

**ASSESING QUALITY OF LIFE THROUGH PATIENT REPORTED
OUTCOME MEASURES AMONG CHEMOTHERAPY PATIENTS AT
BMCHRC - A PILOT STUDY**

Dissertation Submitted to



The IIHMR University, Jaipur

For the partial fulfilment for the award of the degree of

Master of Business Administration (MBA)

In

Hospital and Health Management

By

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Under the Supervision and Guidance of

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2022

DECLARATION BY STUDENT

I hereby declare that this dissertation titled ASSESING QUALITY OF LIFE THROUGH PATIENT REPORTED OUTCOME MEASURES AMONG CHEMOTHERAPY PATIENTS AT BMCHRC - A PILOT STUDY is the bonafide record of my original research work. I declare that it has not been submitted to any other university or institution for the award of any degree or diploma. Information derived from the published or unpublished work of others has been duly acknowledged in the text.



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Date: 03-07-2022

BMH/HRD/2022/ 641

Date: June 30th, 2022

To whomsoever it may concern

This is to certify that **Dr. Shree Priya Dhanee**, in partial fulfillment of the award of the degree of MBA (Hospital and Healthcare Management) from the **IIHMR University, Jaipur** has successfully completed her internship at BMCHRC during **1st April 2022 to 30th June 2022**.

She has done her work satisfactorily during dissertation period.

We wish her all the best for her future endeavors.


Deepika Joshi



Sr. Manager – Human Resource

ACKNOWLEDGEMENTS

This project has been a remarkable learning experience filled with exceptional guidance, support, inspiration, and counselling from the organization staff. I am extremely grateful to IIHMR University and BMCHRC for this incredible internship opportunity.

My deepest gratitude goes out to Dr. Subha Pathania (Medical Superintendent) for believing in me and providing me opportunities to prove myself during the course of the internship.

I am deeply indebted to Dr. Sonal Rai (Quality Manager) for being there for me whenever I needed her and for her invaluable patience and feedback. Words cannot express how her guidance has made my journey enriching. I am also extremely grateful to Vansh Choudhary (Quality Executive) for his support both as a mentor and a friend.

I want to express my gratitude for Dr. Kanika Jindal being such a wonderful mentor. The success of this project would not have been attainable without her guidance and support.

Lastly, I would be remiss in not mentioning Rishabh Arora, for his help in the editing, late-night feedback sessions and moral support.

ABSTRACT

Introduction: India is ranked third in the world in terms of the number of cancer cases. According to the National Cancer Registry Program statistics, over 13 lakh individuals in India are diagnosed with cancer each year. The quality of life has long been a problem in oncology, particularly for those with a specific type of cancer. PROMs are self-report instruments, similar to patient-reported experience measures that evaluate experience and satisfaction with care. Information is immediately collected from the patient without any interpretation on the part of a doctor or any person.

Methodology: This day-care ward-based cross-sectional study was conducted at BMCHRC during April and May 2022 where stratified random technique was used. With a sample size of 250, structured interviews were used to gather data and was analysed by Microsoft Excel and IBM SPSS (version 28.0.1.1) statistical package software.

Results: The showed that among 250 cancer patients, 123 (49.4%) ($121 + 2 = 123$) were classified as having a QOL score below average. While 110 people (16%) got high QOL scores, only 16 people (6.4%) had extremely high QOL scores. The mean QOL score across the board was 71.08 ± 12.25 . The quantity of CT cycles and QoL were shown to be strongly correlated. The majority of patients (61.2%) who had finished three or more CT cycles indicated a moderately favourable or favourable degree of quality of life.

Conclusion: This study found that cancer patients have a wide range of symptoms that negatively affect their quality of life. It is necessary to establish methods for effective symptom management and to improve QOL. A short assessment of patients in this group for symptom load and quality of life using a straightforward and unambiguous questionnaire, as we did in our study, would undoubtedly aid in providing better symptom-directed therapy

Given how poorly the chemotherapy patients performed on the symptom scales, physicians should pay close attention to how to prepare the patients for the acute toxicities of therapy. The findings demand that a psycho-oncology service be extensively used at BMCHRC to address psycho-social outcomes.

Keywords: Quality of Life, Patient Reported Outcome Measures, EORTC, Cancer, Global Health Status, Chemotherapy, and Psycho-Oncology.

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ABBREVIATIONS

ICMR	Indian Council of Medical Research
PROM	Patient Reported Outcome Measures
PREM	Patient Reported Experience Measures
PCOR	Patient Centered Outcome Research
PCORI	Patient Centered Outcome Research Institute
SF-36	36-Item Short Form Survey
VR-12	Veterans RAND 12
HUI	Health Utilities Index
EORTC	European Organisation for Research and Treatment of Cancer
QLQ	Quality of Life Questionnaire
QOL	Quality Of Life
NABH	National Accredited Board of Health
HRQOL	Health Related Quality of Life
SPSS	Statistical Package for the Social Sciences
GHS	Global Health Score
CT	Chemotherapy
HNC _a	Head and Neck Cancer
BMCHRC	Bhagwan Mahaveer Cancer Hospital & Research Centre
IPOS	International Psycho-Oncology Society

INTRODUCTION

A variety of conditions that can affect any part of the body are included under the umbrella term "cancer," which is a broad concept. Other terms used include neoplasms and malignant tumours. The fast growth of abnormal cells that quickly beyond their normal range and move to other organs is one of the characteristics of cancer. This process is known as metastasis. Widespread metastases are the primary cause of cancer deaths. [1].

