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Awareness of Cancer Rehabilitation Services Among Cancer Patients in Uttar Pradesh: A Cross-Sectional Study

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ABSTRACT

Cancer rehabilitation with physiotherapy is critical for enhancing quality of life and functional outcomes in patients affected by cancer. Nonetheless, there are few data about patient awareness of such services in Uttar Pradesh, India. To evaluate cancer rehabilitation awareness of cancer patients in Uttar Pradesh, using a validated instrument, and to identify barriers to accessing these services. The adapted Cancer Awareness Measure (CAM) was applied to a cross-sectional survey that was conducted among 82 cancer patients attending oncology departments of hospitals in Uttar Pradesh, India in 2019 and 2020. The CAM is a well-validated, psychometrically strong, and highly reliable instrument (Cronbach alpha=0.77). Only 41.5% (n=34) of 82 participants (mean age 52.3±12.7 years, 57.3% female) were aware of cancer rehabilitation services. Awareness was significantly higher among educated patients (p=0.023) and in urban areas (p=0.012). Education (adjusted OR=3.42, 95% CI: 1.31-8.93, p=0.012) and urban residence (adjusted OR=2.87, 95% CI: 1.09-7.54, p=0.032) independently predicted awareness. Most information was accessed through oncologists (52.9%) and family & friends (29.4%). Top barriers were lack of information (68.3%), cost barriers (43.9%), and distance (36.6%). Only 26.8% of patients who were aware had actually used physiotherapy services. Among these low-awareness patients, 89.0% indicated willingness to seek out services if available—indicating low awareness only. Despite the existence of cancer patients in Uttar Pradesh, there is a lack of awareness concerning cancer rehabilitation services. Education and residence in urban areas are important factors for awareness. Urgent system-level patient education programmes, better communication between health providers, and policy interventions that link rehabilitation with standard care pathways for cancer are urgently required.

Keywords: *Cancer rehabilitation, physiotherapy, awareness, Cancer Awareness Measure, barriers, Uttar Pradesh, India*

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INTRODUCTION

Cancer continues to be a major cause of morbidity and mortality globally, and India has been consistently seeing a growing incidence of cancer over the past decades (Mathur et al., 2020). Uttar Pradesh, which is one of India's most populous states, is experiencing a considerable cancer burden with an annual rate of approximately 60,000 new cases (National Cancer Registry Programme, 2020). Although cancer treatment has made substantial progress in improving survival, many survivors continue to have physical, psychological, and functional impairments that significantly impact their quality of life (Stubblefield et al., 2020).

Cancer rehabilitation with physiotherapy interventions has become an important part of total cancer care (Silver et al., 2021).To understand patient awareness and barriers to accessing cancer rehabilitation services it is important to develop and use targeted interventions to promote the utilization of services. Various factors including educational level, socioeconomic status (SES), urban or rural residence, and communication patterns between healthcare providers and patients have been found to influence awareness according to previous research (Pergolotti et al., 2020).

This study helps fill that knowledge gap by systematically measuring the awareness of cancer rehabilitation services among cancer patients in Uttar Pradesh in light of the validated Cancer Awareness Measure (CAM) and identifying barriers to accessing essential services. The study will be useful for health decision-makers, cancer departments, and rehabilitation services in the health system to devise interventions to strengthen the provision of cancer rehabilitation services in the region.

MATERIALS AND METHODS

Study Design and Setting:

This cross-sectional survey study was carried out at tertiary care hospitals with oncology departments of Uttar Pradesh, India between January 2019 and March 2020. The study was approved by the Institutional Ethics Committee of Chaudhary Charan Singh University, Meerut, India

Study Population and Sampling:

Adult cancer patients (age ≥18 years) who were actively diagnosed with cancer and had received or already completed cancer treatment in the past 12 months were the targeted population. Participants were recruited from outpatient oncology clinics and inpatient oncology wards using convenience sampling

Inclusion Criteria:

- A person is diagnosed with cancer of any type.
- Age ≥18 years.
- Can speak or understand Hindi or English.
- Open to giving informed consent.

