

# Multidisciplinary approach to meeting the Information Needs of women with Breast Cancer

RADHA SAINI, VIRGINIA MULCAHY

Breast Center, Princess Margaret Hospital, Toronto, Canada

**Abstract:** Patients with breast cancer have very high information needs especially about their disease, likelihood of cure, the treatment of their disease, investigative tests, and amongst these all; prognosis is one such area about which patients with breast cancer ask questions. Several studies have found that younger women have continued needs for information about future fertility, coping with changes to sexuality, management of premature menopause, preventive treatments, genetic counseling, diet, exercise and complimentary therapies and this persists for several years even after treatment ends. Unmet information needs can lead to depression, anxiety, psychological problems, repression of emotions and undue fears that may hamper the patient's treatment regime and have significantly effect on her coping skills, compliance patterns and health recommendations. The objectives of the study were to provide psychosocial information to patients with breast cancer and to assist their families cope with diagnosis and prognosis. It also aimed to establish a comprehensive approach to patient education within breast cancer center so as to help patients assess hospital and community services in a timely manner and it also facilitated their participation in treatment and continuity of care across multiple settings. The New Patient Information NPI and Patient Information Organizer PIO (NPI/PIO) was developed to respond to information needs and information management needs of women with Breast Cancer. All the women were asked to study it and a 20 minute telephone-survey at 1 month (T1) and 6 months (T2) post receipt NPI/PIO was undertaken namely investigator- developed survey which included 23 questions. The data was analyzed subsequently and it revealed that women were very much satisfied with the NPI and stated that it helped them to cope, they had satisfaction with their treatment decisions, it decreased their anxiety and depression patterns and brought about new degrees of hope. PIO helped them to organize and manage wide range of information they received throughout their continuum of care. Results also reveal that nurses and other health care professionals not only play a very significant role by providing information to patients and their families and hence alleviating their apprehensions, fears, anxieties and concerns but at the same time they also support cognitive strategies by which patients can cope with more effectively with treatment related strategies.

**Key words:** *Breast cancer, information needs.*

## Introduction

Many people with cancer want detailed information about their cancer, diagnosis, prognosis and treatment options and women with breast cancer are amongst those with the strongest information needs<sup>1</sup>. A diagnosis of breast cancer and the ensuing treatment are new experiences for most women and it is clear from a number of studies that they have high information needs irrespective of the type of treatment they receive<sup>2</sup>. Infact, information seeking has been identified as a coping strategy of the breast cancer "survivor personality"<sup>3</sup>. Information allows one to discriminate the safe from the unsafe, to make the appropriate preparatory responses and to reduce the inherent aversive ness of being on a state of uncertainty. Information is the key to acceptance and help with anxiety and fears<sup>4</sup>. Unmet information needs are believed to increase emotional distress for patients (e.g. increased anxiety and depression), psychosocial complaints and subsequently hamper patient's adjustment to their illness<sup>5</sup>. depression and anxiety can interfere with cognitive functioning and adherence to health recommendations<sup>6,7</sup>. Patients with cancer who receive information report benefits including increased satisfaction with treatment choices, increased satisfaction with patient-doctor interactions and decreased levels of anxiety and distress<sup>8</sup>. a decrease in hospital admissions, length of stay and medication usage was reported when patients in a general medical ambulatory practice received regularly scheduled telephone calls

from a member of the health care team<sup>9</sup>. The role of nurses in informing patients seemed to be important even before hospitalization<sup>10</sup>. The need for creative, innovative and flexible programs to provide patients with information before the procedure to allay patients fears, and to plan for discharge in this setting is a major challenge in the field of surgical oncology<sup>11</sup>. The New Patient Information NPI and Patient Information Organizer PIO (NPI/PIO) were developed to respond to information needs and information management needs of women with Breast cancer.