Globally, cancer is the leading cause of death, and by 2020, 10 million deaths are anticipated due to the disease. [1]. The most frequent types of new cancer cases in 2020 were:

- Breast (2.26 million cases).
- Lung (2.21 million cases).
- Colon and Rectum (1.93 million cases).
- Prostate (1.41 million cases).
- Skin (non-melanoma) (1.20 million cases); and
- Stomach (1.09 million cases).

The following were the leading reasons for cancer deaths in 2020:

- Lung (1.80 million deaths).
- Colon and rectum (916 000 deaths).
- Liver (830 000 deaths).
- Stomach (769 000 deaths); and
- Breast (685 000 deaths).

Every year, 400,000 or more kids are getting diagnosed with cancer. The cancers that are diagnosed most frequently vary by nation. Cervical cancer is the most common kind in 23 nations.

According to the National Cancer Registry Program statistics, over 13 lakh individuals in India are diagnosed with cancer each year. The surge is attributed to sedentary lifestyles, increased urban pollution, obesity, tobacco, and alcohol usage, among other factors.

According to the Indian Council of Medical Research (ICMR), cancer cases in India will climb by 12% in the next five years. Breast cancer, cervical cancer, and oral cancer are the most common types of cancer among Indians. [2]

As per research, in the Eastern Rajasthan males have a high prevalence of tobacco-related malignancies, including lung cancer along with head and neck cancer, and screening detectable cancers (breast and cervix) was noted in females. In comparison to earlier research from the region, the frequency of lung cancer in females was shown to be high. A very high incidence of gallbladder cancer in this region, particularly among women, is another cause for worry. [3]

A precise cancer diagnosis is essential for appropriate and effective therapy since each kind of cancer has a unique treatment strategy. Common treatments include surgery, radiation, and/or systemic therapy (chemotherapy, hormonal therapies, and targeted biological therapies). When selecting a treatment strategy, both the cancer and the patient must be taken into account. The treatment process must be finished within a predetermined time limit in order to get the desired therapeutic effect.

What does PROMs mean?

Health outcomes are modifications to one's health condition following medical intervention. PROMs are assessments that patients fill out to report about their health in particular, significant to their QoL. Physical, mental, and social symptoms and functionality can all be assessed. PROMs have also been called health-related quality of life indicators. PROMs are self-report instruments, similar to PREMs that is patient-reported experience measures that evaluate experience and satisfaction with care. Information is immediately obtained from the patient without any interpretation on the part of a doctor or any person. [4]

There are presently no notable patient-centred outcome studies conducted in India (PCORs). According to the PCOR Institute (PCORI), PROs are now receiving the attention they deserve in the United States; nevertheless, India has not yet adopted the idea. All choices pertaining to India's health should be based on information obtained from PROs in hospitals. [5]

Benefits of PROM

PROMs supplement existing data on the quality of treatment and services offered by providing insight into the effectiveness of care from the perspective of patients. Patient-reported outcomes are critical for determining whether or not health-care interventions and procedures improve the wellbeing of the patients and their and quality of life. PROMs are more

prominently being used by decision-makers to assess the effect of medical interventions on mortality rates and quality of life factors associated to health.

- PROMs are utilised in addition to conventional, clinically based outcomes to provide a more thorough understanding of outcomes and efficiency.
- PROMs aid in the enhancement of service delivery by allowing for the evaluation of service effectiveness, finding patients who would benefit from treatments and exchanging best practises are all examples of this.
- PROMS can be used to evaluate the quality and efficiency of care, allowing for a possible change in health care resources planning from a volume-based to a value-based paradigm.
- PROMs can assist in resource allocation choices in order to make sure that investments promote advances in population health. [6]

PROMs Instruments

There are several PROMs instruments on the industry. The tools used by PROMs may either be categorised as general (used by a wide variety of persons) or condition-specific (used to evaluate outcomes that are typical or distinctive to certain illnesses or fields of medicine). It is typically advised to utilise both general and condition-specific instruments since they give complementing data. Effectiveness, broad usage, meaningfulness, appropriateness, practicality, and availability of population norms are all factors to consider while choosing PROMs instruments. Four widely used generic PROMs instruments should be taken into account for a national PROMs programme: the SF-36 family includes the EQ-5D along with the HUI, VR-12 and PROMIS. [6]

The EORTC

A worldwide non-profit organisation called the European Organisation for Research and Treatment of Cancer (EORTC) was founded in 1962. The EORTC's mission is to bring together multidisciplinary groups of oncologists and basic scientists to perform, develop, coordinate, and promote cancer research throughout Europe. Research is often conducted using large, prospective, randomised, multicentre cancer clinical trials. [7]

EORTC versions:

