



Patient Reported Experience Measure and Patient Reported Outcome Measure in Patients Undergoing Cancer Chemotherapy: A Case Study

Priyata R¹, Rajni Y^{2*}, Sandip T¹ and Neelesh J³

¹Kalinga University, Faculty of Pharmacy, India

²Amity University, India

³Balco Medical Centre, India

***Corresponding author:** Rajni Yadav, Amity University, Raipur, Near Manth, Raipur, Chhattisgarh, 493225, India, Email: rajniyadav303@gmail.com

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Abstract

The purpose of the "Healthcare Surveillance of Cancer" study is to learn more about patients' perspectives, management techniques, symptoms, and outcomes of Cancer chemotherapy. Results show that most of the patients suffer from severe side effects like insomnia, constipation, stress, anxiety and loss of appetite being the most prevalent symptoms. With the intention of assisting all National Health Service(NHS) organizations in gathering PROMs and PREMs across a range of conditions, the patient-reported outcome measures (PROMs), patient-reported experience measures (PREMs) were introduced. In order to offer a measure that can be used to assess the clinical and financial efficacy of interventions and services, the goal is to gather specific PROMs and PREMs from each secondary care patients. This paper details the difficulties faced and solutions put in place using PROM and PREM survey.

Keywords: Cancer; PREM; PROM; Chemotherapy

Abbreviations: NHS: National Health Service; PREMs: Patient-Reported Experience Measures; PROMs: Patient-Reported Outcome Measures; MRI: Magnetic Resonance Imaging; VBHC: Value-Based Healthcare; PSMs: Patient Satisfaction Measures.

Introduction

Cancer is one of the major causes of death worldwide. Now-a-days more than lakhs of cases of cancer were diagnosed

every year. These patients frequently have a protracted and intense healthcare journey, starting with diagnosis and ending with long-term follow-up. Most commonly caused Cancer is Breast Cancer, Prostrate Cancer, and Lung Cancer.

One of the most prevalent malignancies in women globally is the breast cancer claimed around 570,000 lives in 2015. Worldwide, more than 1.5 million women (or 25% of all women with cancer) receive a breast cancer diagnosis each year [1,2]. Breast cancer is incurable mostly because it is a

metastatic cancer that frequently spreads to distant organs such the liver, brain, lung, and bone. A favourable prognosis and a high chance of survival can result from early detection of the illness. Mammography is a frequently used screening method for breast cancer detection that has been shown to successfully lower death rates. Over the past ten years, additional screening techniques have also been used and researched, such as Magnetic Resonance Imaging (MRI), which is more sensitive than mammography [3]. The chance of developing breast cancer can be increased by a number of factors, including sex, aging, oestrogen, family history, gene mutations, and an unhealthy lifestyle [4].

Patient's thoughts regarding the care they received are a valuable source of information about quality because they can offer a variety of viewpoints and insights into areas of healthcare that medical professionals may not be aware of. As a result, the application of patient-reported experience measures (PREMs) in the context of value-based healthcare (VBHC) is receiving more attention in an effort to enhance quality. The outcome we got from the patients after the therapy also helps the healthcare providers to better focus on the treatment they provide which is carried out by the patient-reported outcome measures (PROMs) [5-7].

This study will help us to understand about the different problems faced by the patients after taking chemotherapy through the help of PROMs and the problems faced by the patients in the healthcare environment during the whole process with the help of PREMs.

What is Patient Reported Outcome Measure (PROM)

Patient Reported Outcome Measures (PROM) are described as "any report that comes directly from patients about a health condition and its treatment" and "without a physician or other third party interpreting the patient's responses" [8]. Patient satisfaction is an indicator that reflects whether or not the care received has fulfilled the patient's requirements and expectations. It is derived from a patient's experiences with care, health outcomes, and faith in the healthcare system [9].

What is Patient Reported Experience Measure (PREM)

Patient Reported Experience Measure (PREM) refers to the collection of data from patients about their healthcare experiences. These measures aim to capture various aspects of a patient's interaction with the healthcare system, including factors like communication with healthcare providers, waiting times, hospital cleanliness and overall satisfaction with the care received.

PREMs help healthcare organizations and providers understand the quality of care from the patient's perspective

and identify areas for improvement. This allows you to see where improvements in patient experience are needed and assess how successful efforts to adjust the patient journey or operational workflows have been. A patient's assessment of their individual experience with the healthcare they have received is measured by PREMs [10]. The quality of care received is reflected in the interpersonal components of the patient experience, which serves as a process indicator. Three areas make up this indicator in general: emotional support, respect and dignity, and good communication [11,12].

Knowing What to Measure

PROMs: Patients fill out standardized, validated forms to determine their own health and well-being. These are known as patient-reported outcome measures [13,14]. A broad range of outcomes, such as symptom severity, disability, impairment, psychological well-being, social functioning, and physical functioning, can be captured by PROMs [13,15,16]. PROMs are frequently used to evaluate changes in outcomes following the introduction of a new intervention (such as therapy, services, or policies), enabling conclusions to be drawn on their efficacy and safety [15,17]. PROMs are also used to track the long-term impacts of treatments as well as the health status of individuals and cohorts [18].

PREMs: Instruments that record a patient's experience receiving care are known as patient-reported experience measures [13,19]. Patient-reported experience measures are mainly used to show patterns in experience scores over time within health services and systems and to characterize unique patient experiences in a variety of health care contexts. Notably, although they are used interchangeably in the literature, PREMs are not the same as patient satisfaction measures. Patient satisfaction measures (PSMs) ask patients to rate their care experience (subjective), whereas PREMs ask patients to record their care experience (objective) [19-21].

Material and Method

Study Design: OPD and Day care Patients based healthcare surveillance.

Methodology: The study was done in a cancer hospital. After the approval of hospital administration as well as patient, the survey was done.

Results and Discussion

As a part of my project I had done this survey on Cancer chemotherapy patients with the help of some questionnaire which is shown below.

