

# Types of Study aims to help patients deal with cancer and better handle the effects of cancer

Aparna S\*, Akshaya S, Gomathi S, Gowri C, Santhiya Priya G, Siva Ranjani S, Dhanapal Venkatachalam

Department of Pharmacology, Sree Sastha Pharmacy College,  
Chembarambakkam, Chennai-123.

apa.pharm@ssiet.in ; aparnasuraboyina3001@gmail.com

## Abstract:

This study aims to identify the informational needs of cancer patients and assess the degree to which these informational needs are satisfied by gauging patient satisfaction. In a sizeable ambulatory cancer facility in Singapore, a self-administered questionnaire created through thorough literature studies was pilot-tested on 11 cancer patients using convenience sampling. The 76-item survey, which had been created to assess self-reported information needs and level of satisfaction with the information obtained while undergoing cancer treatment, was distributed to all eligible patients visiting the clinic over 5 months. The 5-point Likert scale was used to evaluate the significance of information and the degree of satisfaction with needs being addressed. The survey was completed by 411 patients in total (about 50%). Most of the elements stated in the questions in each option were regarded as essential, and almost all patients desired information regarding the condition, tests and investigations, therapy, side effects, sexuality, psycho-social support, and financial problems. Patients were generally satisfied with the information given, particularly about diagnosis and diagnostic tests, treatment, and overall experience, according to responses, but there are still information needs that must be met more effectively and efficiently. The results of this study corroborate earlier findings that cancer patients undergoing treatment have a wide range of informational requirements. Despite significant differences that reflect the complexity of cancer patient education, respondents were generally satisfied with the information supplied.

**Keywords:** Patient information needs, cancer, communication, satisfaction, importance of information, sexuality, and supportive care background.

## BACKGROUND:

- A cancer diagnosis is a highly traumatic event that causes psychological stress.
- The nature of the disease requires that the patient become aware of the disease, make difficult decisions about further treatment, and terms with consequences of diseases and associated side effects of treatment.
- Given the complexity of the disease and treatment options, as well as the psycho-social implications associated with the disease, cancer patients and their families will need information and emotional support throughout their illness and treatment.
- With the shift to ambulatory care, proper patient education becomes increasingly important as most patients and their caregivers suffer treatment-related problems and side effects at home.
- The need for self-management of illness and treatment-related problems is further enhanced by the more aggressive and long-term treatment available today.
- Providing information to cancer patient can help them make decision prepare for the treatment and manage the associated side effects reduce anxiety and depression increase treatment satisfaction, improve family communication, and helps improve quality of life and well-being.
- Educating patients and meeting their information needs and fundamental aspects of patient-centered care. Only well-informed patients can be active partners in the treatment process.
- As patient education is an integral part of the health profession and role patients' satisfaction with the information provided is an important indicator of the

quality of care needed. Their satisfaction is associated with better patient adherence to medical recommendations, improved outcomes, loyalty to a facility, increased willingness to recommended services to adhere and reduced risk of malpractice lawsuits.

- The article focuses on the information needs of the patient undergoing cancer treatment and their level of satisfaction with the information received. Data and additional study information from their actual and preferred source information will be described.
- The purpose of the study is to identify the information needs of cancer patients undergoing treatment. Identify gaps between information currently received and needed by measuring satisfaction. Identify sources of information and patient preferences for them.

## METHODS:

### Sample And Setting:

The National Cancer Centre Singapore (NCCS) ambulatory treatment unit patients were invited to take part in the study.

70% of Singapore public cancer patients are treated at NCCS, a tertiary medical facility.

Patients are eligible if they meet the following criteria:

1. Had a cancer diagnosis and was receiving treatment.
  2. Could understand and communicate in English and Mandarin.
  3. Were 21 years of age or older.
- Patient with cognitive impairment, Terminal illness, or those who were informed of their diagnosis were not permitted to participate in the study.

The patient was given the needs assessment questionnaire after giving their agreement to participate in the trial, either in English or Chinese depending on their preferences. Additional collected were demographic, socioeconomic, and clinical details to determine the cancer type and it got the therapy.

