I had defined resilience for my D. Phil in Psychology, Little did I know that I would be undergoing a test of resilience by becoming a cancer patient? After the initial shock subsided, I came to RGCI from Allahabad for best possible treatment. I believed in the Doctors to take care of the physical aspect of the disease but at the psychological level I wanted to participate in the healing process. Cancer is only a 'dis-ease' and my body has more strong, healthy and normal cells than the weak, confused malignant cells. I decided to give my body all the positive messages needed to foster a healing environment. Luckily I have an extremely supportive family and many friends and well-wishers. My parents, siblings, husband and two small daughters did everything necessary for good prognosis - comfortable environment, regular anti-cancer diet (olive oil, plums, tetra packed grape juice, coconut water....) and relevant books. These external changes, encouraging mails/smses were definitely extremely helpful but ultimately my journey had to be my own. After first chemo therapy rehospitalization for neutropenia was rather unexpected. Thereafter, nourishment, evening walks and relaxation/visualization became an integral part of my life.

Evening walks helped me to connect with Nature and see the harmony ever present. Because I had read and believed that walks improve immunity, I actually found myself becoming stronger by each passing day. Only the first week after chemo I allowed the body to rest and accepted the weakness/side-effects as normal transitory phase of the treatment. By tenth day or so body could reain enough strength initially for short then for long walks. Relaxation and visualization/auto suggestion were never discontinued. I used to do them at least twice daily without fail. Relaxation involved deep breathing and focusing on each body part and joints from head to toe and imagining them to become loose, limp, light and distressed. One childhood friend, now a reputed hypnotherapist had given me a specific imagery. She suggested to see chemo drugs as coming from the 'jata' of Lord Shiva and as Ganges cleanses everything, my journey from Gangotri via Hardwar, Rishikesh, Allahabad to Varanasi (where I have a positive association with KFI) is helping me to get cleansed and disease-free. During this journey the sideeffects are seen as muddy water which finally subsides.

Initially my whole focus was to make the lumps disappear and naively enough I assumed that surgery would be avoided. Doctors told me that I have responded very well to chemo and to avoid recurrence surgery is required. So, now I am again relying on relaxation - visualization to have a successful surgery with minimum blood loss and also to help me have minimum side-effects and a healthy mind-body post surgery. I thank God for helping me undergo this journey so far successfully with the help of doctors, family, friends and well-wishers."

As a clinician, I recommend that most patients don't reject standard techniques, at least as one option. People should become so strong so as to heal themselves through finding peace of mind and developing a clear conscience. Drugs and Surgery buy time and may cure but patients need to work to change their lives.

Doctors work in light; they are verbal, logical and scientific. The patient's world may be dark but there are sources of illumination: within each of us is a spark. Call it a divine spark and you can light the way to health. There are no incurable diseases but only incurable people.

> Dr. A. K. Dewan Medical Director **RGCI & RC Newsletter**



QUALITY OF LIFE ISSUES IN ONCOLOGY

Introduction

Traditionally, the outcomes in cancer treatment were measured in terms of overall survival, disease-free survival and/or tumor response. With increasing implementation and success of multi-modality treatment, cancer has become a chronic disease more than a fatal one. The number of long-term survivors has increased. In patients cured of their disease, long-term sequelae of treatment may result in physical and/or emotional impairment. In incurable cancers, the aim of treatment is palliation of symptoms. In conventional treatment evaluation, there is no mention of assessment of physical or emotional impairment compromising the routine life of long-term survivors and the clinical benefit seen in patients living with cancer. Hence, conventional end-points used for the evaluation of treatment need a change. Recent compelling evidence shows, that patients who feel better, live longer. In fact, if one identifies patients who are not doing well and intervene, one may hope to improve not only the patients' sense of well-being, but also the length of their lives. Thus, quality of life (QoL) has become an important issue.

What is Quality of Life?

Quality of life (QoL) is a multidimensional concept. The World Health Organization's definition of health, a state of complete physical, mental, and social well-being and not merely the absence of disease of infirmity', has a strong underpinning about the quality of life. In clinical practice, QoL refers to the functional effect of an illness and its treatment on a patient, from the patient's point of view. This appraisal takes into account the patient's satisfaction with the current level of functioning in comparison to what he or she perceives to be possible or ideal. As such, each patient sets his/her own expectation level and provides his/her own opinion as to what level of dysfunction is acceptable or tolerable.