BALCO Medical Centre
Patient reported experience measure (PREM) - OPD consultation

Name of Patient: _____ UMRD: _____
Date of Talking: _____ Age: _____ Sex: _____
Diagnosis: _____

- How much time from your day (including travel and waiting for the doctor) do you estimate you have spent for coming for OPD consultation?
A. <2 hours, B. 2-4 hours, C. 4-6 hours, D. >4 hours
- How much money do you estimate you have spent (travel, time off from work etc.) coming to the OPD for consultation?
A. <Rs 500, B. Rs 500-1000, C. Rs 1000-3000, D. >Rs3000
- Do you have to give up work or take time off for OPD consultation?
A. Yes- Half day B. Yes- full day C. No
- Would you like reminders for OPD appointments?
A. Yes B. No
- Overall quality of OPD consultation
A. Very Satisfied B. Satisfied C. Neutral D. Unsatisfied E. Very unsatisfied
- OPD registration/ Billing desk
A. Very Satisfied B. Satisfied C. Neutral D. Unsatisfied E. Very unsatisfied

Figure 1: PREM Form.

"WellChem" Questionnaire

Name of patient: _____ UMRD _____
Date of talk _____
Age _____ Sex _____ Diagnosis _____

Cycle of chemotherapy / Immunotherapy _____ Regimen _____

Are you on chemotherapy? Yes/No

Do you need to stay in bed or a chair during the day? No / A Little/ Quite a lot/ Very much

Do you need help with eating, using toilet, washing? No / A Little/ Quite a lot/ Very much

Are you drinking enough fluids – at least 2 litres fluids? Yes/No

Are you eating small frequent meals? Yes/No

Do you enjoy your food? Yes/No

Do you have tingling / numbness hands/feet? Yes/No

Is this getting worse? Yes/No

Are you being intimate with your spouse? Yes/No

Do you use barrier contraception? Yes/No

Are you keeping your mouth clean? Yes/No (brush twice, saline mouth wash)

Do you have a thermometer? Yes/No

Do you know how to take temperature? Yes/No (if No, let us learn it today!)

Do you have any trouble taking a long walk? No / A Little/ Quite a lot/ Very much

Do you have any trouble taking a short walk? No / A Little/ Quite a lot/ Very much

Are you short of breath? No / A Little/ Quite a lot/ Very much

Do you have pain? No / A Little/ Quite a lot/ Very much

Does the pain affect your daily life? No / A Little/ Quite a lot/ Very much

Are you taking pain killers? Yes/No

Is the pain controlled on current painkillers? No / A Little/ Quite a lot/ Very much

Do you have trouble sleeping? No / A Little/ Quite a lot/ Very much

Do you lack appetite? No / A Little/ Quite a lot/ Very much

Do you feel nauseated? No / A Little/ Quite a lot/ Very much

Have you vomited? No / A Little/ Quite a lot/ Very much

Are you constipated? No / A Little/ Quite a lot/ Very much

Have you had diarrhea? No / A Little/ Quite a lot/ Very much

Have you had difficulty in concentrating on things like reading a newspaper or watching television? No / A Little/ Quite a lot/ Very much

Do you feel tense? No / A Little/ Quite a lot/ Very much

Do you worry? No / A Little/ Quite a lot/ Very much

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Do you feel irritable? No / A Little/ Quite a lot/ Very much

Do you feel depressed? No / A Little/ Quite a lot/ Very much

Do you have difficulty remembering things? No / A Little/ Quite a lot/ Very much

Has your physical condition or medical treatment interfered with your family life? No / A Little/ Quite a lot/ Very much

Has your diagnosis or medical treatment caused you financial difficulties? No / A Little/ Quite a lot/ Very much

Do you feel counseling will help you to feel better? Yes/No

Will you feel relaxed in the atmosphere of our daycare? No / A Little/ Quite a lot/ Very much

How would you rate your overall health during the past week? (Circle)
1 2 3 4 5 6 7
Very poor excellent

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

Any suggestions to improve the service provided to you? (We value your suggestions!)

Any other Comments for Chemo team?

(a)

(b)

Figure 2: (a) and (b) PROM Form.

Graphs and Table

I had collected approximately 150 patients out of which 37 patients are of breast cancer and the outcome was as follows:

For this study I have collected the followings data from PROM

Prom Result for Breast Cancer

S.NO	PROM Parameter	Total Patients: 37	
1	On Chemotherapy?	Yes: 36	No:1
2	Stay in bed or a chair during the day?	No: 27	A Little: 5
		Quite a lot: 3	Very much: 2
3	Need help of others with eating, using toilet?	No: 32	A Little: 3
		Quite a lot: 2	Very much: 0
4	Drinking enough liquids at least 2 litres a day?	Yes: 29	No: 8
5	Eating small frequent meals?	Yes: 33	No: 4
6	Tingling/numbness on hands/feet?	Yes: 25	No: 12
7	Is this getting worse?	Yes: 4	No: 33
8	Are you keeping your mouth clean?	Yes: 37	No: 0
9	Do you have a thermometer?	Yes: 19	No: 18
10	Do you know how to take temperature?	Yes: 18	No: 19
11	Do you have any trouble taking a long walk?	No: 17	A Little: 9
		Quite a lot: 9	Very much: 2
12	Are you short of breath?	No: 29	A Little: 7
		Quite a lot: 1	Very much: 0
13	Do you have pain?	No: 11	A Little: 17
		Quite a lot: 9	Very much: 0
14	Do you have trouble sleeping?	No: 25	A Little: 6
		Quite a lot: 4	Very much: 2
15	Do you lack appetite?	No: 19	A Little: 7
		Quite a lot: 7	Very much: 4
16	Do you feel nauseated?	No: 23	A Little: 6
		Quite a lot: 7	Very much: 1
17	Have you vomited?	No: 26	A Little: 9
		Quite a lot: 2	Very much: 0
18	Are you constipated?	No: 31	A Little: 1
		Quite a lot: 5	Very much: 0
19	Have you had diarrhoea?	No: 35	A Little: 2
		Quite a lot: 0	Very much: 0
20	Have you had difficulty in concentrating on things?	No: 19	A Little: 14
		Quite a lot: 3	Very much: 1
21	Do you feel tense?	No: 12	A Little: 19
		Quite a lot: 4	Very much: 2
22	Do you worry?	No: 13	A Little: 12
		Quite a lot: 11	Very much: 1
23	Do you feel irritable?	No: 18	A Little: 7
		Quite a lot: 9	Very much: 3
24	Do you feel depressed?	No: 20	A Little: 6
		Quite a lot: 10	Very much: 1
25	Do you have difficulty remembering things?	No: 23	A little: 6
		Quite a lot: 8	Very much: 0
26	Has your physical condition or medical treatment interfered with your family life?	No: 30	A Little: 5
		Quite a lot: 2	Very much: 0