## Materials and Methods

Sixty three (63) women with Breast cancer, irrespective of their stage of cancer were selected and New Patient Information Package and Patient Information Organizer (NPI/PIO) was distributed to them at the Breast Center, Princess Margaret Hospital (PMH), Toronto, Canada. All the women were asked to study it. 20 minute telephone-survey at 1 month (T1) and 6 months (T2) post receipt of New Patient Information Package and Patient Information Organizer (NPI/PIO) was undertaken. Survey included 23 questions and was named investigator- developed survey. 6 questions collected demographic information and the rest other questions were asked about participant's satisfaction with content, readability and use of information provided and impact of NPI/PIO on their coping. The data was then statistically analyzed and patients satisfaction with NPI/PIO at 1 month and 6 months interval was made.

## Results

**Table 1 : Patient Satisfaction– NPI T1 : N = 63; T2 : N = 48**

S No	Patient Satisfaction : NPI	T1 %	T2 %
1	Easy to understand	95	100
2	Shared with family/friends	57	69
3	Helped with coping	70	79
4	Had no effect on coping	21	19
5	Didn't help with coping	9	2
6	Should be continued	92	98

95% of patients at T1 and 100% of patients at T2 found the NPI easy to understand. 70% of women at T1 and 79% at T2 reported that NPI helped them with coping. More than half of the patients shared the NPI with family and friends. More than 90% of women agreed to the fact, that it should be continued and also stated that it was quite easy to understand.

**Table 2 : Patient Satisfaction– PIO T1 : N = 63; T2 : N = 48**

S No	Patient Satisfaction PIO	T1 %	T2 %
1	Helped with organizing health care information	65	40
2	Should be continued	84	79

At T1, 65% of participants reported that PIO helped them to keep track of their health care information. At T2, 40% of participants were still using the PIO to help them manage the health care information. At T1, 84% of participants desired their willingness that PIO should be continued whereas at T2, 79% participants desired their wish to continue PIO.

**Table 3 : Patient Satisfaction Survey with NPI/PIO– Participant Demographics T1 : N = 63; T2 : N = 48.**

		T1 %	T2 %
Age (yrs)	30 – 49	29	29
	50 – 69	54	52
	> 70	14	19
Education	High School	33	38
	College/University	59	60
First Language	English	92	100

In the age group 50 – 69 yrs, as many as 54% of participants at T1 and 52% at T2 expressed their satisfaction with NPI/PIO. As many as 59% participants at T1 and 60% participants at T2 having University education expressed their satisfaction with NPI/PIO.

**Table 4 : Nurse Satisfaction Survey with Management of NPI/PIO (N = 4).**

1	<b>Storage of Materials</b>	Yes
	NPI/PIO always available	100%
2	<b>Distribution of NPIs</b>	
	No difficulties encountered with distribution	100%
	Time available to review contents with patients	75%
3	<b>Contents of NPI</b>	
	Satisfaction with contents and format	75%
4	<b>PIO</b>	
	Satisfaction with information organizer	75%

All nurses reported that NPI/PIO was always available and they did encounter any difficulty with distribution of NPI/PIO to patients. Three nurses also indicated that they were always able to review the NPI contents with their patients.

The women who were surveyed in 3 months reported that New Patient Information Package (NPI) and Patient Information Organizer (PIO) helped them to organize and manage the wide range of information they received throughout their continuation of care.

## Discussion

It is obvious that most patients prefer to be well informed about their situation<sup>12-15</sup>, because they use cognitive mediation to cope with stressful events<sup>17-19</sup>. Lack of knowledge about breast cancer may be source of considerable patient anxiety or may contribute to a “wall of silence” where energy used for repression and denial drains the patient of important energy resources needed for recovery<sup>20</sup>; hence there is need to develop and establish a comprehensive approach to patient education within the Breast Cancer Center where patient and their families get enough information to allay their fears and concerns related to diagnosis, investigations, treatment, likelihood of cure and prognosis and keeping all these in view, NPI/PIO was developed.