1. EORTC QLQ-C36
2. EORTC QLQ-C30 version 1.0
3. EORTC QLQ-C30 (+3)
4. EORTC QLQ-C30 version 2.0
5. EORTC QLQ-C30 version 3.0

The EORTC QLQ-C30 version 3.0 is the most widely used tool for assessing QoL in cancer patients, despite the great number of created tools to assess patient well-being. The EORTC QLQ-C30 is a collection of 30 self-reported questions that assess various aspects of patient functionality, overall health, and cancer-related symptoms. It consists of five multi-item functional scales (role, physical, cognitive, emotional, and social functioning), three multi-item symptom scales (fatigue, pain, and nausea and vomiting), individual items related to common cancer symptoms (dyspnoea, insomnia, appetite loss, constipation, diarrhoea, and financial difficulties), and two questions assessing overall QoL. The EORTC QLQ-C30 has been translated into over 110 languages and validated in a variety of cancer patient samples across the globe. [7]

The EORTC QLQ-C30 is shown in Appendix C. [Figure 3]

All multi-item scales and single-item measures have a score range of 0 to 100, with a greater score indicating a higher level of response. As a result, a high score on a functional scale indicates a healthy level of functioning, but a high score on a symptom scale indicates worsening of symptoms. A high global health status / QoL score indicates a high QoL.

The scoring principle for all of these scales is the same:

1. Calculate the raw score by averaging the items that contribute to the scale.
2. Standardize the raw score using a linear transformation, ranging from 0 to 100; a greater score indicates a higher ("better") level of functioning or a higher ("worse") degree of symptoms.

Figure 1: Scoring the EORTC QLQ-C30 version 3.0

Technical Summary

In practical terms, if items $I_1, I_2, \dots, I_n$ are included in a scale, the procedure is as follows:

Raw score

Calculate the raw score

$$RawScore = RS = (I_1 + I_2 + \dots + I_n) / n$$

Linear transformation

Apply the linear transformation to 0-100 to obtain the score S ,

$$\text{Functional scales: } S = \left\{ 1 - \frac{(RS - 1)}{range} \right\} \times 100$$

$$\text{Symptom scales / items: } S = \{(RS - 1) / range\} \times 100$$

$$\text{Global health status / QoL: } S = \{(RS - 1) / range\} \times 100$$

Range is the difference between the maximum possible value of RS and the minimum possible value. The QLQ-C30 has been designed so that all items in any scale take the same range of values. Therefore, the range of RS equals the range of the item values. Most items are scored 1 to 4, giving $range = 3$. The exceptions are the items contributing to the global health status / QoL, which are 7-point questions with $range = 6$, and the initial yes/no items on the earlier versions of the QLQ-C30 which have $range = 1$.

Figure 2: Scoring table of the QLQ-C30 version 3.0

	Scale	Number of items	Item range*	Version 3.0 Item numbers	Function scales
Global health status / QoL					
Global health status/QoL (revised) [†]	QL2	2	6	29, 30	
Functional scales					
Physical functioning (revised) [†]	PF2	5	3	1 to 5	F
Role functioning (revised) [†]	RF2	2	3	6, 7	F
Emotional functioning	EF	4	3	21 to 24	F
Cognitive functioning	CF	2	3	20, 25	F
Social functioning	SF	2	3	26, 27	F
Symptom scales / items					
Fatigue	FA	3	3	10, 12, 18	
Nausea and vomiting	NV	2	3	14, 15	
Pain	PA	2	3	9, 19	
Dyspnoea	DY	1	3	8	
Insomnia	SL	1	3	11	
Appetite loss	AP	1	3	13	
Constipation	CO	1	3	16	
Diarrhoea	DI	1	3	17	
Financial difficulties	FI	1	3	28	

For all scales, the *RawScore*, *RS*, is the mean of the component items:

$$RawScore = RS = (I_1 + I_2 + \dots + I_n) / n$$

Then for **Functional scales**:

$$Score = \left\{ 1 - \frac{(RS - 1)}{range} \right\} \times 100$$

and for **Symptom scales / items** and **Global health status / QoL**:

$$Score = \{(RS - 1) / range\} \times 100$$

RESEARCH QUESTION

What are the Patient Reported Outcomes in patients undergoing chemotherapy in the day care of Bhagwan Mahaveer Cancer Hospital and Research Centre?

OBJECTIVES

- To study the Patient Reported Outcome in Cancer patients undergoing chemotherapy in the day care of the hospital.
- To examine the association of the Health-Related Quality of Life with the socio-demographic characteristics, cycle of chemotherapy etc.
- To evaluate research methods, including protocols, data gathering tools, sample recruitment techniques, and others.
- To assist in implementing of the process of PROM in the hospital as recommended by NABH (5th edition).