Table 1: PROM Data for Breast Cancer.

Statistical Graphs and Pie Charts

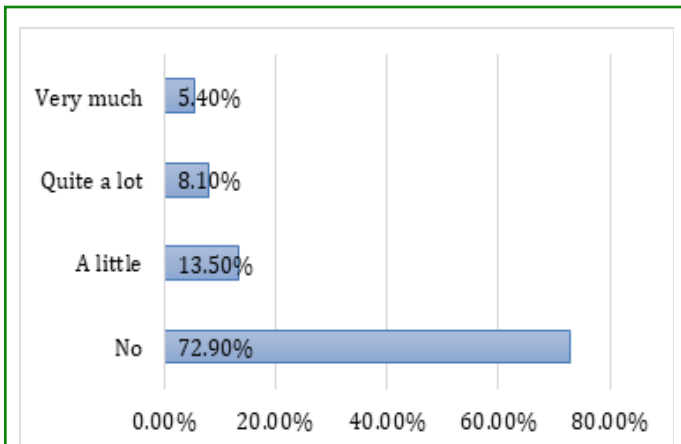


Figure 3: Stay in Bed or a Chair during the Day.

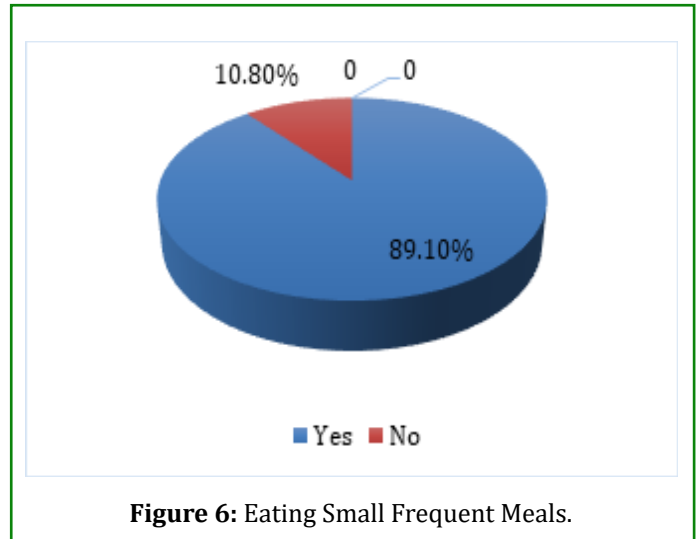


Figure 6: Eating Small Frequent Meals.

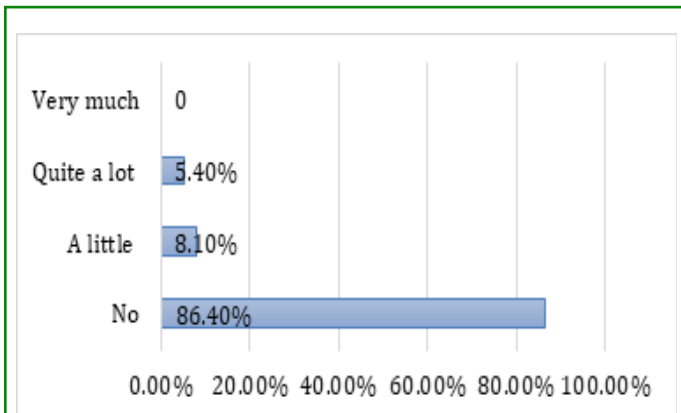


Figure 4: Need Help with Eating, Using Toilet, Washing.

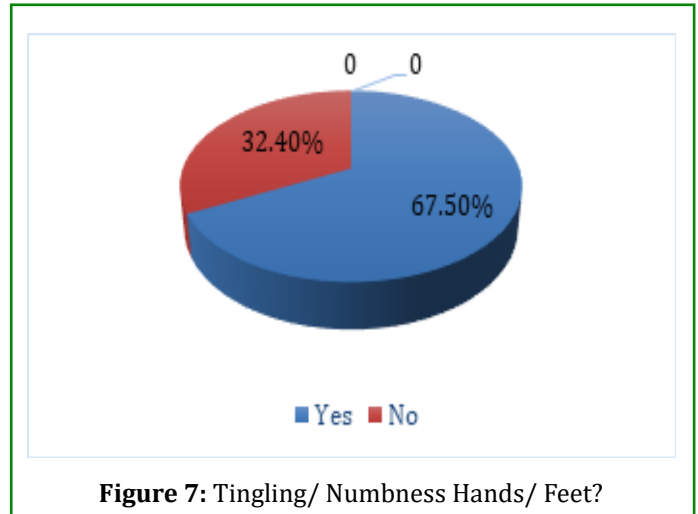


Figure 7: Tingling/ Numbness Hands/ Feet?