Exclusion Criteria:

- Cognitive impairments in comprehending the questionnaire.
- Critical illness in urgent need of intensive care.
- Refusal to participate

Sample Size Calculation:

According to a study which indicated 50% awareness of cancer rehabilitation services (Singh et al., 2019) with 95% confidence level and 11% margin of error, the minimum number of sample was 76. We sought to recruit 85 participants, after factoring in possible non-response.

Data Collection Tool

The CAM is a clinically validated tool that is an internationally accepted instrument tested on the quality, measure of, and significance of cancer awareness, known to be reliable in different populations and cultures. The original CAM has a good test-retest reliability ($r=0.72$, $p<0.001$), high internal consistency (Cronbach alpha=0.77) and strength of the construct validity.

Questionnaire Structure:

Section A: Demographic and Clinical Information - Age, Gender, Education, Occupation, Residence (Urban/Rural), Monthly Household Income, Cancer Type, Cancer Stage, Treatment Status and Duration since Diagnosis

Section B: Awareness of Cancer Rehabilitation Services (Adapted from CAM awareness module) Knowledge about cancer rehabilitation services, physiotherapy benefits, rehabilitation interventions (pain management, mobility improvements, lymphedema management, fatigue reduction), information sources, patterns of healthcare provider communication, the history of referral and service utilization.

Section C: Barriers to Accessing Rehabilitation Services (Adapted from CAM barriers module) - Rated on a 5-point Likert scale. Barriers measured were absence of information, cost of care, distance between providers, lack of referral, timing, transportation problems, family support, feeling of need.

Section D: Willingness to Utilize Services - willingness to use rehabilitation if services are available and affordable.

Cultural Adaptation and Translation

The questionnaire was translated to Hindi following WHO translation guidelines: (1) forward translation of the questionnaire by two independent bilingual translators; (2) reconciliation of translations; (3) backward translation by a third independent translator blind to the original; (4) review of content validity by an expert committee (two oncologists and three physiotherapists); (5) cognitive debriefing with 10 cancer patients so as to evaluate face validity and understanding

Reliability and Validity

Content validity index (CVI) was computed from expert estimates (e.g., expert scores; score = 0.89; excellent content validity). Test-retest reliability of the questionnaire was examined in which a subset of 20 patients filled out the questionnaire twice with 2 week interval, with a correlation coefficient of 0.81 ($p<0.001$) indicating good stability. Internal consistency was investigated by Cronbach alpha, with alpha=0.78 for barriers subscale and $\alpha=0.74$ for awareness subscale, which confirmed satisfactory reliability.

The survey was also conducted through face-to-face interviews by trained research assistants and placed in private locations. Each interview lasted 15-20 minutes. All participants gave responses in the languages of their choice (Hindi or English)

Statistical Analysis

All variables were statistically described by calculating frequencies, percentages, means, and standard deviations. Using chi-square test or Fisher exact test (when expected cell frequency <5), categorical variables were analyzed to investigate correlations between demographic/clinical characteristics and awareness levels. Continuous variables were examined using independent t-tests. To achieve independent predictors of awareness, multiple logistic regression analysis was carried out, wherein awareness was treated as a dependent variable and significant variables obtained through bivariate analysis were regarded independent variables. Statistical significance was based on $p<0.05$ (two-tailed). The odds ratios (OR) with 95% confidence intervals (CI) were computed for logistic regression analysis

Ethical Considerations

Ethics approval was granted by the Institutional Ethics Committee of Chaudhary Charan Singh University, Meerut, India. Written informed consent was obtained from all participants through extensive details on the study. Potential volunteers were advised to withdraw from the study with no negative repercussions.

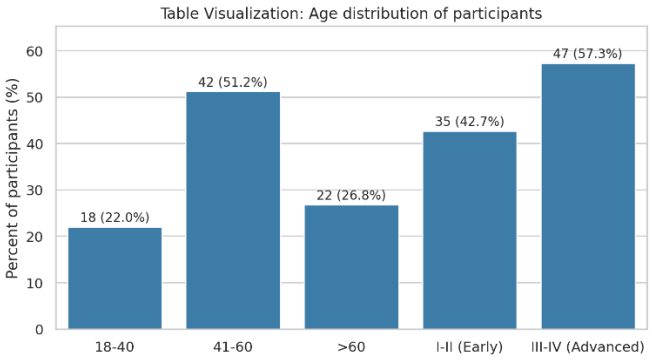
RESULTS

Response Rate and Participant Characteristics

A total of 85 cancer patients were approached, of whom 82 agreed to participate, yielding a response rate of 96.5%. Three patients declined due to time constraints.