LITERATURE REVIEW

“Health Related Quality of Life of Cancer Patients in Ethiopia”	“Tadesse Melaku Abegaz et al. (2018) studied 150 cancer patients at the University of Gondar in Ethiopia. From January 1 to August 30, 2017, a prospective hospital-based cross-sectional study was created with the objective of assessing the health-related quality of life (HRQoL) of Cancer patients in Ethiopia. (SPSS) version 20 was used to compile all of the statistical data.”	“Emotional and cognitive functions were among the highest functional status scores that remained generally unaltered, according to the study. On the symptom scale, nausea and vomiting were by far the most frequent compliance, followed by fatigue. Another finding on this study indicated that surgery showed a positive impact on the global health status of patients since it could bring a radical cure of the diseases if it is followed by adequate adjuvant therapy. Health related quality of life of cancer patients was found to be low in Ethiopia.”
“Quality of Life of Cancer Patients Treated with Chemotherapy”	“In the years 2018–2020, authors Anna Lewandowska et al. (2020) conducted a population-based, multi-area cross-sectional research among patients of the Clinical Provincial Hospital in Rzeszów's Podkarpackie Oncology Center, with the goal of evaluating cancer patients' quality of life during oncological chemotherapy treatment. Prism 4.0 software was	“The findings of this study revealed that there was no correlation between the age, gender, social status, marriage, or employment and quality of life. There was an association observed between the severity of the disease and the quality of life. The patients reported the most significant problems accordance to the psychometric features, EQ-5D-5L profile and quality of life, with self-care and feeling worried and sad.”

	used to collect and analyse all of the data from the 800 patients in the trial.”	
“Quality of Life in Cancer Patients undergoing Chemotherapy”	“Ali Dehkordi, M. Saeed Heydarnejad, and Daryoush Fatehi performed a study with the objective of describing the quality of life in solid tumour cancer patients during various chemotherapy cycles. The trial, which took place in a Tehran hospital, involved 200 cancer patients. The EORTC QLQ-C30 was adapted and used to evaluate patients' quality of life (QoL).”	“There was no correlation between QoL and any of the following factors: marital status, age, sex, length of illness, financial situation, or job function. Furthermore, there was no connection found between patients' QoL and their degree of schooling. Nonetheless, there was a substantial difference in QoL between patients who had 2 Chemotherapy cycles and those who had 3-5 CT cycles. According to this study, encouraging cancer patients to finish a CT course has a substantial influence on the way their treatments turn out and how well their lives are going.”
“Quality of Life among Cancer Patients”	“Anice George et al. (2017) did a study in Karnataka with 768 cancer patients in stages III and IV with the objective of assessing QOL and finding a link between QOL and demographic and disease-related variables. The QOL questionnaire version II was used to collect data, which was then analysed using the SPSS programme version 16.”	“They discovered that common symptoms reduced QOL significantly, and that financial burdens were the most significant impediments to symptom management. Quality of life was found to improve as income increased but was unaffected by demographic factors.”
“Quality of life in cancer patients	“Harinder Singh et al. (2014) used the EORTC QOL- C30 questionnaire in a prospective, non-interventional, observational study at a tertiary	“It was discovered that GHS and four symptoms, including insomnia, pain, lack of appetite, and financial problems, were statistically

undergoing chemotherapy in a tertiary care centre in Malwa region of Punjab”	care centre in Punjab to assess QOL and physical/ psychological stress among 131 cancer patients during their chemotherapy sessions. Analysis of variance (ANOVA) was used to compare the different groups.”	significant. They also found that as the chemotherapy session went, the patients' quality of life increased dramatically.”
“Symptom burden and quality of life in advanced head and neck cancer patients: AIIMS study of 100 patients”	“Ajeet Kumar Gandhi et al. (2014) used the EORTC- HN35 and EORTC QOL- C15- PAL questionnaires to assess the symptom burden and QOL among incurable in advance Patients with head and neck cancer who received palliative radiations in observational research on 100 advanced HNCa patients.”	“Insomnia and pain along with loss of appetite and fatigue were determined to be the top four most prevalent symptoms. Physical functioning was found to be impaired by 23%, while emotional functioning and QOL were shown to be affected by 50%.”
“Patient-reported outcomes of cancer survivors in England 1–5 years after	“Adam W Glaser et al. (2013) undertook research to assess the feasibility of collecting population-based patient-reported outcome measures (PROMs) for assessing quality of life (QoL), in order to guide the creation of a national PROMs programme for cancer and to begin reporting	“The study found that this way of assessing cancer survivors' quality of life is possible and acceptable to the majority of survivors. Identification will be possible through the systematic gathering of population-based PROMs around the country. and assistance of survivors' individual needs, as well as comparison of outcomes by service provider.”

diagnosis: a cross-sectional survey”	outcomes in a UK cohort of survivors. With a sample size of 4992, it was a cross-sectional population-based sampling strategy.”	
“Health – related quality of life of Kuwaiti women with breast cancer: a comparative study using the EORTC Quality of Life Questionnaire”	“Authors Shafika A Alawadi and Jude U Ohaeri (2009) conducted a study with the objective of highlighting scores on the Health Related-QOL scale for Kuwaiti women with breast cancer, as well as assessing the variables that predict the GQOL scale and the QLQ's five functional scales –in comparison to international data. With a sample size of 348, the study was done at the KCCC's medical oncology department.”	“The relatively large number of people who met the criterion for optimal functioning provides evidence to support increased national health education concerning cancer's psychosocial prognosis. Clinicians caring for Kuwaiti breast cancer patients should pay special attention in educating them, given their poor performance on the symptom measures and they should be treated for the immediate toxicities of treatment as well as for weariness and pain.”

