

# Quality of care in cancer: An exploration of patient perspectives

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## ABSTRACT

**Introduction:** Patient satisfaction is as important as is the care itself. When the patient has a disease like cancer it becomes even more important. A cancer patient not only suffers from the disease but also undergoes substantial mental trauma, agony, stress, uncertainty, and apprehension. There are limited studies in India eliciting patient's views on the quality of care being received by cancer patients. **Methodology:** A cross-sectional triangulation data transformation model mixed method design (Quant + Qual) was used to conduct the study between March and May 2015 among patients attending specialty hospitals providing oncology services in Odisha, India. The quantitative data were collected using Patient Satisfaction Questionnaire-18 to assess satisfaction. The qualitative data were obtained through in-depth interviews using open-ended questionnaire. **Results:** The results showed that general satisfaction among the patients was 60%. The maximum score was obtained for the communication of doctors. The qualitative findings revealed that travel for distant places for minor illness, waiting period, and lack of services at the primary care facilities were reasons for patient's dissatisfaction. **Conclusion:** The study found that the patients were generally satisfied with the quality of services. However, more studies should be conducted including perceptions of the patients as well as the caregiver.

**Keywords:** Cancer, India, Odisha, patient perspectives, patient satisfaction, quality of care

## Introduction

The World Health Organization (WHO) (2009) and The International Council of Nurses (2006) state that the overall goal is highest possible health for all people, and providing high-quality care is one approach for reaching this goal. Patient has often been associated with powerlessness against the medical facilities.<sup>[1]</sup> In the era, when one talks about the innovations and technological advances in medical science, the basis of all such developments which is ensuring that each patient gets the needed care should not be forgotten. It is equally important to determine if the patient is satisfied with the care he or she receives. Patient

satisfaction is the concept most often used in research within the healthcare sciences.<sup>[2]</sup> "Quality of care" is a concept that can be given different meanings, depending on different cultures but it is considered by researchers to be a multidimensional concept.<sup>[3]</sup>

Patient satisfaction is an evaluation of the quality of care, an outcome variable in its own right, and is an indicator of weaknesses in the service.<sup>[4]</sup> Patient satisfaction is an important consideration because it strongly impacts both physical and mental health-related quality of life.<sup>[5]</sup> There is evidence suggesting that satisfaction levels are associated with health outcomes by affecting health-related behaviors, patient compliance, and motivation to seek care.<sup>[6-8]</sup> Studies indicate that global satisfaction is affected by many factors other than the quality of service delivery; it may include factors such as

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patients' demographics,<sup>[9,10]</sup> diagnosis,<sup>[11,12]</sup> treatment program,<sup>[13]</sup> and chronicity of disease. Patient's satisfaction denotes the extent to which health care needs of the clients are met to their requirements. Patients carry certain expectations before their visit to hospital and the resultant satisfaction or dissatisfaction is the outcome of their actual experience.<sup>[1,14]</sup>

Cancer care in itself is different from the care of other illness. It is more so over, because, in some case it is a "care beyond cure." In providing health care services the patients' satisfaction cannot be neglected, as it is important as much as the treatment and even the cure of the disease. Especially, when it comes to cancer care, the patients' satisfaction has to be given priority, as the patient is not only struggling with the disease but also with mental agony, trauma, financial constraint, uncertainty of life, and the like so many other critical issues affecting the wellbeing of cancer patient.<sup>[15]</sup>

There are limited patient satisfaction studies in India especially on the cancer patients. The present study tried to explore the satisfaction of cancer patients attending specialty hospitals providing oncology services in Odisha.

## Methodology

### Study design, participants, and setting

A cross-sectional triangulation data transformation model mixed method design (Quant + Qual) was used to conduct the study between March and May 2015 among patients attending specialty hospitals providing oncology services in Odisha, India. In this design, both types of data are given equal emphasis and collected simultaneously. As well, one type of data is transformed into other type with the intent to interrelate different data types.<sup>[16]</sup> In this study, both quantitative and qualitative data were collected at the same time, and the qualitative data (transition data) were converted to quantitative data using Krippendorff's<sup>[17,18]</sup> content analysis. Since this was an exploratory study, sample size calculation was of little value.<sup>[19]</sup> Based on pragmatic considerations, we decided to interview 100 patients. The sample was drawn from a previous study conducted by the same research team.<sup>[20]</sup> Based on the patient list used in the previous study and considering a 30% nonresponse we approached 123 patients using a random sampling technique until the desired sample of 100 was reached. Patients who agreed to participate and devote time were included in the qualitative study. A total of 22 in-depth interviews were conducted. To maintain maximum diversity among the sample, patients were selected purposively. Length of the interviews ranged from 15 min to a maximum of 40 min.

The patients who agreed to participate in the study were interviewed in a neutral setting. Among these patients, who were uncooperative, unable to spend time for the evaluation related to the study, had state of confusion and/or impaired cognition, who could not engage in conversation because of the severity of disorders and who did not give consent were excluded.