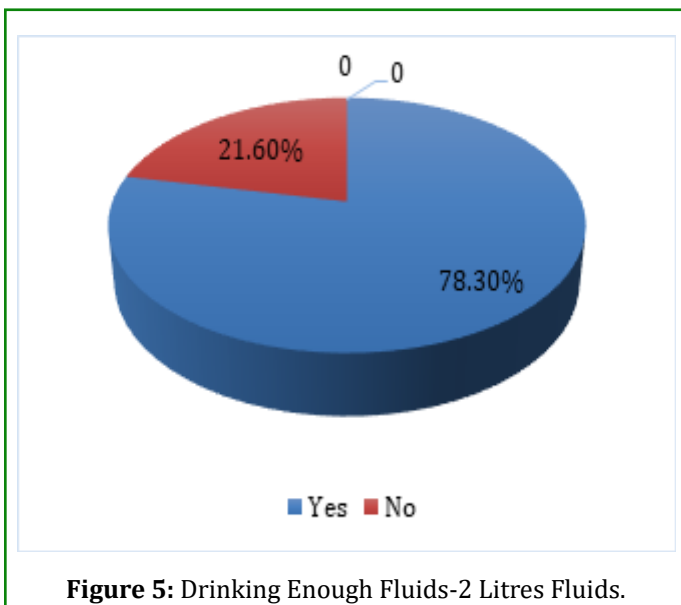


Figure 5: Drinking Enough Fluids-2 Litres Fluids.

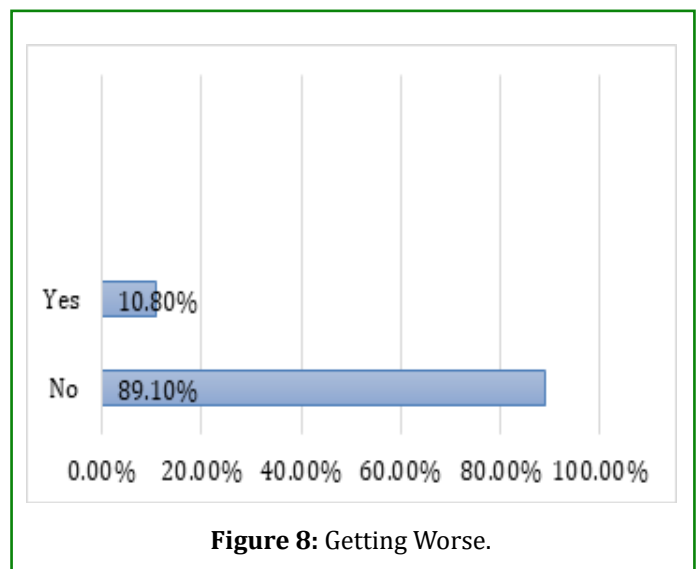


Figure 8: Getting Worse.

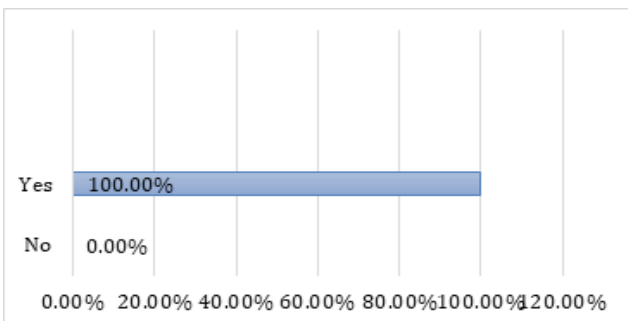


Figure 9: Mouth Clean.

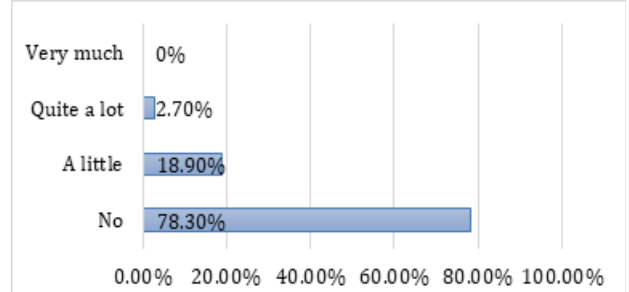


Figure 13: Short of Breath.

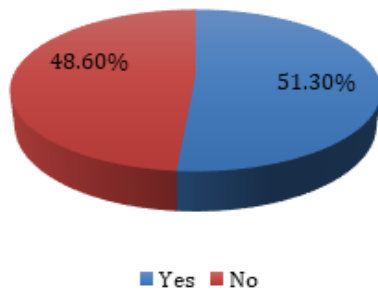


Figure 10: Thermometer.

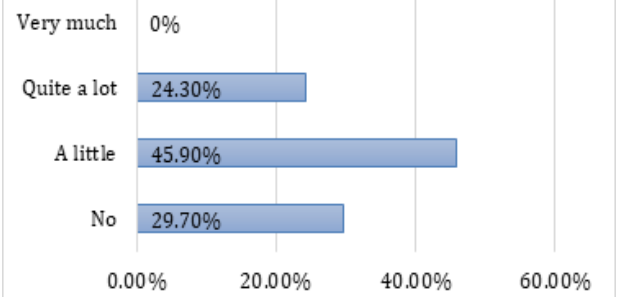


Figure 14: Have Pain.

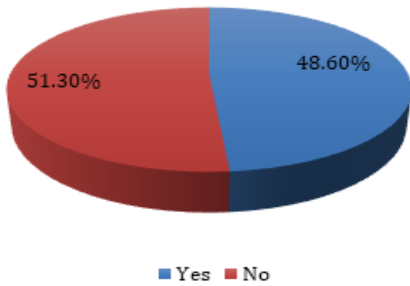


Figure 11: How to take Temperature.

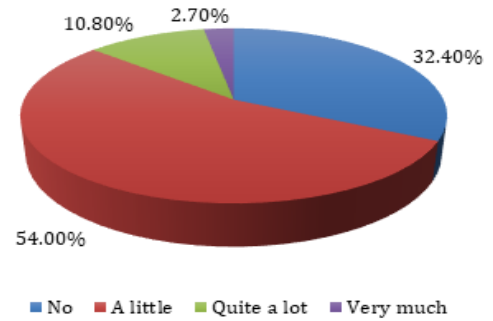


Figure 15: Pain Affect you Daily Life.