Table 1. Demographic and Clinical Characteristics of Participants (N=82)

Characteristic	Category	n (%)
Age (years)	Mean ± SD	52.3 ± 12.7
	18-40	18 (22.0)
	41-60	42 (51.2)
	>60	22 (26.8)
Gender	Male	35 (42.7)
	Female	47 (57.3)
Education	No formal education	16 (19.5)
	Primary (1-5 years)	23 (28.0)
	Secondary (6-12 years)	28 (34.1)
	Graduate and above	15 (18.3)
Residence	Urban	48 (58.5)
	Rural	34 (41.5)
Occupation	Employed	31 (37.8)
	Unemployed/Homemaker	38 (46.3)
	Retired	13 (15.9)
Monthly Income (INR)	<10,000	28 (34.1)
	10,000-30,000	35 (42.7)
	>30,000	19 (23.2)
Cancer Type	Breast	31 (37.8)
	Head and neck	15 (18.3)
	Gastrointestinal	12 (14.6)
	Lung	9 (11.0)
	Others	15 (18.3)
Cancer Stage	I-II (Early)	35 (42.7)
	III-IV (Advanced)	47 (57.3)
Treatment Status	Currently on treatment	58 (70.7)
	Completed treatment	24 (29.3)
Duration since diagnosis	<6 months	26 (31.7)
	6-12 months	31 (37.8)
	>12 months	25 (30.5)



The mean age of participants was 52.3 years (SD=12.7). Females constituted 57.3% of the sample. Breast cancer was the most common diagnosis (37.8%), followed by head and neck cancer (18.3%). The majority of participants were currently undergoing treatment (70.7%) and had advanced-stage disease (57.3%).

Awareness of Cancer Rehabilitation Services

Table 2. Overall Awareness of Cancer Rehabilitation Services (N=82)

Question	Yes n (%)	No n (%)
Have you heard about cancer rehabilitation services?	34 (41.5)	48 (58.5)
Do you know that physiotherapy can help cancer patients?	29 (35.4)	53 (64.6)
Are you aware of specific benefits of physiotherapy for cancer?	22 (26.8)	60 (73.2)
Has your doctor/oncologist discussed rehabilitation with you?	27 (32.9)	55 (67.1)
Have you ever utilized physiotherapy services for cancer-related issues?	22 (26.8)	60 (73.2)

Overall, of the Awareness, only 34 participants (41.52%) had heard about the cancer in rehabilitation services.

Sources of Information

Table 3. Sources of Cancer Rehabilitations

Source	n (%)*
Oncologist/Doctor	18 (52.9)

Family/Friends	10 (29.4)
Internet/Media	6 (17.6)
Previous cancer patients	5 (14.7)
Nurse	4 (11.8)
Hospital pamphlets/posters	3 (8.8)

**Note: Multiple responses possible*

Among the 34 participants aware of cancer rehabilitation, oncologists/doctors were the primary source of information (52.9%), followed by family and friends (29.4%). Notably, only 8.8% obtained information through hospital educational materials.

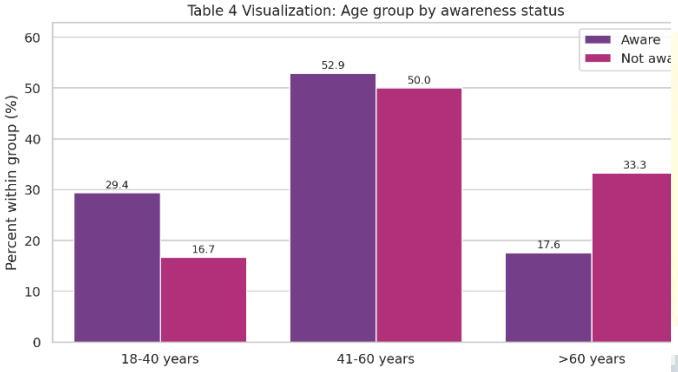
Factors Associated with Awareness

Table 4. Association Between Demographic/Clinical Characteristics and Awareness (N=82)