### Study tool and data analysis

We used Patient Satisfaction Questionnaire-18 to assess satisfaction including age, sex, marital status, education, employment status, family pattern, and address of residence. The questionnaire has seven subscales: General satisfaction (GS), technical quality, interpersonal aspects (interpersonal perception method), communication (COM), financial aspects (FIN), time spent with doctor, and accessibility and convenience, which give scores in these domains. Higher value indicates more satisfaction. The quantitative data were reported as descriptive.

An open-ended questionnaire was prepared for the in-depth interview. The tool was devised after rigorous literature review and on the basis of our previous research on patient-reported challenges and barriers in care seeking and similar studies conducted outside India.<sup>[20-24]</sup> The tool was used to explore the views of patients on the services provided in the hospital they visited as well as any suggestions for improvement. As this was a transformative mixed method study, the qualitative data were transformed into quantitative data. The transformation of the qualitative data began using content analysis to identify themes for each question. This was accomplished by reading the answers from all participants to each survey question as a whole. Then data for each question were categorized into overall themes associated with the question. Themes for each question were then assigned a number and considered a variable. Numbers were entered into SPSS Version 20.0, IBM Corp., Armonk, NY for each participant reflecting the most predominant theme of their answers to each individual question. The authors independently identified the patterns and subthemes of the interviews. Togetherness, similarities, and differences in the patient's perspectives were looked for, within as well as between the professions involved.<sup>[18]</sup>

### Ethical consideration

The ethical clearance was taken for the study proposal from the Institutional Ethical Committee, Indian Institute of Public Health Bhubaneswar. Informed consent was obtained from all participants, and they were reassured regarding confidentiality. To maintain anonymity of the patients, unique identity code was used for each of them.

## Results

The study sample consisted of 43 (43%) females and 57 (57%) males of which 71% were married. Majority of the patients were between the ages of 21 and 40 years with a mean age of 37 ( $\pm 12.7$ ) years. Around 60% of the sample reported to have completed graduation or above degrees. Of the total patients, one-fifth belonged to the below poverty line category. From the sample patients, 30% reported to be suffering from the disease from 2 or more years [Table 1].

Table 2 describes the overall patient satisfaction score along with the scores of the subscales. The highest level of satisfaction

was noted in communication aspects (63%) and followed by interpersonal behavior of doctors. GS level was 60%. All other satisfaction scores were above 50%.

### Qualitative interview findings

A total of 22 patients were interviewed in the study. The major dominant themes that emerged from the qualitative data are depicted in Table 3.

#### Good behavior of doctor

The patients reported that the behavior of the doctor attending to them was good. This was reported by 13 out of the 22 participants. However, few respondents informed negatively about the support staff such as nurses and attendants in the hospital.

#### Long waiting hours

Majority of the respondents reported that a specific doctor was appointed to them. During their follow-up visit, in the case of absence of the assigned doctor, they were not attended by a substitute doctor rather were asked to wait till the appointed doctor was available or were asked to take another appointment. Longer waiting hours was reported by 16 out of the 22 patients. Getting a bed for admission was another issue that was highlighted.

#### Distance and location

Over 50% of the patients reported of having difficulty in traveling from their residences to the cancer hospital. They reported of losing their pay at work to get the follow-up check-up done. They also reported that transportation and food charges were high.

#### Services at health centers

Almost all the patients reported that they did not get any follow-up services at the primary care centers. They were referred or suggested to visit the cancer hospital even for minor ailments like a cough and cold. Even if the doctor at the primary care centers prescribed drugs for minor ailments, they insisted the patients visit a cancer hospital.

Based on the findings from the quantitative scores as well as the qualitative interviews, communication and behavior of doctor, accessibility and time spent in the hospital influenced the patient satisfaction levels. However, no statistical tests were conducted to determine the association.

## Discussion

This study assessed the satisfaction level among cancer patients attending specialty hospitals providing oncology services in Odisha, India.

It was interesting to note that the majority of patients in the sample were graduate and above. Previous evidence suggests that educational qualification can also affect the level of satisfaction. A study by Singh *et al.*<sup>[25]</sup> found that the level of patient satisfaction on the hospital services was high among the more qualified patients.