The central Institutional Review Board of Singapore Health Services has its approval for their study, all participants provided written informed permission

#### Need Assessment Questionnaire:

Based on through study, we created 76 item survey questionnaires for self-reporting. An expert team of 15 oncology nurses evaluated the items attentively. After making the questionnaire we tested its validity in pilot research with 11 eligible patients. During research, no instruments are taken out and no adjustments are required.

The survey topics are:

- Diagnosis
- Tests
- Investigation
- Surgery
- Radiation therapy
- Chemotherapy
- Hormone therapy
- Clinical trials
- Sexual aspects of care
- Psychological aspects of care
- Supportive care
- Financial support

#### Overall experience

Respondent was asked to rate the information related to this domain on the 5-point like-rt scale, Based on their importance (1-not, 2-slightly, 3-neutral, 4-important, 5-very)

Similarly based on satisfaction with information related to each domain provided by NCCS staff on the 5-point like-rt scale (1-not, 2-dissatisfied, 3-neither satisfied nor dissatisfied, 4-satisfied, 5-very satisfied). The discrepancy between significance and satisfaction was taken into account as a sign of information delivery inadequacies.

#### Statistical Methods:

To achieve the precision level at least 40s patient was estimated. The precision level of +/- 0.05 for the mean satisfaction level for the width of 95% confidence interval. The importance and satisfaction level were estimated using a mean 95% confidence interval for each domain.

The weighted mean satisfaction level for overall experience was calculated as the mean product of satisfaction and importance level response. By this weighted mean satisfaction was calculated.

Then finally mean and weighed mean importance values were compared with for importance or satisfaction using one sample t-test. When a patient has not answered any items, they can be removed from that domain-specific analysis. Using SPSS Version 20, statistical analysis is performed.

#### RESULT:

Demographic information is presented, followed separately by 12 aspects of domain care. Based on the relatively unique and specific component of the topic or construct of interest, 12 domains are grouped. They are

- Diagnosis and test
- Surgery and radiation therapy, chemotherapy, hormonal therapy, clinical trials
- Sexual aspect, psychological aspect, supportive care.

#### Response Rate and Characteristics of Respondents:

- ❖ A Total of 826 Patients were treated from October 2015 to February 2016.
- ❖ 341(41%) withdrew from the study, 33(4%) patients were excluded due to incomplete return of the questionnaire, 12(1%) withdrew, and 29(4%) did not return the questionnaire.
- ❖ This Resulted in the final sample of 411 patients (50%).
- ❖ 316people responded in English (77%) and remaining 95(23%) responded in Chinese.

#### Diagnostic Procedure and Diagnosis:

In this study, the domains of diagnostic test and diagnosis received 396 and 405 complete responses, respectively. Both diagnosis (mean = 4.39; P-value 0.001) and diagnostic tests (mean = 4.48; P-value 0.001) had mean Like-rt scores for relevance that were greater than 4 (=important). The mean Like-rt satisfaction scores for diagnostic tests were higher than 4 (=satisfied) (mean = 4.07; P-value = 0.026), but lower than 4 (=0.035) for diagnosis (mean = 3.93). The questions measuring "being informed about the causes of the cancer of the type of cancer you have" (mean = 3.71; P-value 0.001) and "being informed about the survival rates for your cancer" (mean = 3.82; P-value 0.001) had lower scoring, which was the cause of this.

#### Clinical Trials, Surgery, Radiation Therapy, Chemotherapy, and Hormone Therapy:

Positive results were obtained from responses to questions about the significance of and degrees of satisfaction with information provided about cancer treatment modalities, with all categories earning a mean rating > 4.

#### Sexual Aspect of Care, Psychosocial Aspect of Care, Supportive Care and Financial Care:

The quality of life is largely dependent on sexuality. In this study, participants ranked sexuality-related information as the least important. Therefore, it was anticipated that the satisfaction score would be higher than the importance score because patients thought sexuality to be the least important.

The level of emphasis given to sexuality may be a result of patients' top priorities being managing their adverse effects and resolving their illness. Chinese respondents in research by NIE and GAO indicated a variety of reasons for not engaging in sexual activity, including exhaustion, physical issues, and lack of interest. Additionally, respondents desired more information on the kinds of

foods, supplements, and complementary therapies that are healthy for them.

