Appendices

Indian Cancer Society: Its Outstanding Services in Cancer Care (ICS Annual report 2010-11)\textsuperscript{82}

Indian Cancer Society (ICS) is a professional body established in 1954 and headquartered in Mumbai and is an initiative to address cancer treatment issues in the country. It has rehabilitation programs, in which they go to help individual patients for providing physical restoration services and psychosocial community adjustment services. They also have a special program focused to help the rural and urban cancer patients with food and medical assistance. ICS runs a professional journal, Indian Journal of cancer. 2011 marks the 50th anniversary of the ICS’ rehabilitation services.

a) HDFC-ICS Cancer Cure Fund

Recognizing the vital need to initiate and complete the treatment for poor cancer patients, a Cancer Cure Fund - a joint initiative of ICS in a collaboration between the HDFC Asset Management Company, was launched on February 8th, 2011 (HDFC-ICS Cancer Cure Fund). With the cooperation of few financial institutes, a debt fund, was initiated the returns of which could be used to assist financially underprivileged cancer patients in meeting their treatment costs. For the first time in India, investors are now be able to donate 50% or 100% of their dividend income from a close ended, capital protection fund with minimal risk to the principal and optimum, but safe returns for the investors, to the ICS to financially assist underprivileged cancer patients.

The HDFC-ICS Cancer Cure Fund received a total collection of about INR 77 crores, of which the Society can expect a donation amount of approximately INR 4.5 crores yearly. The first installment of this donation was disbursed towards the medical costs of poor cancer patients in November 2011. Over a 3 year period, the total fund flow to ICS for cancer treatment is expected to be INR 12-13 crores. This fund will go a long way in helping the poor of our country to initiate and complete treatment of this disease. It is a pioneering initiative, first of its kind in
the world, for enlisting the support of well wishers of this cause on a pan India basis and was possible with the outstanding championship by HDFC AMC and the HDFC Group.

b) Mobile Cancer Detection Camps
For nearly 60 years of its existence, the ICS has been at the forefront in the fight against cancer armed with the belief and motto that ‘Cancer When Detected Early, Is Curable’. Since 1983, ICS has been holding Mobile Cancer Detection camps (MCDCs) in Maharashtra, Karnataka, Gujarat, Goa and Chhattisgarh. These camps encourage people to avail of cancer detection screening at nil or just 20% of the normal cost. ICS has branches in Delhi, Kolkata, Nagpur, Bangalore, Patna and Lucknow have continued to do exemplary work in their respective territories.

c) Collaboration with Sir Ratan Tata Trust (SRTT)
In December 2009, Sir Ratan Tata Trust (SRTT), came forward to assist the Indian Cancer Society in its efforts to provide financial aid to underprivileged cancer patients undergoing treatment at the Tata Memorial Hospital and the Bai Jerbai Wadia Hospital for Children. In this joint initiative, every month, SRTT funds part of or the entire treatment cost of 5 patients suffering from cancer, both children and adults, selected by ICS after full due diligence.

d) Cancer Registries
The Mumbai Cancer Registry was established in June 1963 as a unit of the ICS with the aim of obtaining reliable morbidity data on cancer, from a precisely defined urban population (Greater Mumbai). The actual compilation of data could however only begin in 1964. Until then, no continuing surveys had ever been undertaken anywhere in India. Initially, up to 1975, the project was initiated in collaboration with and with financial support from the Biometry branch of the National Cancer Institute Technology of the Government of India at New Delhi. Since September 1981, the project has been partially supported by the Indian Council of Medical Research, at New Delhi. The registry has been collecting essential data pertaining to cancer
patients in the resident population of Greater Mumbai. Data collected has been analyzed by a team of experts. During the period 1964-2009, a total of 3,02,000 cancer cases have been registered and 15,60,000 cancer deaths were detected among resident of Mumbai. A report based for the year 2007 is under process. During 2008, 11287 incidence cases were registered 5229 Males and 6058 Females. Cancer of Lung among Males and Cancer of Breast among Women were leading.

e) Satellite Cancer Registries
Satellite Cancer Registries were established in population zones of the sizes in Maharashtra state. This step was taken so that the cancer problem throughout the state could be investigated in department, in the light of experience gained from Mumbai Metropolitan Registry. The first satellite registry was established in Pune City in 1972, the second in Aurangabad in 1978 and third at Nagpur in 1980.