SAMPLE SIZE

According to 2017 research, the same instrument revealed that more than 80% of cancer patients had low quality of life. [8]. The population size was 500 and the margin of error was 5%. With a confidence interval of 95 percent our sample size was 218. We had the opportunity to conduct 250 thorough interviews over the research period.

STUDY DURATION

The study was carried out in the hospital for the period of over two months.

DATA COLLECTION AND SAMPLING

- A stratified random technique was used in this cross-sectional study, which was conducted in a hospital. Patients were selected from the BMCHRC day care ward.
- Patients undergoing chemotherapy were included in the study, however, those receiving chemotherapy for the first time were excluded.
- Patients unwilling to be a part of the survey as well as patients unable to speak (due to mouth cancer and similar reasons) were also excluded. Patients who were under palliative or supportive care were also not a part of the study.
- Participants aged more than 18 and less than 65 were only included in the study. Ineligible patients included those who were too physically sick, too mentally distraught, or illiterate in Hindi.
- An exploratory survey was done with the help of a questionnaire and all the information in the questionnaire was provided by the patient. The QOL tool was translated into the regional (Hindi) language because it was a standardised instrument.

STATISTICAL ANALYSIS

Microsoft Excel was used to enter the data, which was then verified for accuracy and completeness. EORTC QLQ-C30 was utilised as the designated formula for data analysis (reference). The statistical tool IBM SPSS (version 28.0.1.1) was used to analyse the data. Using objective criteria, we did descriptive statistics.

The Quality-of-Life score for each patient was generated. Patients with score above 70 were considered having a high Quality of Life while those below 40 were considered having a below average Quality of Life.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The hospital provided its ethical permission before data collection through the Medical Superintendent and the Quality Department. Each study participant gave their informed permission after being fully informed of the study's objectives.

Appropriate measures were stated to ensure data security, privacy, and confidentiality.

IMPLICATIONS OF RESEARCH

Patients share their experiences using PREMs, such as satisfaction scales, which provide insight into their experience with their health care service that already exists in the BMCHRC. The findings of this study may be leveraged to use and employ PROMs to guide clinical practises, planning, and policies, health services programming, comparative effectiveness analysis, performance assessment, and quality improvement activities at the hospital.

RESULTS

To calculate global QOL, the tool's items are scored in both directions. 28 of the 30 items were on a Likert 4-point scale, with responses ranging from "not at all" (1) to "very much" (4). The final two items were all on a seven-point semantic scale. The response options for items 29 (on overall physical condition) and 30 (on overall QOL) varied from "very poor" (1) to "excellent" (7). The overall tool's Quality of Life score ranged from 100 to 33, with a maximum of 100 and a minimum of 33.

Out of 250 patients, 136 (54.6%) were between the ages of 51 and 65, and 160 (64%) were females. The majority of them, or 77 (30.8%), had breast cancer, which was followed by 41 cases of ovarian cancer (16.4%). Among the male population 19(7.6%) were found suffering from Lung Cancer. [\[Table 1\]](#)

Table 1: Socio-demographic and clinical characteristics

Variables	Value (%)
Age Groups	
18-39	47(18.5%)
40-54	100(40.2%)
55-65	103(41.4%)
	Mean= 50.05
	SD= 12.09
Gender	
Male	90(36%)
Female	160(64%)
Diagnosis	
Breast Cancer	77(30.8%),
Ovarian Cancer	41(16.4%).
Lung Cancer	19(7.6%)
Others	113(45.2%)
Category	
Cash	111(44.58%)
RGHS	50(19.68%)
Bhamashah/Cheranjeevi	35(14.06%)
Empanelled	29(11.65%)
Others	12(4.82%)
BPL	8(3.21%)
CGHS	5(2.01%)

The findings also indicate that 245 individuals, or 98.4% of them, believed their physical performance was extremely low.

76 (30.5%) had their financial situation affected by their medical condition or treatment, and they strongly believed that their physical state had lowered their financial standing. Furthermore, 39(92.7%) were not receiving assistance from friends and family.

Pain had an impact on the majority of participants' physical well-being 113 (45.3%). Insomnia was experienced by 81 (32.5%) and fatigue by 137 (55%). Most of the participants were observed to have constipation 124(49.8%) and only few had diarrhoea 51(20.4%).

61 (24.5%) of the participants reported feeling severely depressed, which had an impact on their psychological well-being. However, most participants—230 (92 percent)—reported feeling very satisfied with their relationships with their spouses and families and receiving supportive care from them.

Regarding cognitive health, 184 (73.9 percent) of the participants reported no memory problems while 65(26.1%) found it difficult to concentrate on things. The majority of them were upbeat and anticipated success.

121(48.6%) suffered from Nausea while 44(17.6%) experienced vomit as one of their major symptoms. Lack of appetite was also observed as one of the major symptoms in 88(35.3%) patients.

61 (24.5%) of the individuals reported feeling extremely depressed, which negatively impacted their psychological health, and 109 (43.7%) felt they were irritable most of the time during the course of the treatment. While receiving chemotherapy, 91(36.5%) patients reported feeling tense and 112(45%) reported feeling worried.