Patients with cancer who have the opportunity to participate in treatment decision making have accrued benefits including decreased anxiety and depression, increased satisfaction with treatment decisions and care received and a high degree of hope<sup>21</sup>. There is increased treatment with compliance and follow up in patients<sup>22</sup>. Similar results were found in this study where 70% of women at T1 and 79% at T2 reported that NPI (New Patient Information) helped them with coping and they discussed it their family and friends also. The need for creative, innovative and flexible programs to provide patients with information before the procedure to allay patients fears and to plan for discharge in this setting is a major challenge in the field of surgical oncology<sup>11</sup>. Formalized patient education programs need to be available with referrals to support groups, education programs, individual counseling and Reach to Recovery should be introduced early in the illness in both written and verbal form in order to accessible when timing is appropriate for the individual<sup>3</sup>. This correlates with our study also where at T1, 65% of participants reported that PIO (Patient Information Organizer) helped them to keep track of their health care information. At T2, 40% of participants were still using the PIO to help them manage the health care information. To ensure a satisfactory balance between recall, understanding and patient well being, supplementary information may be most beneficial when provided on an individual basis<sup>23</sup>. In the present study more than 90% of participants at T1 and T2 were satisfied with NPI and wanted that it should be continued and similarly with PIO, majority of the patients were satisfied and wanted that supplementary information be provided to patients on an individual basis. By addressing such information needs, healthcare professionals will not only fulfill a basic responsibility to those being treated but they also support cognitive strategies by which patients can cope with more effectively with treatment related strategies<sup>24</sup>. In the present study nurses and volunteers played a significant role in distributing of NPI/PIO and 75% of nurses discussed the contents of NPI/PIO with patients and were also satisfied with the contents and the format of NPI/PIO.

## References

1. Cassileth B R, Zupkis R V, Sutton-smith K V, March B A : Information and participation preferences among cancer patients. *Annals of Internal Medicine*, 1980 : 92; 832f – 36.
2. Harrison E D, Galloway S, Graydon J, Wickham P S, Rich B L : Information needs and preference for information of women with breast cancer over a first course of radiation therapy. *Patient Education and Counseling*, 1999 : 38; 217 – 25.
3. Fredette S L: Breast Cancer survivors : concerns and coping. *Cancer Nurse* : 1995 : 18 (1); 35 – 46.
4. Treif P M & Donohue S M: Counseling needs of women

- with breast cancer: What the women tell us. *Journal of psychosocial Nursing and Mental health services*: 1996, 34; 24 – 29.
5. Mesters I, Bornevan D B, Boer D M, Pruyn J: Measuring information needs among cancer patients: Patient education and counseling; 2001, 43, 253 – 62.
  6. Gentry W D: *Handful of behavioral medicine*, Guildford Press, New York, 1984.
  7. Krisher H P, Darley S A, Darley S M: Fear provoking recommendations, intentions to take preventive actions and actual preventive actions: *Journal Pers Soc Psychiatry*, 1973, 26; 301 – 08.
  8. Thewes B, Meiser B, Richard J, Friedlander M: The fertility and menopause related information needs of younger women with a diagnosis of Breast Cancer: A qualitative study: *Psycho oncology*, 2003, 12; 500 – 11.
  9. Wasson J, Gaudette C, Whaley F et al: Telephone care as a substitute for routine clinic follow up: *JAMA*, 1991, 267: 1788 – 93.
  10. Suominen T, Kilpi L H, Pekka L: Nurses role in informing breast cancer patients and nurses opinions: *Journal of advanced nursing*: 1999, 19; 6 – 11.
  11. Llwelllyn J.: Short stay surgery: Present Practices, Future trends: *AORNJ*: 1991, 53; 1179 – 90.
  12. Lazarus R, Folkman S: *Stress appraisal and coping*, Springer, New York, 1984.
  13. Mishel M H: Perceived uncertainty as a stress information in illness: *Research in nursing and health*: 1984, 7; 163 – 71.
  14. Dodd M J: The efficacy of proactive information on self care in chemotherapy patients: *Patient education and counseling*: 1988, 11; 215 – 25.
  15. Bubella N, Galloway S, McCay E, McKibbin A, Nagle L, Pringle D et al: Factors influencing patient's information needs at time of hospital discharge: 1990, 16; 21 – 28.
  16. Padilla G V, Grant M M, Rains B I, Hensen B, Bergstrom N, Wong D et al: Distress reduction and effects of preparatory teaching films and patient control: *Research in Nursing and Health*: 1981. 4; 375 – 87.
  17. Hartfield M J, Cason C L, Cason G J: The effect of information about a threatening procedure on patient's expectations and emotional distress: *Nursing Research*: 1982, 31; 202 – 02.
  18. Ziemer M M: Effects of information on post surgical coping: *Nursing Research*: 1983, 32; 282 – 87.
  19. Sime A M, & Libera M B: Relationship of preoperative fear, type of coping and information perceived about surgery to recovery from surgery: *Journal of Personality and Social psychology*: 1985, 34; 716 – 24.
  20. Messerli, Garamendi, Romano: Breast Cancer : as a technique of crisis of Intervention: *American journal of orthopsychiatry*: 1980, 4; 50.
  21. Davison J B, Degner F L, Morgan R, Thomas R M: Information and Decision making Preferences of men with Prostate cancer: *Oncology Nursing Forum*: 1995, 22; 1402 – 07.
  22. Stewart D E, Buchegger P M, Lickish G M, et al: The effect of educational brochures on follow up compliance in women with abnormal Papani colour smears: *Obstetric Gynaecology*: 1994, 83; 583 – 85.
  23. Damian D, Tattersali M H N: Letters to patients: improving communication in cancer care: *The Lancet*: 1991, 338; 923 – 25.
  24. Rainey C L: Effects of preparatory patient education for Radiation oncology patients: *Cancer*: 1985, 56; 1050 – 61.