At the same time, patients also indicated a preference for taking dietary supplements, whose use during cancer treatment is debatable and may even be hazardous because they may interfere with the effects of medications. Therefore, knowing what kinds of foods and supplements, such as traditional Chinese medicine, may be useful may aid patients in choosing the right foods and supplements to improve their overall health and prevent nutritional deficiencies. In 2012, researchers at the same institution looked into how many adult cancer patients used complementary and alternative medicine (CAM).

They found that 66.7% (n = 146) said they did, and 80.8% said they used natural products like herbal remedies, special diets, dietary supplements, and vitamins and minerals. Though the question about being educated about things you can do to help yourself get well-earned high satisfaction ratings from respondents, the question on "potential side effects caused by cancer treatment and how to cope with them" received low ratings.

To provide complete care, a multidisciplinary team approach is crucial due to the complexity of cancer and its treatment. This study found that additional knowledge of such services is required even if multidisciplinary care is provided in the study environment as routine practice most respondents considered financial information on treatment costs and financial help to be crucial.

Economic challenges might be a big worry due to high treatment costs, lack of insurance coverage, and income loss, as the majority of patients (77%) of study participants got two or more treatment modalities.

Therefore, it's crucial to attend to their informational needs regarding the financial costs of cancer treatment and sources where financial assistance may be available to lessen their anxiety and stress.

#### **Overall Experience:**

The weighted mean satisfaction score was 0.04 (95% CI 3.98- 4.10; P-Value = 0.180). The mean like-rt values for overall importance and satisfaction were 4.41 (95% CI 4.34- 4.47, P value 0.001) and 4.03 (95% CI, 3.97- 4.09; P value= 0.348)

The item "having a variety of information sources" (mean = 3.79, P value= 0.010) fell below this cutoff even though information revealed, items in this domain had a mean like-rt score of more than 4 (mean= 4.02, P value= 0.02)

#### **LIMITATIONS:**

First, the convenience sample was collected from a single outpatient cancer site in Singapore. This may not be representative of the entire population.

Another limitation is the high rejection rate. So there may be a non-response bias.

It is possible that the views of this group may not be fully explored and we may have underestimated the extent of the unmet need for the information

Nevertheless, the cancer center in Singapore is one of the largest institutes, treating approximately 70% public cancer patients.

In addition, the obtained responses from a significant range of adult cancer patients with a tumor type is one of the most common types of cancer in Singapore.

The study also excluded cancer patients who were unaware of their diagnosis, the confidentiality of information about cancer diagnosis remains among residents, and some families are required to be truthful for protection.

Although the survey consisted of both English and Mandarin speakers, Malays and Indians may have been excluded.

16.1% of Malaysians and Indians also participated in the survey, 3% of its resident population in 2015, Malaysians made up 13.3% and Indians made up 9.%

Overall this is the representation of the population as in 2015. Chinese made up to 74.3%

The researchers and research tool were developed based on an extensive literature review and the basis of a validated questionnaire.

All of the items listed in the 12 components, measuring different aspects of care indicate that these items are essential to cancer patients, suggesting some external validity.

#### **CONCLUSION:**

The devastating news that a patient has cancer affects every part of their life. Additionally, cancer treatment has evolved to be aggressive and sophisticated. To assist cancer patients in making decisions and coping, as well as possibly enhancing their happiness with the services they receive and the results of their treatment, it is vital to recognize and meet their information needs. To help healthcare workers identify areas in which improvement is required and tailor education programs to fulfill these requirements, it is crucial to understand what information is relevant to cancer patients and how satisfied they are with the information they get. This would make it possible to allocate resources more effectively and aid healthcare organizations in providing high-quality, patient-centered care. The study's findings suggest that cancer patients undergoing treatment have a variety of informational needs. They are especially interested in learning more about their illness, treatments, research findings, psycho-social issues, and financial elements of care. The results also reveal that respondents were generally less satisfied with the information they received on sexual, psychological, supporting, and financial elements of care but more satisfied with information about diagnosis and diagnostic tests, therapy, and information delivery methods. Information distribution may be compromised as a result of the consultation process's timing constraints. "More critical information," such as disease and therapy, may be more emphasized by healthcare providers when communicating with patients. These limitations underscore the significance of thinking about more efficient and effective information-sharing techniques to ensure. The study also discovered some inconsistencies in the assessments of significance and degrees of satisfaction for topics like "sexual aspects of care." Further research would be helpful to determine the

reasons for these discrepancies, as this study was not intended to analyze specific reasons for the value of any one informational domain.