The total score of QoL was categorized into four: Above 90 - very high QOL, 71–90 - high QOL, 41–70 - average QOL and 0 - 40 low QOL. The improved QOL among cancer patients is shown by the higher score (table form representation category, score, and frequency, mean)

[\[Table 2\]](#)

[Table 2](#) reveals that out of 250 cancer patients, 123 (49.4%) (121 + 2 = 123) fell into the group of patients with below-average QOL scores. While 110 people (16%) got high QOL scores, only 16 people (6.4%) had extremely high QOL scores. The mean QOL score across the board was 71.08 ± 12.25 .

Table 2: Percentage and Frequency of Quality-of-Life Score Categories (n=250)

Categories	Score	Frequency (%)	Mean±SD
Low	Below 40	2(0.8%)	71.08±12.25
Average	41-70	121(48.6%)	

<i>High</i>	71-90	110(16%)	
<i>Very High</i>	Above 90	16(6.4%)	

Scores in the various categories of the QOL domains are shown together with their frequency and percentage distribution in Table 3. Based on the proportion of categories provided in the original QOL questionnaire, the scores were divided into high, average, low, and extremely low categories to determine the domains that were most negatively impacted. Out of 250, 221(88.8%) participants had a high level of physical functioning. Out of them, 151(60.6%) had high role functioning but 128(39.4%) had below average role functioning. Furthermore, 179(71.9%) had a high emotional functioning and 70(28.1%) had below average emotional functioning. Cognitive 206(82.7%) and social functioning 233(93.6%) among the patients were observed to be high in the majority.

Table 3: (n=250) Frequency and Percentage of score in the various quality of life domains

Domains	Frequency (%)			
	Very Low (0-25)	Low (26-50)	Average (51-75)	High (76-100)
Physical Functioning	0(0.0%)	4(1.6%)	24(9.6%)	221(88.8%)
Role Functioning	12(4.8%)	44(17.7%)	42(16.9%)	151(60.6%)
Emotional Functioning	2(0.8%)	12(4.8%)	56(22.5%)	179(71.9%)
Cognitive Functioning	0(0.0%)	10(4.0%)	33(13.3%)	206(82.7%)
Social Functioning	0(0.0%)	1(0.4%)	15(6.0%)	233(93.6%)

The QoL and factors including age, sex, and patient payment category did not correlate with one another.

Table 4: CT cycle frequency and quality of life in cancer patients (n=250)

Quality of life

<i>Number of CT cycles</i>	Non-favourable	Fairly Favourable	Favourable	Sum
3≤	20(27.02%)	37(50%)	17(22.9%)	74

4-5	8(12%)	44(65.7%)	15(22.4%)	67
6-10	8(11.7%)	31(45.6%)	30(42.2%)	69
≤10	7(17.5%)	21(52.5%)	12(30%)	40
Total	43(17.2%)	133(53.2%)	74(29.6%)	n=250

The evidence for the association between QoL and the number of CT cycles is found in [Table 4](#). As demonstrated, the majority of patients (53.2%) had a fairly favourable quality of life. The quantity of CT cycles and QoL were shown to be strongly correlated. Most patients (61.2%) who had finished three or more CT cycles indicated a fairly favourable or favourable degree of quality of life. [\[Table 4\]](#)

This might suggest that the CT procedure used in cancer treatment is directly associated to QoL.

DISCUSSION

Most of the questions were clearly understood and easy to answer during pilot testing of the validated sections of the generic electronic PROM. Nevertheless, feedback indicated that several enhancements and modifications were needed, particularly regarding:

- The language barrier was one of the prime hurdles during the survey. For the survey to be filled by the patients themselves, it needs to be translated in the language most prevalent and understood by the majority in the hospital i.e., Hindi.
- The EORTC QLQ-C30 features several questions on fatigue that might be consolidated into one to make the survey easier for patients to complete.
- Sequencing of the questions can be improved to placing similar questions together.
- The survey must also include a 'Not Applicable' section because some questions do not apply to all patients.
- A remarks section could be advantageous to the survey's aim, as there are a few views expressed by patients that are not inquired about in the survey.

In our patient group, fatigue, constipation, pain, and nausea are the top 4 symptoms, listed in decreasing order of frequency.

The majority of patients claimed that their nausea and vomiting were mainly under control, owing to the fact that they were provided essential drugs to alleviate these symptoms from the start of chemotherapy.

The total mean QOL score of the study population was 105.32 ± 12.93 , according to study by Anice George et al., and comparable results were reported in the current study. However, this study shows that only 50% of the population average and below average QOL. The study confirms the statistics of the WHO which states that the most common cause of cancer in females were of breast cancer and men were most affected by lung cancer.

STRENGTHS AND LIMITATIONS OF THE STUDY

Strengths:

- The study's strength is its homogeneous patient cohort, which emphasises practically upon all general symptoms that may be attributed to any type of cancer and so eliminates any bias or heterogeneity in the results.
- The scale, which encompasses the most significant components of inpatient hospital care from the patient's perspective, could be beneficial for evaluating cancer patients' experiences at BMCHRC and in similar settings across the country.