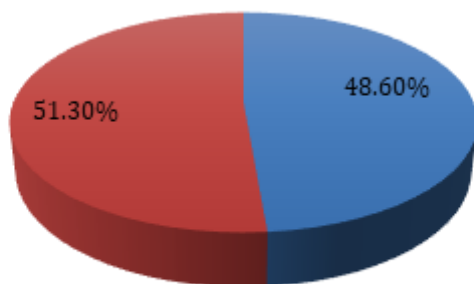


Figure 12: Trouble Taking a Long Walk.

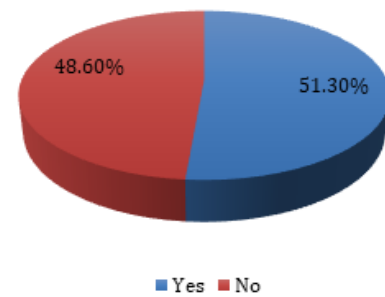


Figure 16: Taking Painkillers.

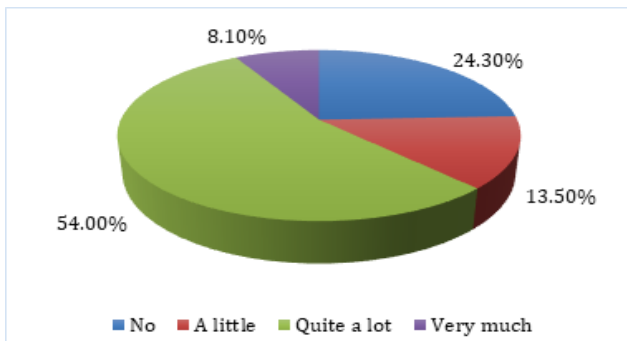


Figure 17: Pain Controlled on Current Painkillers.

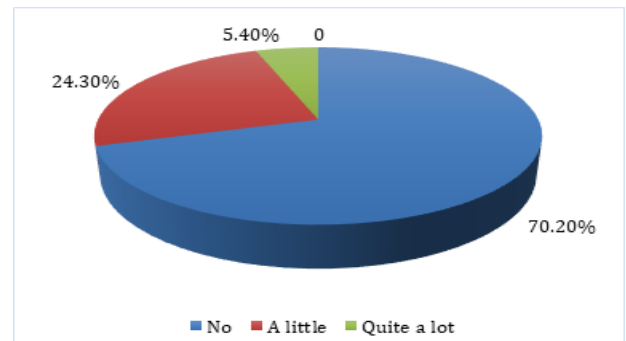


Figure 21: Vomited.

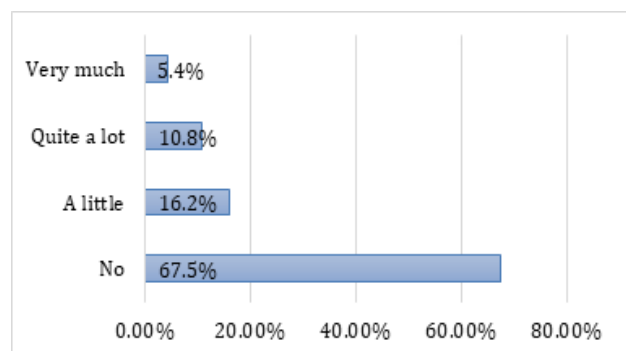


Figure 18: Having Trouble in Sleeping.

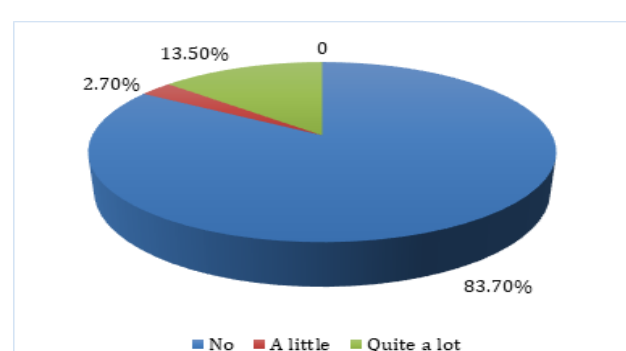


Figure 22: Constipated.

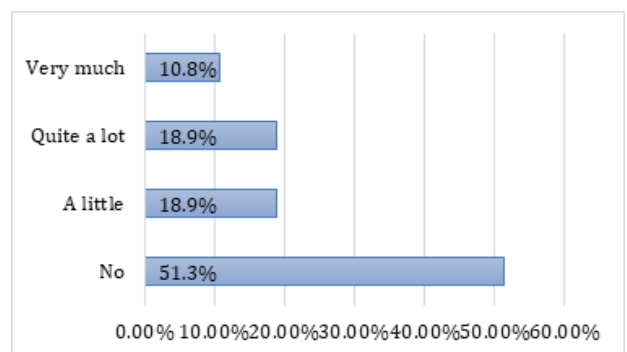


Figure 19: Lack Appetite.

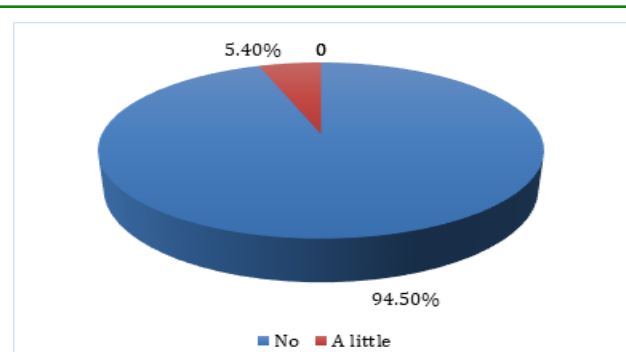


Figure 23: Diarrhoea.