f) Mobile Digital Mammography Van
Indian Cancer Society has launched “The Hope Express”, the India’s first Mobile Digital Mammography Van on 22nd October 2010 exclusively for women and started conducting Women’s Cancer Detection Camps at very nominal charges for screening and early detection of breast cancer. This camp is conducted at the workplace or in the community by a Gynaecologist, Mammography Technician, ENT Surgeon and Pathology Technician of the Indian Cancer Society.

g) Membership Linked Cancer Insurance Scheme
In collaboration with the New India Assurance Company Ltd, Indian cancer society has launched a cancer specific insurance policy to Indians. It is unique and extremely cheap when compared to general health insurance policies. The ICS Cancer Insurance Scheme was the first cancer insurance scheme in India and was launched in 1985. It continues to be popular and has received good patronage during these years. Members can opt for Cancer Insurance coverage of INR 50,000/- or INR 2 lakhs at very nominal premiums. This policy is open to all patients up to 70 years. To avail this facility, one should be a member of Indian Cancer Society with a membership fee of INR 200.
h) Karnataka Branch of ICS

The Bangalore Hospice Trust came into existence in the year 1994 and the in-patient facility Karunashraya started functioning from 1st May 1999. They continue to render compassionate care and assistance to terminally ill cancer patients. Karnataka Cancer Society conducts cancer educational and detection camps in Karnataka and neighboring states. The main objective is to educate the public about cancer, its possible risk factors, early detection and preventive measures. They have a bus fitted with miniature radiography and pap test facilities. There are community programs at Dharmashala I and Dharmashala II, which are helpful for meeting the patients’ and their attendants’ needs.

5.3.2. Shirdi Sai Baba Cancer Care Endowment Fund and Other Supports

Shirdi Sai Baba Cancer Hospital and Research Center, Manipal, supported by Shamdasani Foundation, Mumbai has established an endowment fund - Shirdi Sai Baba Cancer Care Endowment Fund to promote cancer care in the community and to extend financial support to the needy patients for treatment of cancer and to facilitate cancer related clinical activities such as awareness, cancer screening and research at the center. The hospital has a social work wing, coordinated by a social worker, to facilitate accruing such assistance for the patients. Different insurance schemes, ESI, reimbursement facilities for the dependants of the employees in different companies etc are available in Manipal hospital. Also the hospital has collaboration with different philanthropic trusts, by which many patients are benefited for the treatment of cancer and different ailments. Manipal Arogya Card, Sampoorna Surakha, Arogya Surakha, Yeshaswini Card, Wajpei Card, MAHE Medicare etc are few of the available facilities for financial assistance for cancer and other treatment, facilitated by the hospital authorities based on payment of a small amount of premiums by the
patients/family. In addition to these certain charitable trusts, owned and operated by different temples/persons such as Krishna Temple Udupi, Sringeri Temple, Annapoornashwari temple Horanadu, Kollur Mookambika Temple, Dr.G Sankar Trust Ambelpedu, Pramod Muthuraj Trust Malpe and Dharmastala are rendering financial assistance to the patients referred by Manipal Hospital.
**Tool. A. Data collection form**

<table>
<thead>
<tr>
<th>Name</th>
<th>Hosp.No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Wt.</th>
<th>Ht.</th>
<th>BMI</th>
</tr>
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</table>

Marital status:
Employment status:
Education: illiterate / I-IV / V-sec. / Inter-UG/PG &>

Family income INR < 5000/Month/INR 5001-10000/month, > 10000/M

<table>
<thead>
<tr>
<th>Diagnosis date</th>
<th>Disease Stage</th>
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Hormone responsiveness of tumor: ER PR HER 2

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<tr>
<th>Lump size</th>
<th>Duration of signs @reporting</th>
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Affected side Right/Left
Menopausal status

Chemo status: Neoadjuvant / adjuvant
FNAC: Yes/No

Biopsy report:

Chemo details/ Drug dose:

Premedication details:
Treatment plan:

Investigations:
Blood R/E Urine R/E RBS Electrolytes
Urea/creatinine/ HbsAg/HIV/LFT/anti HCV/
Blood Grouping, Cross matching / Others
Biopsy/Histopathology/Immunohistochemistry/FISH

