



General Medicine Original Article

Impediments of Cancer Survivorship and Palliative Care: A Mixed-Methods Study in a Tertiary Healthcare Facility in Odisha, India

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ABSTRACT

Objective: Measure the satisfaction level of patients visiting a tertiary level cancer institute in Odisha, identify the factors associated with the satisfaction level and assess the health system challenges related to quality service provision for cancer survival.

Material and Methods: Analytical cross-sectional study was carried out using a mixed-methods approach in a tertiary cancer care unit in Odisha among 538 cancer patients using the Patient Satisfaction 32 questionnaire and the Patient Health Questionnaire (PHQ)-9 questionnaire.

Results: There were 41% and 43% of outdoor and indoor patients who were below poverty line. Hindu was the predominant religion (>90%), 10% were illiterates and 90% were married in each category. Breast cancer (16%) was predominant among outdoor patients, whereas, it was stomach cancer (15%) among indoor patients. The PHQ median score for females was 1.5 and 1 each for indoor and outdoor patients, respectively. Nearly, 72% and 57% of males and females had mild depression to adjustment disorders statistically significant at $P < 0.05$. 90% of outdoor and 68% of indoor patients with a greater frequency of visits were significantly more depressed than their counterparts. All those accompanied by people other than their family members also showed higher values of adjustment and mild depressive features (69%) at $P < 0.05$. About 81% were satisfied with both general services and staff and nearly 40% with treatment and diagnosis.

Conclusion: It gave us demographic details of cancer morbidity and its associates besides validating the survivorship framework in the Indian setting. Self-help anonymous and rehabilitation centres for a holistic integrative approach at the primary level of care need to be done.

Keywords: Cancer care, Patient satisfaction, Survivorship

INTRODUCTION

Cancer is one of the significant causes of death, contributing to an excessive morbidity burden and necessitating immediate action to combat this public health threat.^[1] Cancer control requires a combination of prevention, early detection and treatment. However, with the dawn of the 21st century, cancer patient management has shifted away from the antecedent model of focusing exclusively on immediate medicaments toward a more integrated holistic approach that ensures treatment and patient well-being. The discussion of these needs begins before the active treatment phase and continues following the therapy to ensure long-term survivorship. It is no longer merely a reaction to heinous cancer but a well-coordinated strategy for averting, treating, curing and ensuring the patient's and family's welfare.^[2,3]

Cancer's consequences vary according to circumstance. Some patients quickly return to everyday life following treatment and maintain a high quality of life. At the same time, others experience the treatment's psychological and physical side effects for an extended period. The symptoms may be mild to severe, debilitating, or even life-threatening. Specific issues are transient or improve over time, while others are progressive or permanent.^[4-9] The critical issue in evaluating any cancer survivorship programme is the absence of a defined and structured modus operandi for adequately calculating the strategy. Halpern *et al.* discovered that models of survivorship care were highly customised to the institution or setting, in which they were provided in a systematic review of nine empirical studies on cancer care. "Normal care" was frequently uncoordinated and highly variable across patients and cancer

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Received: 15 September 2021 Accepted: 29 June 2022 EPub Ahead of Print: 21 September 2022 Published: 23 November 2022 DOI: 10.25259/IJPC_74_2021

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programme.^[9,10] The trajectories of survivorship are examined within the framework of Porter's hierarchy, which consists of three tiers: Health status, recovery and health sustainability.^[11-15] Cancer patients face significant mental, physical, financial and emotional strain. As a result, the demand for healthcare providers to meet the complex needs of cancer patients multiplies exponentially. Patient satisfaction has been identified as a critical component of palliative care – improving both the patient's and family's quality of life.^[14,15] In addition, palliative care is used to benchmark and compare hospitals. However, there is scant evidence regarding the quality of healthcare services from the perspective of patients and caregivers. As a result, this study assessed the level of satisfaction among cancer patients who visited a tertiary health-care facility and examined the facility's impediments and provision of palliative care.