The assessment of QoL, as used in oncology, is the level of performance in 6 major domains of life:

- Physical disease symptoms and treatment side effects
- 2. Functional ability to perform usual activities
- Psychological mood, sense of well-being
- 4. Social family, friends, leisure
- 5. Sexual desire, performance
- Work usual level of activity as compared to the normal level for that individual.

Each of these can be measured by objective assessments of functioning and subjective perceptions of health.

Why Assess Quality of Life in Oncology Practice?

- To identify, describe and compare cancer treatment effects and side-effects on patients receiving different treatment modalities/regimen.
- To assess patient's QoL outcomes, identify rehabilitation needs and focus efforts to improve outcomes.
- As a prognostic variable to assess whether QoL scores predict response to treatment modalities.
- As a screening tool with multidimensional QoL to alert healthcare providers to morbidities that may go undetected (unexpected physical or emotional difficulty).
- As an alternate end-point in treatment evaluation, given that increasing survival is the aim. When treatment outcomes are expected to be equal in comparable treatment, QoL issues determine the selection of a particular treatment.

A full assessment of the outcomes of cancer treatment involves a consideration of its impact not only on length of life, but also quality of life.



How is Quality of Life Measured?

Karnofsky and Burchenal in 1949 stressed that in addition to survival, subjective improvement was equally important to the evaluation of patients' responses to treatment. In 1984, US FDA demanded that efficacy of the new anti-cancer agents be demonstrated by improvement in survival or evidence of enhanced quality of life. It is particularly important to consider OoL outcomes when treatment is given with palliative intent or when toxic therapy is likely to yield only modest survival benefit. Broadly, the QoL issues are different in patients under active treatment, during palliative care, for survivors and for healthy individuals who are at a known high risk.

Which Instrument?

There are no 'gold standards' to assess QoL, but several scales are available to monitor function and effects of treatment. The choice of a measure depends on the QoL question being asked, the population being studied and the group to which it is to be compared.

Calman described QoL in inverse relation to the size of the gap between an individual's expectations and the real situation; the smaller the gap the better the quality of life. In a palliative setting, one has to keep this in mind, as the person's expectations are often adjusted as acceptance of functional limitations, secondary to disease progression, particularly in elderly patients.

- Functional Living Index Cancer (FLIC): Initially, the most widely used assessment, it is a 22-item scale with physical well-being and emotional sub-scales.
- 2. The Medical Outcomes Studies SF-36 is one of the best developed and validated general health status measures. It is a 36-item questionnaire that assesses patient health related OoL in eight dimensions or domains: physical functioning, limitations of role functioning from physical limitations, bodily pain, general perception of health, vitality, role limitations from emotional problems, social functioning, and mental health.
- Cancer Rehabilitation Evaluation System (CARES), a 139-item scale across 6 QoL domains, captures content on disruption of daily activity due to disease and treatment.
- 4. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ30) is a modular QoL survey that consists of a core cancer survey and modular site-specific surveys that supplement the main instrument. The scales have a core of questions that are applicable to all patients with cancer and specific modules for

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certain disease sites (e.g. breast, prostate, and lung cancer). The EORTC OLO-30 core questionnaire consists of six multi-item function scales (physical functioning, role function, social function, emotional function, cognitive function, and overall OoL), three symptom scales, and six single items.

5. Functional Assessment of Cancer Therapy (FACT), which adds an aspect of patient assessment regarding the difference between prior and present functions, is a general multidimensional QoL instrument for cancer patients. It is divided into domains for physical well-being, social and family well-being, and relationship with doctor, emotional well-being, and functional well-being.

In a palliative setting, specific measures for assessing symptom levels (including pain), psychological morbidity, and functional dependency scales would be more appropriate towards measuring the overall QoL. Additional scales, not developed specifically for cancer but widely used, are Psychological Adjustment to Illness Scale (PAIS) and Sickness Impact Profile (SIP).

Traditionally, these assessments have been in the form of interviews or forms to be filled during clinical visits. However, the use of trained telephone interviewers in some trials has been found to be more effective, being away from the hectic clinical setting.

Over the past 30 years, the field of QoL assessment has become sophisticated and methodologically rigorous. QoL instruments have made important contributions to therapeutic clinical studies, particularly concerning symptomatic treatments, where the clinical benefit ratio has shown improvement in weight, analgesic consumption and daily activities that may not be aptly reflected in the response evaluation measurements. particular match, in terms of its sensitivity, specificity and interpretability between a study and its QoL instrument will all ultimately depend on the conceptual approach taken to measure QoL. Validated, translated questionnaires are available for use. The challenges posed by socio-economic and cultural differences in our population, the practicality of administration, make it necessary to develop indigenous tools and techniques for accurate assessment. Using the knowledge gained through QoLs to introduce timely measures for improving outcomes is another challenge in our settings.

