CONNECTING PATIENTS TO SURVIVORSHIP PROGRAMS

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ABSTRACT

INTRODUCTION
METHODOLOGY
A symptom checklist was developed based on various discussions with various oncologists. This was then translated to Marathi and then translated back to English. Survivors who attended the 10th Indian Breast Cancer Conference were administered the survey. A consent note was included in the survey. A total of 115 survivors from 3 major cities from Maharashtra participated.
RESULTS
Some of the issues that respondents experienced, pain 68% ,disturbed sleep 55% , fatigue 66%,, loss of concentration 43.4 %, anxiety 62 % , sadness 5%, fear 47 %, restlessness 55.6 %, peripheral neuropathy 55 %.
Results of 3 to 5 years of survival pain 81% ,disturbed sleep 60% , fatigue 63.6%, loss of concentration 50%, anxiety 50% , sadness 45.4%, fear 36%, restlessness 54%, peripheral neuropathy63 %.
6 to 10years of survival pain 77% ,disturbed sleep 68% , fatigue 673%, loss of concentration 54%, anxiety 77% , sadness 54%, fear 50%, restlessness 68%, peripheral neuropathy 41%.
CONCLUSIONS
Survivorship programs are disjointed and not accessed by patients. Long term survivors learn to live with a problem instead of seeking help. There has to be more efforts in addressing their problems. Programs need to be inclusive of caregivers and information and skill based.

INTRODUCTION

Survivorship is misunderstood and misrepresented in many patients.

a. It is problem driven
b. It is doctor driven
c. It does not include psycho-social aspects

When does survivorship begin and when does it end was a query put forward by a survivor. In discussions within the Breast Friends support group, one realizes that there is a great disparity in what the beneficiaries needs and what the provider feels is important. This chasm challenges the survivorship program because it is not beneficiary driven. One of the challenges that the program faces was that the program is accessed only when there is a problem, be it physical or psycho-social. The Indian Breast Cancer Survivors Conference is an annual conference addresses the various issues survivors face during and post treatment.

METHODS AND MATERIALS

A symptom checklist was developed in English and Marathi.
Consent was also taken.
The survey was either filled by the respondent or where the respondent was illiterate, the survey was filled by a volunteer

लक्षणे	प्रतिसाद
केस गळणे	
म्युकोसायटिस/ तोंडात व्रण	
शस्त्रक्रियेच्या जागी बधिरपणा	
अतिसार (जुलाब)	
बद्धकोष्ठ	
मळमळणे	
उलटी होणे	

Pain 1. No hurt 2 - Hurts little bit 4 - Hurts little more 6 - Hurts even more 8 - Hurts whole lot 10 - Hurts worst	
Giddiness	
Disturbed sleep	
Fever	
Fatigue	
Loss of appetite	
Weight Loss	
Weight Gain	
Skin & Nail changes	
Sexual Issues	

RESULTS

Symptoms	Results – Overall %	Results- 3 to 5 yrs Survival %	Results- 6 – 10 yrs Survival %
Pain	68	81	77
Disturbed sleep	55	60	68
Fatigue	66	63.6	67.3
concentration	43.4	50	54
Anxiety	50	50	77
Sadness	53	45.4	54
Fear	47	36	50
Restlessness	55.6	54	68
Peripheral Neuropathy	55	63	41

Responses were analysed based on years of survival post completion of treatment.

DAY 1	Session Name	Session Type
9.00 - 10.00 am	Registration	
10.00 am	Inaugration	
10.15 - 11.30	Genetic Aspects of Breast Cancer	lecture
11.40 - 12.20	Diet and Exercise to prevent Breast Cancer	lecture
12.20 - 12.45	Discussing Breast Cancer diagnosis with children	lecture
12.45 - 2.00	LUNCH	
2.10 - 3.30	Late Side Effects of Treatments	panel
3.40 - 4.15	Complementary Alternative Therapies	panel
4.15 - 5.15	Expressive Art Therapy	workshop
DAY II		
9.30 - 10.00	Legal Rights of Cancer Patients	lecture
10.05 - 10.30	Tackling Anxiety and Depression	workshop
10.30 - 11.00	Tea Break	
11.00 - 12.00	Lymphodema symptoms and Management	workshop
12.00 - 12.30	healthy Diet	workshop
12.30 - 1.00	Yoga	workshop
1.05 - 1.15	Vote of thanks	
	LUNCH	

DISCUSSION

Survivorship care in cancer is to help patients and caregivers cope with all aspects of treatment and improve quality of life.

The way a programs works is to refer at the beginning the newly diagnosed patient to a survivorship clinic to help patients understand and adjust to the cancer diagnosis and treatment that follows.

Being a part of the programs allows the patient to learn skills to cope with both the short term and long term side effects of treatment that can potentially impact all aspects of wellness.

CONCLUSIONS

Survivorship programs are disjointed and not accessed by patients.
Long term survivors learn to live with a problem instead of seeking help. There has to be more efforts in addressing their problems.
Programs need to be inclusive of caregivers and information and skill based.