Limitations:

- Because the study was confined to a particular state and BMCHRC was only selected for the study the findings cannot be applied across the country.
- Cancer patients who gave consent were only interviewed.
- Only at a single point of time were the QoL assessments and the symptoms assessments conducted. Therefore, one cannot assess the impact of chemotherapy on improvement of symptoms and QOL. Additionally, we did not classify the patients according to disease subtypes.
- It's important not to overlook communication barriers, which are especially prominent in the case of Head and Neck Cancer. Also, the majority of patients come from low socioeconomic backgrounds and have a limited educational background.

As a result, a concise and explicit questionnaire, like the one we employed in our research, could be the solution to this intriguing challenge. Though not yet established,

a thorough and constructive contact with patients utilising such instruments may lead to better anti-cancer drug compliance and improve the country's overall abysmal prognosis of malignancies.

SUGGESTIONS

- PROMs collected electronically might be more affordable and offer information more quickly than hardcopy surveys (e.g., provide prompt feedbacks to the medical professionals).
- Respondents who complete self-reported PROM surveys may also feel less burdened because replies based on interviews may have introduced biases for people who may have preferred to reply in private.
- The EORTC QLQ – HDC29 can be used for patients undergoing chemotherapy to perceive specific chemotherapy related symptoms and problems. Multiple other disease or treatment specific questionnaire should be developed.
- Evaluating whether respondents' self-reported item interpretations are consistent with intended meanings is essential to determining whether survey results offer genuine interpretations. It can be done by using cognitive interviews, a qualitative, evidence-based technique designed specifically to examine if a survey question meets its objectives.
- Patients with significant scores in the cognitive wellbeing should be recommended to a psycho-oncologist.
- In-addition, Physicians should pay close attention to prepare the patients for the acute toxicities of therapy as well as how to better deal with fatigue, constipation, pain, and nausea as those were the four symptoms that were primarily observed in our cohort. For Example- Many patients reported pain and numbness in their legs, which the physician can examine in patients with comparable symptoms.
- Despite the hospital being recognised by various schemes, several patients were unable to use them and sought advice. They could receive guidance and information about this from the floor coordinators and PREs.
- According to a research by Gilbar O et al., there were substantial differences between patients who discontinued therapy and those who finished it in terms of adjustment and psychological distress. [10]

Communication on the significance of adherence and the potential negative effects of nonadherence, as well as simplicity of the patient's drug schedule (if possible), are interventions to enhance compliance to chemotherapy regimens, and inclusion of a member of the family or caregiver in the discussion. Always provide written documents along with the verbal instructions.

- Further research into the explanatory factors of disparities in cancer patients' healthcare experiences is recommended.

Importance of Psycho-social counselling

- Many cancer patients struggle to acclimatize to their condition as it progresses, and on a physical level, cancer and its treatment have clear effects on body image with differences between “visible cancers” such as head and neck cancers as well as breast cancer and “less-visible cancers” such as lung cancer and leukaemia.
- A number of regulatory bodies, such as the International Psycho-Oncology Society (IPOS) Standard on Quality Cancer Care, have ordered routinely identifying and treating distress. According to this criterion, emotional distress should be counted as the sixth vital sign and the psychosocial domain of cancer care must be incorporated into normal treatment.
- In one study, only 40.2% of survivors reported having discussed the possible emotional or interpersonal effects of cancer with their doctors, and more than 90% of the barriers that survivors identified in seeking grief counselling or approaching support networks involved ignorance of available services or a false belief that they were not available. [\[9\]](#)
- There are around 30 tools (DT or the ESAS), being used in BMCHRC for the screening of patients. However, the screening is limited to patients that are either referred by the doctors to the psycho-oncologist or patients that are routinely screened within the wards. Most of the patients undergoing chemotherapy within the day care wards of the hospital do not benefit from the screenings (as only the follow-up patients are screened) and are mostly unaware of the availability of the psycho-oncology services available in BMCHRC.

FINANCIAL SUPPORT AND SPONSORSHIP

Nil.

CONFLICTS OF INTEREST

There are no conflicts of interest.

CONCLUSION

According to this study, people with cancer have a wide range of symptoms that negatively affect their quality of life. All healthcare providers must provide timely and proper information and care to patients. It is necessary to establish methods for effective symptom management and to improve QOL. The main challenges are symptom management and the requirement to develop methods that give patients a sense of greater control over their illness and course of therapy. A short assessment of patients in this group for symptom load and quality of life using a straightforward and unambiguous questionnaire, as we did in our study, would undoubtedly aid in improving symptom-directed therapy while achieving the cherished goal of palliative care.

Increased public health education on the psychosocial prognosis of cancer is supported by the relatively high number of patients who met the criterion for excellent functioning on the social, emotional, physical, cognitive, role functioning scales. It is especially impressive how optimistic they seem in the face of such a terrible condition. However, given how poorly the chemotherapy patients performed on the symptom scales, physicians should pay close attention to how to prepare the patients for the acute toxicities of therapy. The findings demand that a psycho-oncology service be extensively used at BMCHRC to address psycho-social outcomes. Psychosocial cancer care can help patients and their families cope with the disease's anxiety and psychosocial morbidity, improve their quality of life during and after treatment, and ultimately boost survival rates.