To the best of our knowledge, the current study is one of the first to analyze unmet information needs in terms of both patient importance for the information as well as patient satisfaction with the information obtained. It is also the first study to evaluate the information requirements of Singaporean cancer patients.

#### REFERENCES:

- Schofield PE, Butow PN, Thompson JF, et al. Psychological responses of patients receiving a diagnosis of cancer. *Ann Oncol.* 2003;14:48–56. doi: 10.1093/annonc/mdg010. [PubMed] [CrossRef] [Google Scholar]
- NS A, HZ K, Yousef W. A comparison of American and Egyptian cancer patients' attitudes and unmet needs. *Cancer Nurs.* 1993;16:193–203. [PubMed] [Google Scholar]
- Bailey R, Clarke M. *Stress and Coping in Nursing.* London: Chapman and Hall; 1991. [Google Scholar]
- Davison BJ, Breckon EN. Impact of health information-seeking behavior and personal factors on preferred role in treatment decision making in men with newly diagnosed prostate cancer. *Cancer Nurs.* 2012;35:411–418. doi: 10.1097/NCC.0b013e318236565a. [PubMed] [CrossRef] [Google Scholar]
- Lo AC, Olson R, Feldman-Stewart D, et al. A patient-centered approach to evaluate the information needs of women with ductal carcinoma in situ. *Am J Clin Oncol.* 2015. pp. 1–8. [PubMed]
- Hesse BW, Arora NK, Beckjord EB, et al. Information support for cancer survivors. *Cancer.* 2008;112:2529–2540. doi: 10.1002/cncr.23445. [PubMed] [CrossRef] [Google Scholar]
- Husson O, Mols F, van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety, and depression among cancer survivors: a systematic review. *Ann Oncol.* 2011;22:761–72. doi: 10.1093/annonc/mdq413. [PMC free article] [PubMed] [CrossRef] [Google Scholar]
- Ubel PA. Is information always a good thing? Helping patients make "good" decisions. *Med Care.* 2002;40:39–44. doi: 10.1097/00005650-200209001-00006. [PubMed] [CrossRef] [Google Scholar]
- Li PWC, So WKW, Fong DYT, et al. The information needs of breast cancer patients in Hong Kong and their levels of satisfaction with the provision of information. *Cancer Nurs.* 2011;34:49–57. doi: 10.1097/NCC.0b013e3181ef77a0. [PubMed] [CrossRef] [Google Scholar]
- Hack TF, Degner LF, Parker PA. The communication goals and needs of cancer patients: a review. *Psychooncology.* 2005;14:831–845. doi: 10.1002/pon.949. [PubMed] [CrossRef] [Google Scholar]
- Miyashita M, Ohno S, Kataoka A, et al. Unmet information needs and quality of life in young breast cancer survivors in Japan. *Cancer Nurs.* 2015;38:1–11. doi: 10.1097/NCC.000000000000201. [PMC free article] [PubMed] [CrossRef] [Google Scholar]
- Davis K, Schoenbaum SC, Audet AM. A 2020 vision of patient-centered primary care. *J Gen Intern Med.* 2005;20:953–957. doi: 10.1111/j.1525-1497.2005.0178.x. [PMC free article] [PubMed] [CrossRef] [Google Scholar]
- Kincey J, Bradshaw P, Ley P. Patients' satisfaction and reported acceptance of advice in general practice. *J R Coll Gen Pract.* 1975;25:558–566. [PMC free article] [PubMed] [Google Scholar]
- Leebov W, Gail S. *Service Quality Improvement: The Customer Satisfaction Strategy for Health Care.* Chicago: American Health Publishing; 1994. [Google Scholar]
- Jenkinson C, Coulter A, Bruster S, et al. Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. *Qual Saf Heal Care.* 2002;11:335–339. doi: 10.1136/qhc.11.4.335. [PMC free article] [PubMed] [CrossRef] [Google Scholar]