Radio diagnosis tests:
X-Rays
USG
Bone scan
Mammography
<table>
<thead>
<tr>
<th>Co morbidities</th>
<th>any</th>
</tr>
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<table>
<thead>
<tr>
<th>Insurance support</th>
<th>yes</th>
<th>no</th>
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<table>
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<tr>
<th>Other habits ,tobacco/smoke/chew/alcohol</th>
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<table>
<thead>
<tr>
<th>Cost of visits</th>
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<tbody>
<tr>
<td>Cost of drugs (chemo and others)</td>
</tr>
<tr>
<td>Laboratory and other investigations</td>
</tr>
<tr>
<td>Cost of surgery and related expenses</td>
</tr>
<tr>
<td>Cost of Radiotherapy and related expenses</td>
</tr>
<tr>
<td>Cost of professional/service charges</td>
</tr>
<tr>
<td>Total direct cost of treatment</td>
</tr>
</tbody>
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<table>
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<tr>
<th>Follow up notes</th>
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</table>
Appendix 3a. Tool B
EORTC QLQ-C 30
We are interested in something about you and your health. Please answer all of the questions yourselves by circling the number applies to you. There are no write or wrong answers. The information that you provide will remain strictly confidential.

Name                                      Age

During last week
1. Did you have any trouble in doing strenuous activities like carrying a heavy shopping bag or suitcase?  
   Not at all  A little  quite a bit  Very much  
   1  2  3  4
2. Do you have any trouble taking a long walk?  
   1  2  3  4
3. Do you have any trouble taking a short walk out outside the house?  
   1  2  3  4
4. Do you need to stay in bed or chair during the day?  
   1  2  3  4
5. Do you need help with eating, dressing, washing yourself or using the toilet?  
   1  2  3  4

During the past week:
6. Were you limited in doing either your work or other daily activities?  
   1  2  3  4
7. Were you limited in pursuing your hobbies or other leisure time activities?  
   1  2  3  4
8. Were you short of breath?  
   1  2  3  4
9. Have you had pain?  
   1  2  3  4
10. Did you need to rest?  
    1  2  3  4
11. Have you had trouble in sleeping?  
    1  2  3  4
12. Have you felt weak?  
    1  2  3  4
13. Have you felt appetite?  
    1  2  3  4
14. Have you felt nauseated?  
    1  2  3  4
15. Have you vomited?  
    1  2  3  4
16. Have you been constipated?  
    1  2  3  4
17. Have you had diarrhea?  
    1  2  3  4
18. Were you tired?  
    1  2  3  4
19. Did pain interfere with your daily activities?  
    1  2  3  4
20. Have you had difficulty in concentrating on things like reading a newspaper or watching television?  
    1  2  3  4
21. Did you feel tense?  
    1  2  3  4
22. Did you worry?  
    1  2  3  4
23. Did you feel irritable?  
    1  2  3  4
24. Did you feel depressed?  
    1  2  3  4
25. Have you had difficulty in remembering things?  
    1  2  3  4
26. Has your physical condition or medical treatment interfered with your family life?  
    1  2  3  4
27. Has your physical condition or medical treatment interfered with your social activities?
   1  2  3  4

28. Has your physical condition or medical treatment caused you financial difficulties?
   1  2  3  4

For the following questions please encircle the number between 1 and 7 that best applies for you.

29. How would you rate your overall health during the past week?
   Very poor  1  2  3  4  5  6  7  Excellent

30. How would you rate your overall quality of life during the past week?
   Very poor  1  2  3  4  5  6  7  excellent

EORTC QLQ-BR23

 Patients sometimes report that they have the following symptoms or problems. Please indicate the extend to which you have experienced these symptoms or problems during the past week.