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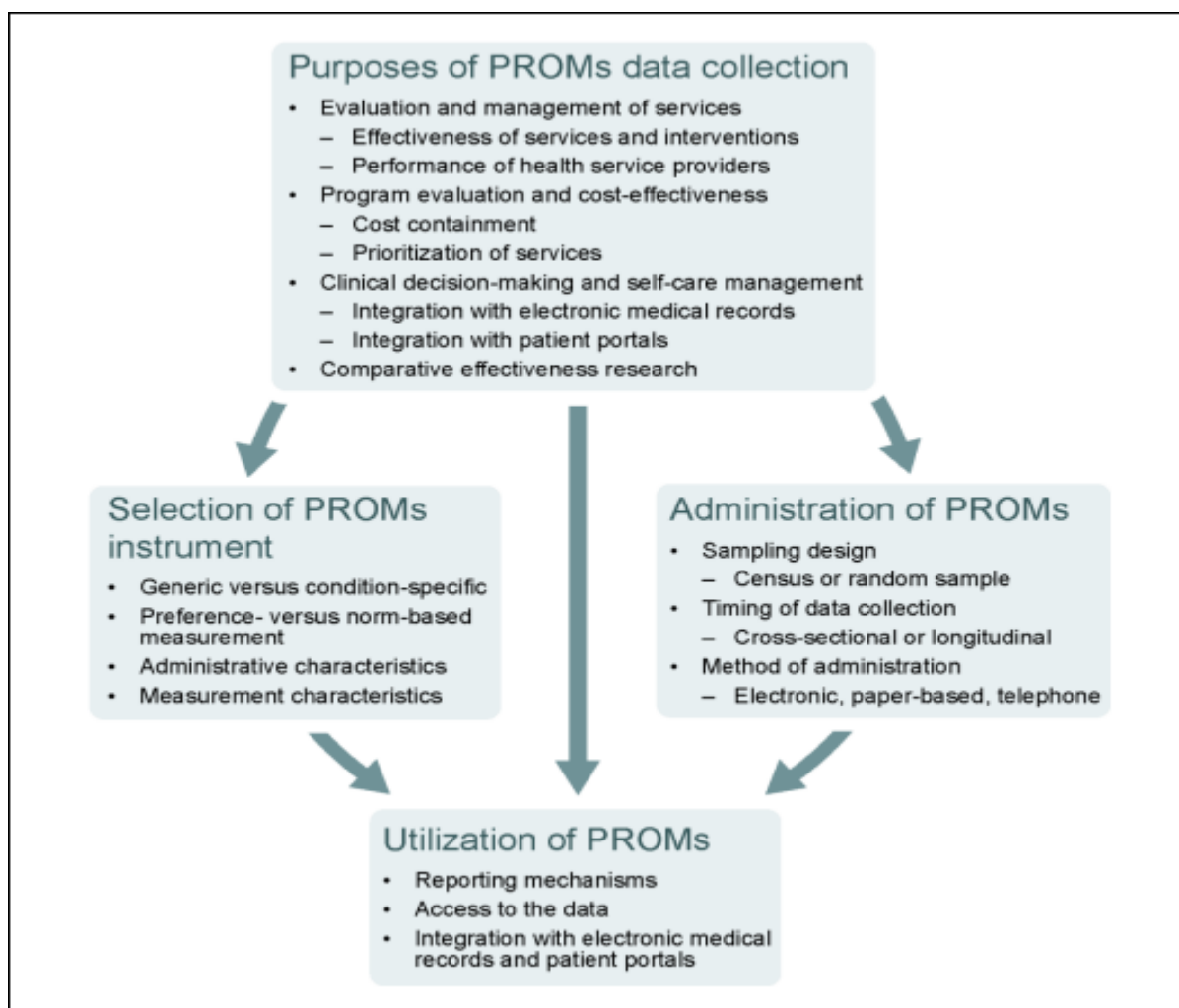
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APPENDIX

Appendix A: Framework to Guide Decisions About PROMs Initiatives



Appendix B: Clinical Areas to Consider for a National PROMs Initiative

Elective Surgeries	Chronic Illness Care
Surveys are typically offered pre- and post-surgery and administered at specific times	Surveys are administered longitudinally (e.g., baseline with annual follow-ups)
Data is used to evaluate patient outcomes following surgeries	Data is used to evaluate patient outcomes over time
Combined generic and condition-specific PROMs instruments	Combined generic and condition-specific PROMs instruments
Examples • Orthopedic surgeries (hip and knee arthroplasty) • Cataract surgeries • Cardiac procedures (coronary artery bypass graft, angioplasty) • Inpatient and major outpatient surgeries	Examples • Renal dialysis • Congestive heart failure • Community mental health • Chronic obstructive pulmonary disease • Cancer treatments (systemic and radiation therapies, surgeries)

Figure 3: Appendix C: The EORTC QLQ-C30

ENGLISH



EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year):

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	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
During the past week:				
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

Please go on to the next page

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor

Excellent