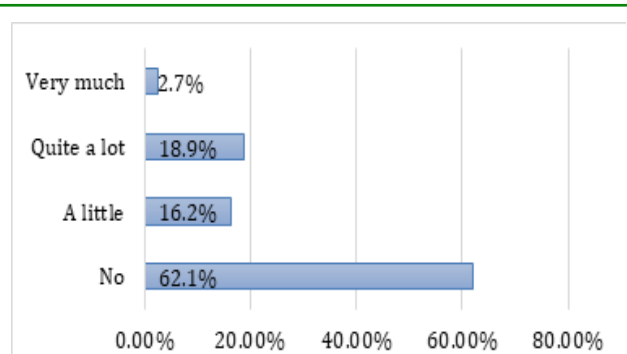


Figure 20: Feel Nauseated.

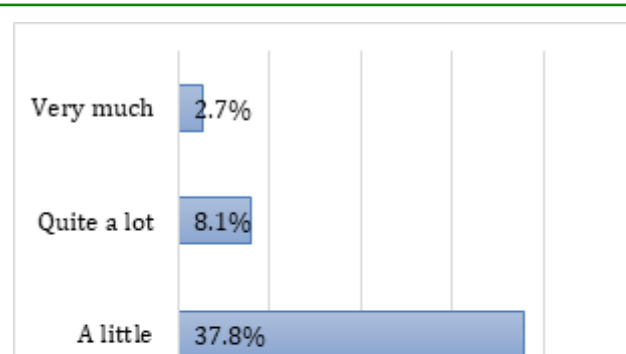


Figure 24: Difficulty in Concentrating.

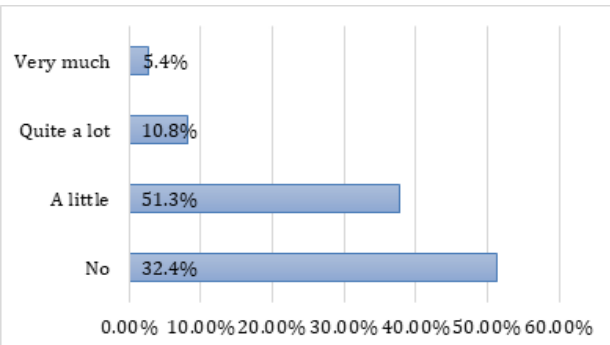


Figure 25: Feel Tense.

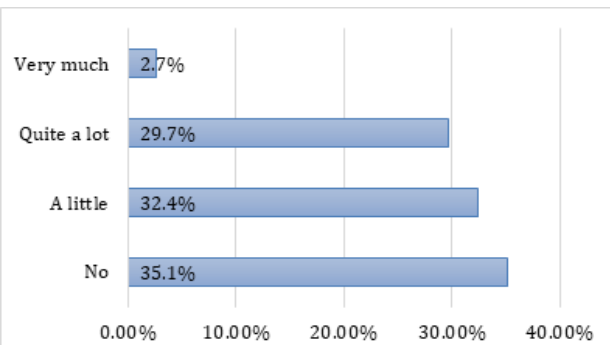


Figure 26: Feel worry.

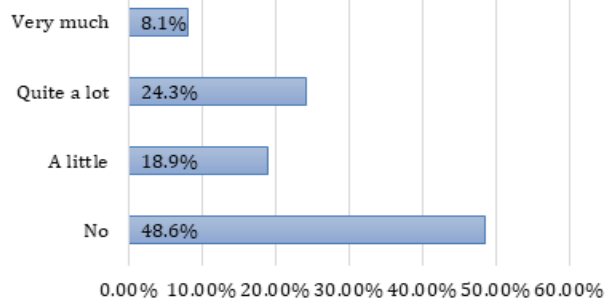


Figure 27: Irritable.

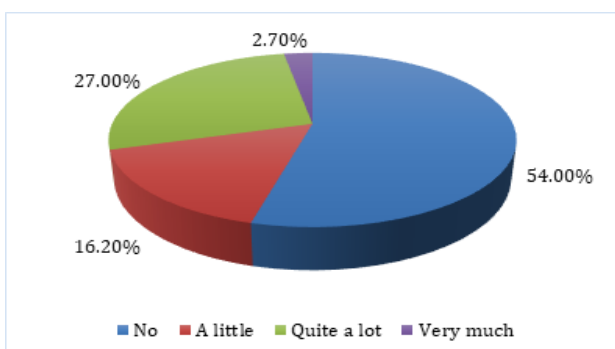


Figure 28: Depressed.

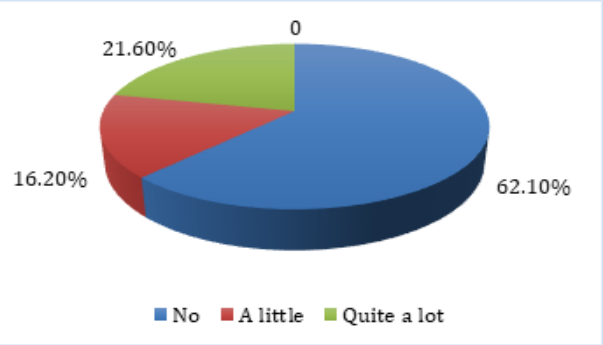


Figure 29: Difficulty Remembering Things.

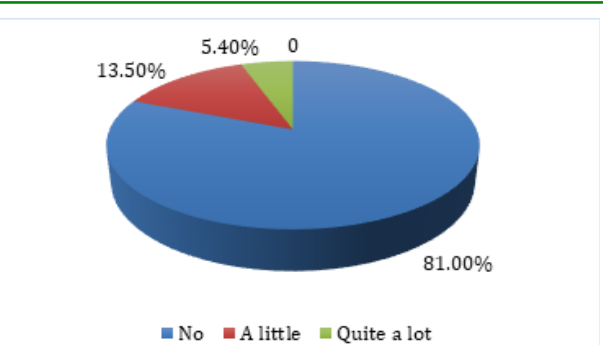


Figure 30: Treatment Interfered with your Family Life.