   Not at  All  A little  quite a bit  very much
   1  2  3  4

31. Did you have a dry mouth?
   1  2  3  4

32. Did food and drinks taste different than usual?
   1  2  3  4

33. Were your eyes painful, irritated or watery?
   1  2  3  4

34. Have you lost any hair?
   1  2  3  4

35. Answer this question only if you had any hair loss.
   Were you upset with the loss of hair?
   1  2  3  4

36. Did you feel ill or unwell?
   1  2  3  4

37. Did you have hot flushes?
   1  2  3  4

38. Did you have head ache?
   1  2  3  4

39. Have you felt physically less attractive as a result of your disease or treatment?
   1  2  3  4

40. Have you been feeling less feminine as a result of your disease or treatment?
   1  2  3  4

41. Did you find it difficult to look at yourself naked?
   1  2  3  4

42. Have you been dissatisfied with your body?
   1  2  3  4

43. Were you worried about your health in the future?
   1  2  3  4

44. To what extent were you interested in sex?
   1  2  3  4

45. To what extent you were sexually active?
   1  2  3  4

46. Answer this question if you have been sexually active?
   To what extend sex enjoyable for you?
   1  2  3  4

47. Did you have any pain in your arm or shoulder?
   1  2  3  4

48. Did you have a swollen arm shoulder?
   1  2  3  4

49. Was it difficult to raise your arm or to move it sideways?
   1  2  3  4

50. Have you had pain in the area of your affected breast?
   1  2  3  4

51. Was the area of your affected breast swollen?
   1  2  3  4

52. Was the area of your affected breast oversensitive?
   1  2  3  4

53. Have you had skin problems in the area of your affected breast?
   1  2  3  4.
**Patient Information**

The patient information sheet and Informed consent form for the participation in the study entitled “Outcomes of Pharmacological management of women with breast cancer in a selected tertiary care hospital” conducted by Daisy P. A. from MCOPS, Manipal.

The purpose of this study is to explore the various outcomes of chemotherapy in breast cancer of all stages. The information that you give will help the health care providers to suggest the best chemotherapeutic regimen for breast cancer therapy, which will provide best clinical and economic outcomes with least scores in symptom scales and maximum scores in functional scales, when quality of life is measured using EORTC QLQ C 30 and EORTC QLQ BR 23. The results of this study may be used in scientific communications or publications for further advancement of science. The data will not be used for any other purpose other than that mentioned above.

**Informed Consent Form**

I have been informed and explained about and understood the study entitled as mentioned above, in the language I understand. I had the opportunity to ask questions and receive satisfactory answers.

I have been given sufficient time to consider the matter of my participation in the study.

I understand that my participation in the study is voluntary and that I have right to withdraw at anytime without giving my reason and without my medical care or legal rights being affected. I understand the procedure of the study as mentioned in the information sheet. I am also assured of confidentiality of any information concerning me. I understand that the results of this study may be used in scientific communications or publications for further advancement of science. I also understand that my data will not be used for any other purpose other than that mentioned above.

If you have any questions about this form or any study related issue, you may contact the following person.

Name : Mrs Sobhana M
Address : Medical Social Worker, Department of Radiotherapy and Oncology, Kasturba Hospital, Manipal.

Telephone No. Office 0820 2922950, Residence: 0820 2571435.

Name and Signature of the patient

Date
Glossary. 62-63,83

1. **Invasive (infiltrating) carcinoma**: An invasive cancer is one that has already grown beyond the layer of cells where it started. Most breast cancers are invasive carcinomas either invasive ductal carcinoma or invasive lobular carcinoma.

2. **Sarcoma**: Sarcomas are cancers that start from connective tissues such as muscle tissue, fat tissue or blood vessels. Sarcomas of the breast are rare.

3. **Descriptive statistics**: A branch of statistics that involves describing or displaying the data and includes the calculation of measures of central tendency and dispersion.

4. **Inferential statistics**: A branch of statistics that involves drawing inferences about the population from which the data set was sampled.

5. **P value**: It indicates the probability that the difference of at least as large as those found in the data would have occurred by chance when the null hypothesis is true. Larger P value favors null hypothesis, smaller P values favors alternate hypothesis.

6. **Odds ratio**: when quantifying the risk for developing a disease, the ratio of the odds can be used as a measurement of comparison between those exposed and not exposed to a risk factor. It quantify the strength of association. It is given by OR=odds of exposed/odds for the unexposed.

7. **Significance level**: The probability that one is prepared to accept that the result was obtained by chance and yet reject H₀. Usually set at 005(5%).
8. Null hypotheses: The hypotheses states that any observed differences or relationships between sets of data are product of chance. The probability that this hypothesis is correct is statistically determined.

9. Kaplan Meier Method: It is a nonparametric procedure for estimating a survivor function. Plots of KM survival curves for treatment and control groups are very common in the medical literature.

10. Regression analysis: Regression analysis is a way of predicting an outcome variable from one predictor variable (simple regression) or many predictor variables (Multiple regression). This tool allow us to go beyond a step beyond the data collected.

11. Cox Regression model: It is a semi parametric proportional hazard model that allow the researchers to estimate parameters describing the relationship between predictors and time to event. A Cox model is a statistical technique for exploring the relationship between the survival of a patient and several explanatory variables.

12. Logistic regression: It is multiple regression but with an outcome variable that is a categorical variable and predictor variables that are continuous or categorical. Using this one can predict which of two categories a person is likely to belong to given certain other information.