Conclusion

Quality of life is an important and essential measure of evaluating treatment outcomes. It is a patient's perspective on the impact of cancer and /or its treatment on his/her life. Its accurate assessment is capable of providing insight into the meaning of the disease and its treatment for the patient. Many instruments are available for the evaluation of QoL. Indegenous tools will further improve the accurate assessment of our population. Above all, QoLs can be helpful in guiding therapy, particularly effective and appropriate psycho-social interventions, which lead to favourable outcomes, not only in the quality but also the quantity of life.

Dr. Rashmi Shirali Physician, Investigator- Clinical Research

Dr. D. C. Doval

Chief, Department of Medical Oncology& Director Research

THYROCON 2011 REVIEW OII ontrove is varied and controversies transcer





Cancer has been a clandestine and a whispered about illness for years together. But human ingenuity has been able to unravel the mystery behind the disease and understand its finer nuances, to a great extent. Thyroid cancer, being the most common endocrine malignancy, was the focus of this year's CME and live surgical workshop. This was organised by the oncology fraternity of Rajiv Gandhi Cancer Institute and Research Center on the 20th and 21st of August 2011 at Crowne Plaza, Rohini in Delhi. The CME focused on various issues pertaining to thyroid cancer and highlighted the treatment strategies to be employed for the different variants of this malignancy. Attended by 250 delegates and faculty members from various prime institutions of the country and abroad, Thyrocon 2011 was a big success. The conference commenced with a welcome address by Dr. A.K.Dewan, the Medical Director of RGCI and RC. This was followed by an introduction to the conference by Dr. P.S.Choudhary, the Organizing Secretary, Director, Nuclear Medicine, RGCI and RC. The operative sessions performed by Dr. Anil D'Cruz, the director of Tata Memorial Hospital and Dr. Ravi Deo, Senior consultant, from Manipal Hospital, Bangalore, gave an exemplary performance of their surgical skills. The international faculty, Dr. Ashok Shaha and Dr. Michael Tuttle from the Memorial Sloan Kettering Cancer Center, were the star attractions in the scientific crowd. Dr. Shaha's presentation on various issues namely, selective treatment of thyroid cancer, brainstorming in well differentiated thyroid carcinomas and complications of thyroid surgery were greatly appreciated by the enthusiastic audience. Dr. Michael Tuttle's talk on the role of Radioactive iodine ablation in differentiated thyroid cancer, role of rTSH in thyroid ablation and metastatic disease were also well received by the audience . Each of the talks by the various speakers highlighted the different issues on thyroid cancer management. The two panel discussions on Well differentiated thyroid cancer and the Medullary and Poorly differentiated thyroid carcinoma, got an applause from the audience. The conference finally concluded with a small session targeted at the general public. This primarily focused on the general populace, aiming at creating awareness, pertaining to the issues with regards to thyroid carcinoma.

Dr. A. K. Diwan, Dr. P. S. Choudhary Dr. Ashish Goyal, Dr. Tapaswani Pradhan

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Please Mark your dates

GASTROCON 201



Recent Advances in Gastrointestinal Malignancies

(CME & Live Endoscopy Workshop)

Hosted by

Department of Gastroenterology Rajiv Cancer Institute & Research Centre, Rohini, Delhi





11th September 2011

Crowne Plaza, Delhi, Rohini

Highlights

- Newer Imaging Techniques
- LECTURES Endotherapy of Esophageal Cancer
- · Endotherapy of Obstructive Jaundice
- Colonic Polyps
- Neuroendocrine Tumours
- . HCC Panel Discussion
- Gall Bladder Cancer Panel Discussion

WORKSHOP

- PEG
- Esophageal Stenting
- Biliary Stenting
- Duodenal Stenting
- Endoscopic Ultrasound . Endoscopic USG
- Stricture Dilatation/APC



Registration

Free for Pre-registered Delegates Spot Registration Rs. 500/-

> Registration Deadline: 4th September, 2011

oup & early registration open, for details visit: www.rgci.org



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Printed & Published by Mr. K. K. Mehta on behalf of Indraprastha Cancer Society & Research Centre and Printed at Raju Art Printers, 18-A, Old Gobind Pura Extn., Street No. 2, Parwana Road, Delhi-51, Tel.: 9871006333 Published from RGCI&RC, Sector-V, Rohini, New Delhi-110085 • Editor: Dr. A. K. DEWAN