#### IMSA News

##### IMSA Chapter Activities Jan-March 06

###### Delhi Chapter

- 05.02.2006 : Dr. S.C. Devgan : "Clinical Meeting" at Hindu Rao Hospital in collaboration with Delhi Rheumatology Association.
- 04.03.2006 : Col. V.P. Chaturvedi, "Clinical Meeting" in collaboration with Delhi Rheumatology Association at Army Hospital Research & Referral, New Delhi in collaboration.

###### Tamil Naidu Chapter

- 08.01.2006 : Dr. P. Chandra, "Politics of Primary Child Health Care".

12.02.2006 : Dr. A. Govindan, "Recent Trends in Imaging Sciences"

12.03.2006 : Dr. Jose M. Eason, "Blood and Marrow Transplantation".

###### Rural CME T.N. Chapter

- 19.02.2006 : Dr. V. Kannan, "Management of Obesity"  
: Dr. V. Sethu, "Burns - Intial Management" and "Obesity - Surgical Management".  
Venue : Madurantagam (Tamil Nadu)

##### Fellows and Members elected during Jan-March 06

###### Fellows

Dr. Shubha Sagar Trivedi  
Dr. R. Umarani  
Dr. Neeta Singh  
Dr. Ravi Kashyap  
Dr. H.P. Pati  
Dr. Prof. Anita Chakravarti  
Dr. Sanjay Mittal  
Dr. Raj Kumar Lalwani  
Dr. Wing. Commander V.G. Vasishta

New Delhi  
Tamil Nadu  
New Delhi  
New Delhi  
New Delhi  
New Delhi  
New Delhi  
New Delhi  
Bangalore

Dr. G.D. Goel  
Dr. Amit Goel  
Dr. (Mrs.) Vibhu Mendiratta  
Dr. W. Selvamurthy  
Dr. S.K. Verma

###### Members

Dr. Nikhil Agarwal  
Dr. Prateek Kumar Mehrotra  
Dr. Tejas Modi

New Delhi  
New Delhi  
New Delhi  
New Delhi  
Udaipur  
New Delhi  
Lucknow  
Gujarat

##### Honours

**H Dr.Chintamani** has been awarded Honorary Fellowship of the Royal College of Surgeons of Edinburgh (FRCS) for his outstanding contribution in the field of surgery Dr. Chintamani is seen receiving the award from the President of Royal College of Surgeon of Edinburgh Mr. R. JAR Smith.



**H Dr. Tarun Gupta** Additional Secretary General IMSA, has been unanimously elected as President elect of Indian Medical Association, New Delhi Branch, for the year 2006-2007.

**Dr. Tarun Gupta** as also been elected Honorary Secretary of Rotary Club of Delhi, Chanakya Puri, New Delhi(R.I.District-3010) for the year 2006-2007.

##### IMSACON 2006

For detailed Information Brochure

Visit IMSA Website [www.imsaonline.com](http://www.imsaonline.com)