Interpersonal rapport and good doctor-patient relationship have been a cornerstone of higher patient satisfaction. Previous studies

**Table 1: Overall sociodemographic characteristics**

Characteristics	Categories	Frequency (%) (n=100)
Age (years)	<20	01 (01)
	21-30	33 (33)
	31-40	33 (33)
	41-50	11 (11)
	51-60	15 (15)
	>60	07 (07)
Sex	Male	57 (57)
	Female	43 (43)
Religion	Hindu	93 (93)
	Non-Hindu	07 (07)
Marital status	Married	71 (71)
	Single	29 (29)
Caste	SC/ST	31 (31)
	OBC	15 (15)
	General	54 (54)
Education	Illiterate	5 (5)
	Primary education	11 (11)
	Secondary and higher secondary	24 (24)
	Graduation and above	60 (60)
Socioeconomic status	APL category	80 (80)
	BPL category	20 (20)
Suffering from disease since	1 year or less	70 (70)
	2 or more years	30 (30)
Amount spent on treatment	One lac or below	62 (62)
	Above one lac	38 (38)
Comorbidity	Yes	16 (16)
	No	84 (84)

APL: Above poverty line; BPL: Below poverty line

**Table 2: Overall patient satisfaction scores**

PSQ-18 scale	Number of items	Maximum possible score	Actual score	Level of satisfaction (%)	Mean±SD
General satisfaction	2	10	6.0	60	3.0±0.4
Technical quality	4	20	12.4	62	3.1±0.4
Interpersonal manner	2	10	6.3	63	3.2±0.5
Communication	2	10	7.0	70	3.3±0.5
Financial aspects	2	10	6.2	62	3.1±0.6
Time spent with doctor	2	10	6.0	60	3.0±0.5
Accessibility and convenience	4	20	12.4	62	3.0±0.4

PSQ-18: Patient Satisfaction Questionnaire-18; SD: Standard deviation

**Table 3: Perception of cancer patients on quality of care**

Response themes	Common responses
Good behavior of doctor	Behavior of the doctor is good Doctors cooperate and communicate nicely
Long waiting hours	Have to wait a long time Takes too much time to get outdoor ticket Takes so much of time, wait for appointment with doctor in a long queue
Distance and location	Don't have a cancer hospital nearby It is difficult and expensive to travel long distances for small things such as cough, cold, and fever Travelling is a difficult for treatment Difficult to come and stay here far longer days
Services at health centers	Not aware where to go and what to do Single doctor is always appointed for our treatment; others do not treat us or hear us Local doctor can't diagnosed cancer and always give pain killer Medicine store not available near hospital

have shown that patients are more satisfied with personal rather than professional qualities of the doctors.<sup>[26]</sup> Similar findings were seen in our study which had the highest level of satisfaction for communication by the doctors. A study conducted by Holikatti *et al.*<sup>[27]</sup> on patient satisfaction showed having a GS of 57%. Our study finding also showed similar results where the patient satisfaction was 60%. The data show that doctor's attitude toward a patient can have an effect on the patient satisfaction levels. Studies have shown that the communication skills of the doctor contributed to the level of satisfaction among the patients as well motivated them to comply with the treatment procedure.<sup>[28]</sup> It is necessary to keep in mind here that the Indian patient is always found to be reluctant to express his negative views at the time of discharge unless his dissatisfaction is very strong. Considering this, the value could be exaggerated to a point. Another limiting factor to be considered while studying the overall satisfaction of the services of any organization is the "masking effect" of a variable with high degree of satisfaction over another with a relatively lower level of satisfaction.

Accessibility is one of the principles of health for all, as stated in Alma-Ata Declaration on primary health care.<sup>[13]</sup> Although the large catchment area of the tertiary cancer facilities makes it less accessible, yet people traveled by the public automated transport for more than an hour to reach there to receive specialized services as was reported in our study. The study also highlighted that the patients were dissatisfied with the lack of basic follow-up services at health centers near their place of residence. They reported that long distance travel was expensive and that there was no guarantee to see the desired doctor. They reported to be referred for minor ailments like a cough and cold from the health facilities near their residence as they suffered from cancer.

Long waiting hours at the outpatient department (OPD) was also reported among the interviewed patients. This could be due to

time management of working health staffs of this hospital and patient overload. The decreased level of satisfaction with the duration of the OPD at the tertiary level could be attributed to a number of factors such as short duration of OPD timings, compounded by late arrival, relative lack of appropriate signboards, and misleading of the ignorant patients by people from private agencies, adding to the cost and suffering.<sup>[28]</sup>

The skills of doctor-patient communication and other relevant areas would go a long way to enhance the level of satisfaction of the patients, considering the fact that most of the patients are drawn to the health facility because of their faith. There is a need for more studies to determine the predictors of patient satisfaction which was beyond the scope of the study due to limited sample size.

### Limitations

Since we relied on information reported by patients, there may be recall bias. However, efforts were made to minimize the effects of recall bias by putting multiple and leading questions. The study could have had more generalizability if all cancer treatment centers including private and various medical colleges and hospitals had been included.

### Conclusion

Determining patient satisfaction is important to improve the healthcare services as well as they also act as a parameter to understand what is working and what is not. The study highlights that there may be a need to strengthen the follow-up mechanism of the patients in the hospitals. The role of primary care centers should also be revisited to manage minor ailments among the cancer patients. Efficient scheduling of appointments and better patient management in the hospitals can also reduce the longer waiting hours. From the study's findings, it can be concluded that patients were generally satisfied with the quality of services. More studies are warranted including the perception of the patients as well as the caregiver.

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### Conflicts of interest

There are no conflicts of interest.

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