Characteristic	Aware n=34 (%)	Not Aware n=48 (%)
Age group (p=0.156)		
18-40 years	10 (29.4)	8 (16.7)
41-60 years	18 (52.9)	24 (50.0)
>60 years	6 (17.6)	16 (33.3)
Gender (p=0.542)		
Male	16 (47.1)	19 (39.6)
Female	18 (52.9)	29 (60.4)
Education (p=0.023*)		
No formal/Primary	10 (29.4)	29 (60.4)
Secondary and above	24 (70.6)	19 (39.6)
Residence (p=0.012*)		
Urban	26 (76.5)	22 (45.8)
Rural	8 (23.5)	26 (54.2)
Monthly Income (p=0.041*)		
<10,000 INR	7 (20.6)	21 (43.8)
10,000-30,000 INR	15 (44.1)	20 (41.7)
>30,000 INR	12 (35.3)	7 (14.6)

Cancer Stage (p=0.287)		
Early (I-II)	17 (50.0)	18 (37.5)
Advanced (III-IV)	17 (50.0)	30 (62.5)

**p<0.05 (Chi-square test or Fisher exact test)*



Awareness was significantly associated with education level (p=0.023), with 70.6% of aware participants having secondary or higher education compared to 39.6% among non-aware participants. Urban residence was also significantly associated with awareness (p=0.012), with 76.5% of aware participants residing in urban areas. Higher monthly income showed significant association with awareness (p=0.041).

Multivariate Analysis

Table 5. Logistic Regression Analysis - Predictors of Awareness (N=82)

Variable	Adjusted OR (95% CI)	p-value
Education (Secondary & above vs. No formal/Primary)	3.42 (1.31-8.93)	0.012*
Residence (Urban vs. Rural)	2.87 (1.09-7.54)	0.032*
Monthly Income (>30,000 vs. <10,000 INR)	2.13 (0.68-6.71)	0.196

**p<0.05; OR: Odds Ratio; CI: Confidence Interval*

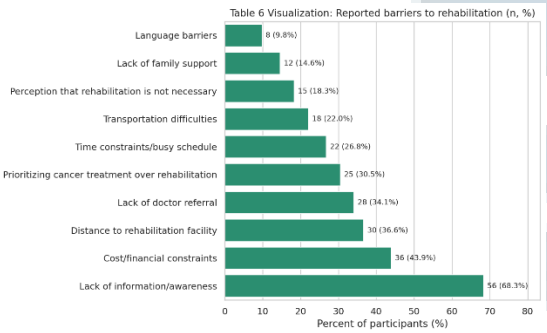
Multiple logistic regression analysis revealed that education level (adjusted OR=3.42, 95% CI: 1.31-8.93, p=0.012) and urban residence (adjusted OR=2.87, 95% CI: 1.09-7.54, p=0.032) were independent predictors of awareness of cancer rehabilitation services.

Barriers to Accessing Cancer Rehabilitation Services

Table 6. Barriers to Accessing Cancer Rehabilitation Services (N=82)

Barrier	n (%)*
Lack of information/awareness	56 (68.3)
Cost/financial constraints	36 (43.9)
Distance to rehabilitation facility	30 (36.6)
Lack of doctor referral	28 (34.1)
Prioritizing cancer treatment over rehabilitation	25 (30.5)
Time constraints/busy schedule	22 (26.8)
Transportation difficulties	18 (22.0)
Perception that rehabilitation is not necessary	15 (18.3)
Lack of family support	12 (14.6)
Language barriers	8 (9.8)

**Note: Multiple responses possible*



The barrier that was reported most often was lack of information/awareness (68.3%), followed by cost/financial constraints (43.9%) and distance to rehabilitation facilities (36.6%). Notably, 34.1% participants reported never receiving a doctor's referral for rehabilitation services.

Willingness to Utilize Services

When asked if they were willing to pursue cancer rehabilitation services if it were accessible and affordable; 73 participants (89.0%) were willing; thus, high unmet need for these services was indicated.