- Poulos GA, Brodell RT, Mostow EN. Improving quality and patient satisfaction in dermatology office practice. *Archives of Dermatology.* 2008;144:263–265. doi: 10.1001/archdermatol.2007.58. [PubMed] [CrossRef] [Google Scholar]
- Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: results from a large study in UK cancer centers. *Br J Cancer.* 2001;84:48–51. doi: 10.1054/bjoc.2000.1573. [PMC free article] [PubMed] [CrossRef] [Google Scholar]
- Rolnick SJ, Altschuler A, Nekhlyudov L, et al. What women wish they knew before prophylactic mastectomy. *Cancer Nurs.* 2007;30:285–291. doi: 10.1097/01.NCC.0000281733.40856.c4. [PubMed] [CrossRef] [Google Scholar]
- Bernstein KI, Promislow S, Carr R, et al. Information needs and preferences of recently diagnosed patients with inflammatory bowel disease. *Inflamm Bowel Dis.* 2011;17:590–598. doi: 10.1002/ibd.21363. [PubMed] [CrossRef] [Google Scholar]
- Maddock C, Lewis I, Ahmad K, et al. Online information needs of cancer patients and their organizations. *ecancermedicalsecience.* 2011;5:1–22. [PMC free article] [PubMed] [Google Scholar]
- Lambert SD, Loiselle CG, Macdonald ME. An in-depth exploration of information-seeking behavior among individuals with cancer—Part 1: Understanding differential patterns of active information seeking. *Cancer Nurs.* 2009;32:11–23. doi: 10.1097/01.NCC.0000343372.24517.bd. [PubMed] [CrossRef] [Google Scholar]
- Veenstra CM, Regenbogen SE, Hawley ST, et al. A composite measure of personal financial burden among patients with stage III colorectal cancer. *Med Care.* 2014;52:957–962. doi: 10.1097/MLR.0000000000000241. [PMC free article] [PubMed] [CrossRef] [Google Scholar]
- Sherwood PR, Donovan HS, Rosenzweig M, et al. A house of cards: the impact of treatment costs on women with breast and ovarian cancer. *Cancer Nurs.* 2008;31:470–477. doi: 10.1097/01.NCC.0000339255.75947.a8. [PubMed] [CrossRef] [Google Scholar]
- Epstein RM, Franks P, Shields CG, et al. Patient-centered communication and diagnostic testing. *Ann Fam Med.* 2005;3:415–421. doi: 10.1370/afm.348. [PMC free article] [PubMed] [CrossRef] [Google Scholar]
- Knight P. *BME Cancer Voice: Exploring the Needs of Black & Minority Ethnic (BME) Cancer Patients and Their Carers.* 2015. [16/06/15]. [ <http://www.blackhealthinitiative.org/BHI%20-%20BME%20Cancer%20Voice%20BME%20Cancer%20Patient%20Experience%20-%20NHS%20England%202015%20Report.pdf>]
- NHS England. *Cancer Patient Experience Survey.* 2012. [16/06/15]. [ <https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/201112-national-cancer-patient-experience-survey-1/201112-national-cancer-patient-experience-survey-reports/495-cancer-patient-experience-survey-national-report-2011-12/f>]
- University of Waterloo. *Survivor Unmet Needs Survey.* 2011. [28/04/15]. [ [https://uwaterloo.ca/propel/sites/ca.propel/files/uploads/files/SurvivorUnmetNeedsUserGuide\\_en.pdf](https://uwaterloo.ca/propel/sites/ca.propel/files/uploads/files/SurvivorUnmetNeedsUserGuide_en.pdf)]
- John Hopkins Medicine. *Patient Satisfaction Survey.* 2014. [28/04/15]. [ <http://www.hopkinsbreastcenter.org/survey/>]
- Iconomou G, Vagenakis A, Kalofonos H. The informational needs, satisfaction with communication, and psychological status of primary caregivers of cancer patients receiving chemotherapy. *Support Care Cancer.* 2001;9:591–596. doi: 10.1007/s005200100259. [PubMed] [CrossRef] [Google Scholar]
- Geller BM, Vacek PM, Flynn BS, et al. What are cancer survivors' needs and how well are they being met? *J Fam Pract.* 2014;63:7–17. [PubMed] [Google Scholar]