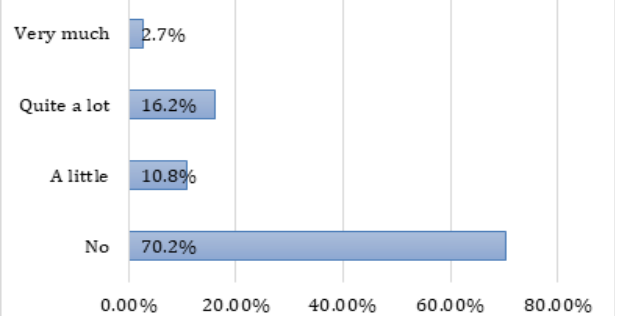


Figure 31: Treatment caused you Financial Difficulties.

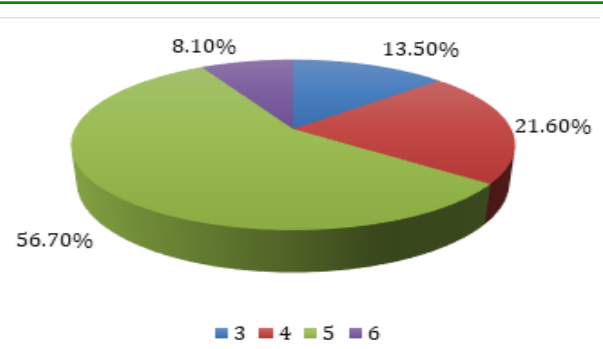


Figure 32: Rate Your Overall Health during Past Week.

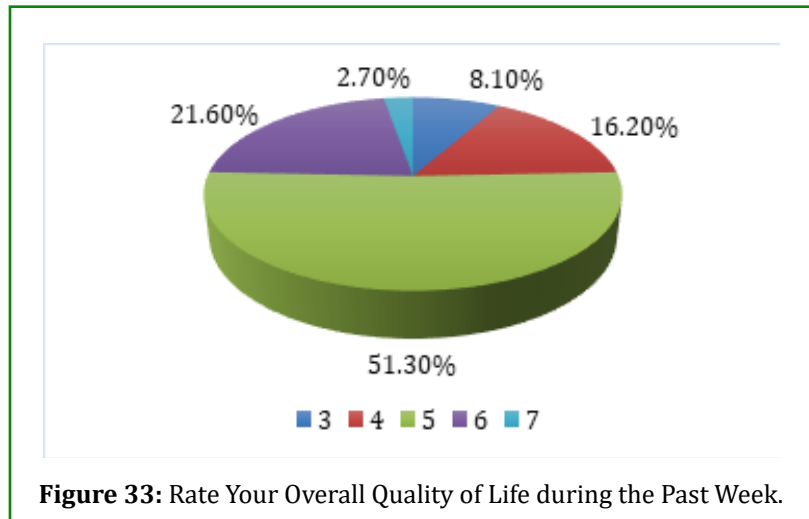


Figure 33: Rate Your Overall Quality of Life during the Past Week.

S. No	Prem Parameters	Total Patients =37				
1	How much time from your day do you estimate you have spent for coming for OPD consultation?	<2 hours: 8		2-4 hours: 9		
		4-6 hours: 2		>4 hours: 18		
2	How much money do you estimate you have spent coming to the OPD for consultation?	<Rs 500: 1		Rs 500-1000: 3		
		Rs 1000- 3000: 2		>Rs 3000: 31		
3	Do you have to give up work or time off for OPD consultation?	Yes-half day: 0	Yes-full day:8		No: 29	
4	Would you like reminders for OPD appointments?	Yes: 37			No: 0	
5	Overall quality of OPD consultation	Very satisfied: 34	Satisfied: 2	Neutral: 0	Unsatisfied: 1	Very Unsatisfied: 0
6	OPD registration/ Billing Desk?	Very satisfied: 35	Satisfied: 1	Neutral: 1	Unsatisfied: 0	Very Unsatisfied: 0

Table 2: PREM Result for Breast Cancer.

Statistical Graphs

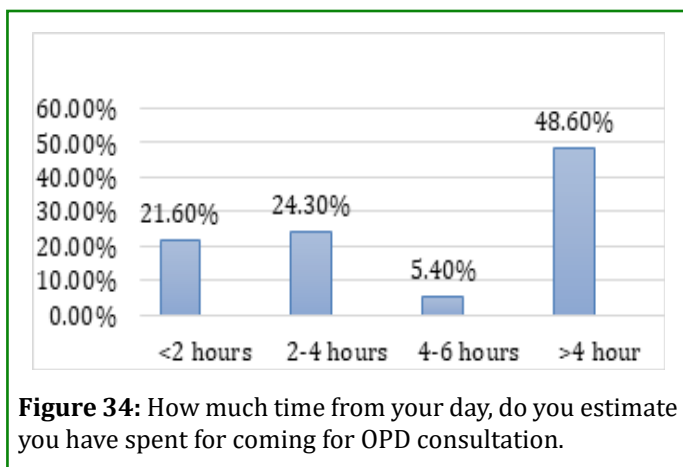


Figure 34: How much time from your day, do you estimate you have spent for coming for OPD consultation.

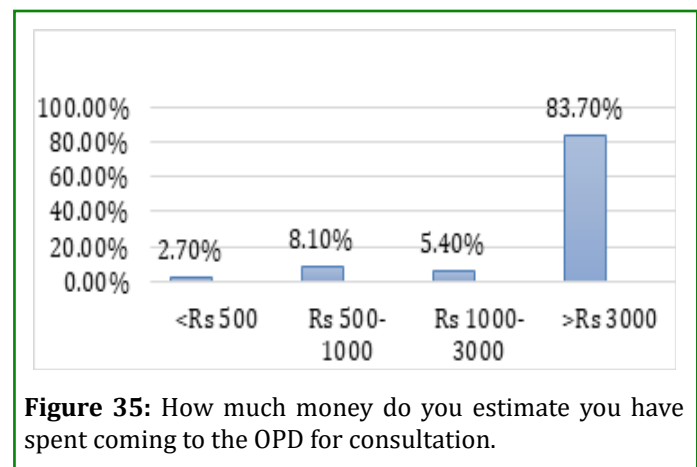


Figure 35: How much money do you estimate you have spent coming to the OPD for consultation.