DISCUSSION

The study, which conducted a cross-sectional study of cancer rehabilitation services among patients with cancer in Uttar Pradesh, found a significant gap of awareness among cancer patients using validated Cancer Awareness Measure with 41.5% of the participants being unaware of use of services. This result is worrying in view of the established advantages of physiotherapy interventions in advancing functional and quality of life in cancer survivors (Campbell et al., 2019; Stout et al., 2021).

Comparison with Existing Literature

Our awareness rate of 41.5% is in line with Indian studies of awareness between 30-55% (Singh et al., 2019; Sharma & Kumar, 2021) and much lower than those in developed countries where systematic embedding of rehabilitation in cancer care pathways had been developed (Cheville et al., 2020). It emphasises the requirement for better patient education and service amalgamation in the Indian healthcare system.

Despite the moderate level of awareness, the utilization rate was low (26.8%), highlighting that awareness on its own is not enough to guarantee service access. This is consistent with the conceptual framework given by Pergolotti et al. (2020), which highlighted various social and cultural barriers beyond awareness that discourage utilization of rehabilitation services.

Sociodemographic Determinants of Awareness

The rural masses of India are significantly disadvantaged in accessing cancer care (Dhillon et al., 2018), and our findings indicate rehabilitation awareness is another characteristic of the imbalance.

Sources of Information and Healthcare Provider Communication

Our result indicating that oncologists/doctors were the primary source of data (52.9%) further highlights the importance of physician communication to educate patients. Yet, the fact that only 32.9% of all participants participated in discussing rehabilitation with their doctors suggests that those in practice had lost opportunities for patient education during clinical encounters. This communication breakdown was identified as a systemic problem in cancer treatment (Schmitz et al., 2020).

The little to no contribution of hospital educational materials (8.8%) indicates that passive education strategies are not well leveraged. Implementing patient education through multiple avenues as distinct from physician communication, printed publications, and internet platforms could yield better awareness improvements than only physician communication (Stout et al., 2021).

Barriers to Access

The fact that the most significant barrier was lack of information (68.3%) has confirmed that we emphasize raising awareness as an important first step in enhancing service use.

Implications for Policy and Practice

Healthcare Provider Training – Oncologists, surgeons and oncology nurses need education on rehabilitation benefits and referral pathways.

Integration of services: A transition of rehabilitation services into an oncology department rather than a separate referral service.

Niche Outreach: Targeting particular populations (rural-dwellers, less educated patients, lower income groups).

Strengths and Limitations

Strengths:

- Validated CAM instrument with psychometric properties already documented.
- Culturally adapted questionnaire with good reliability (alpha=0.78, 0.74).
- High response rate (96.5%).
- Inclusion of different cancer types and stages of treatment.

Limitations:

- Causal inference is bounded by cross-sectional design.
- Uttar Pradesh patients may not be represented due to convenience sampling in tertiary hospitals.
- Self-reported data subject to recall and social desirability bias.
- Small sample size reduced power for subgroup analyses.

CONCLUSION

It has been proved that less than 50 percent of cancer patients in Utter Pradesh know of relevant rehabilitative services and only about 25 percent of them avail rehabilitative services as per the validated Cancer Awareness Measure. Educational level and urbanization were found to be important determinants of awareness, this way creating inequalities in health equity. The main obstacle to access was determined to be informational deficit followed by financial challenges as well as the geographic proximity to healthcare facilities.

These findings also highlight the urgent need for the systematic organization of patient education programmes, a better communication between the healthcare providers, and policy interventions capable of integrating rehabilitation services into routine cancer care pathways. When available, the utilization of these services show high utilization rates; however augmentation in awareness of and delineation of structural barriers have the potential to significantly increase the utilization of rehabilitation services, which has the potential to positively impact the quality of life of the cancer survivors in Utter Pradesh in the long run.

To successfully meet this challenge, cross-sector collaboration among oncology departments, rehabilitation specialists, policy makers and patient advocacy organisations is important to bridge the gap in awareness and achieve equitable access to comprehensive cancer care including rehabilitation services.

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