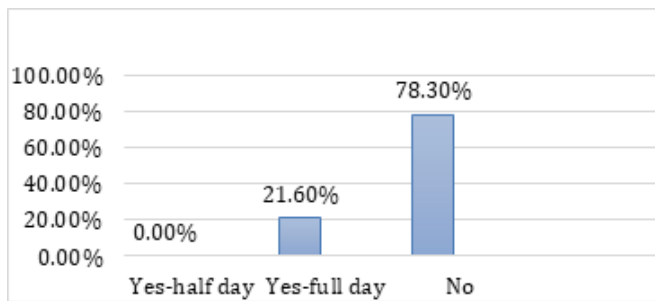


Figure 36: Do you have to give up work or take time off for OPD consultation.

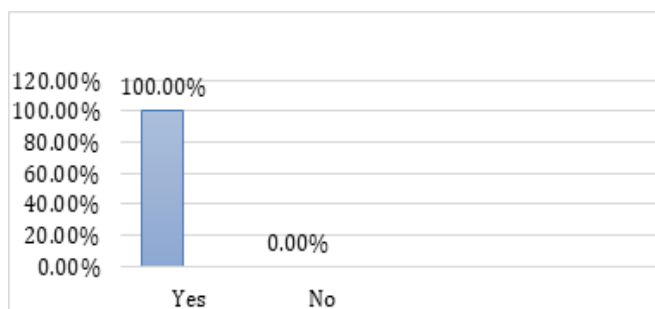


Figure 37: Would you like Reminders for OPD Consultation.

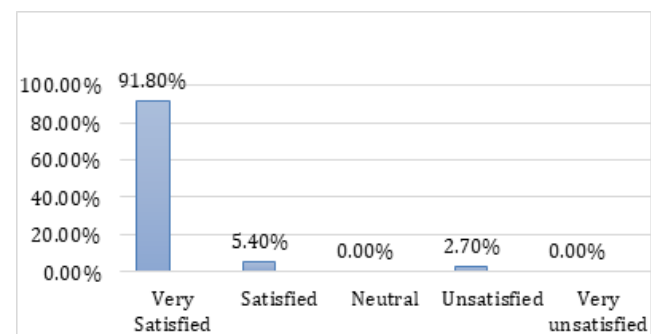


Figure 38: Overall Quality of OPD Consultation.

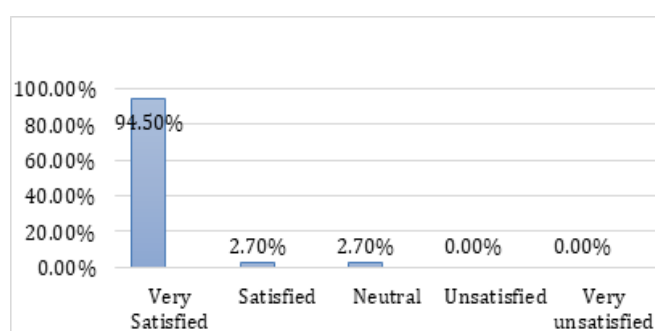


Figure 39: OPD Registration/ Billing Desk.

Discussion

According to the survey, patients were rather satisfied with how well they were communicated with and dealt with symptomatic side effects. Patients expressed a strong desire to take part in the study as patient representatives, however approximately half of them actually did so and provided feedback. It is important to think about when to include patients in the study process. We requested patient participation at the onset of chemotherapy, and patients' involvement in the study occurred concurrently with their chemotherapy treatment. Given that it can be challenging for the patient to complete the task while receiving cancer treatment, this may be a crucial moment. Both PREM and PROM questionnaire had been constructed in two languages one is English and the other is Hindi, so that it is easy for the patient to understand the questions and answer it properly. It's possible that the patient representative's questions in the PREM and PROM questionnaire were not sufficiently thorough to identify potential areas for improvement. For instance, more detailed inquiries regarding the management of side effects and when they occurred may have disclosed disparities between the two groups. Overall, the patients' participation has guaranteed that the questionnaire was significant from their point of view. Many patients reported symptoms that were not included in the questionnaire about side effects. Out of 150 patients of Cancer chemotherapy which includes various types of Cancer like Ovary, Testis, Lung, Breast, Oral, Liver etc., I have only focussed on the Breast Cancer patients as the percentage of Breast Cancer patients were high in comparison to other Cancers. During the survey, several patients had initially consented to take part in the interviews, some later denied to take part due to some reasons. The survey was conducted right after the patient's chemotherapy treatments ended, when they were still dealing with side effects. In particular, tiredness can affect a patient's capacity to carry out daily tasks at this point, which may account for the low participation rate because patients may require extra energy to engage in activities like talking right after the chemotherapy. Some patients did not participated as they were not able to talk properly due to certain type of oral and tongue cancer, so in their behalf there attendees answered few questions. This short survey with patients of Cancer chemotherapy made it easier for the healthcare professionals to track the adverse effects and symptoms quickly.

Conclusions

Patients expressed great satisfaction with the way nurses and physicians handled side effects of chemotherapy. The results of the study point to the necessity for a more extensive side effect questionnaire for symptom tracking than the one currently in use in our regular treatment.

According to the survey it was concluded that:

- Majority of the patients doesn't drink enough water during the entire day.
- Majority of the patients don't have thermometer and also they don't know how to take temperature.
- Most of the patients suffer from Insomnia and severe headaches.

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