MATERIAL AND METHODS

Study design, settings, sample and participants

We conducted an explanatory mixed-method study in a tertiary cancer care centre in Cuttack, Odisha, India. We interviewed a total of 538 participants – 337 outpatients and 201 inpatients – using structured questionnaires. With a satisfaction level of 70% in the Indian context,^[16,17] the required sample size was calculated to be 322 with a 5% error to achieve an 80% power and a 15% non-response rate. After conducting a preliminary analysis of the quantitative data, we developed an interview guide and conducted 40 in-depth interviews with patients, staff nurses and physicians. The Institute and State Research Ethics Committees granted ethical clearance. All necessary precautions were taken to ensure confidentiality and anonymity, as well as obtaining necessary prior permission. All participants provided written consent.

Study variables

We assessed survivorship among cancer care patients using a hybrid questionnaire. Our questions were developed using the Iron Triangle framework – cost, quality and access – Porter's Hierarchy – health status and recovery – and Donabedian's component of care – structure, process and outcome.^[11-14,18] The Patient Health Questionnaire (PHQ)-9 was used as a multipurpose instrument for screening, diagnosing, monitoring and quantifying depression severity. The Patient Satisfaction (PATSAT) 32 questionnaire was used to assess patients' perceptions of service providers. Patient outcome, knowledge, health promotion, patient satisfaction, functional status, nutritional support, social support, rehabilitation, cost and surveillance were the major domains covered by the tool. This instrument has been validated and piloted.

Data management and analysis

The quantitative data were analysed using the Statistical Packages for the Social Science, V.20. We calculated mean and

median satisfaction scores for services. The scoring guideline for PATSAT was used to estimate satisfaction levels among patients. Chi-square was used for non-parametric analysis and ANOVA for the continuous variable. All calculations were made at 5% alpha value, 95% Confidence Interval at significant $P < 0.05$.

The in-depth interviews were digitally recorded, transcribed, translated and analysed using thematic analysis. The interviews were open-coded using MAXQDA software (MAXQDA Analytics Pro 2020, VERBI GmbH, Berlin, Germany). The related codes were next grouped.^[27] The Consolidated Criteria for the Reporting of Qualitative Research guideline was used to report the study.^[27,28] All authors were involved in the analysis. The authors' diverse educational and professional backgrounds, along with their experience in public health research, facilitated a broadened interpretation of the findings.

RESULTS

Out of 538 patients, 52% ($n = 277$) were female, 42% ($n = 225$) were living below poverty line, 10% of had no formal education, 10% were unmarried and around 37% ($n = 197$) were insured. The predominant cancer was breast cancer (16%).

[Figure 1] the box and plot show depiction of the satisfaction scores for general services for males versus females. The median satisfaction score of females indoors was found to be 3 which was skewed and was higher than for men. The interquartile range for females was varied – ranging from 2 to 4. In comparison, outdoor females had a score of 3.5 with a range from 3 to 4.

The association of patient-traits with depression as per the PHQ-9 is presented in Table 1. It was found among indoor patients; nearly, 72% of males and 57% of females had mild depression to adjustment disorders and the rest were moderate to severely depressed ($P = 0.001$). Moreover, among the mild category of both indoor and outdoor respondents, it was the elderly group that had the highest prevail at high significant statistical values ($P < 0.001$). Similarly, the unmarried, APL and those referred by others had higher depressive symptoms which, however, did not carry statistical significance. The new patients outdoor had significantly higher mild depressive tendency (67%) than the follow-up patients and also across all the grades of depression. This was, however, non-significant for indoor patients. It was also found that nearly 90% of outdoor patients and 68% of indoor patients with a greater frequency of visits, that is, >2 were more depressed than their counterparts at statistically significant values. All those accompanied by people other than their family members also showed higher values of adjustment and mild depressive features (69%) at $P < 0.05$.

Satisfaction of patients attending the outdoor department was analysed and tabulated based on satisfaction for general

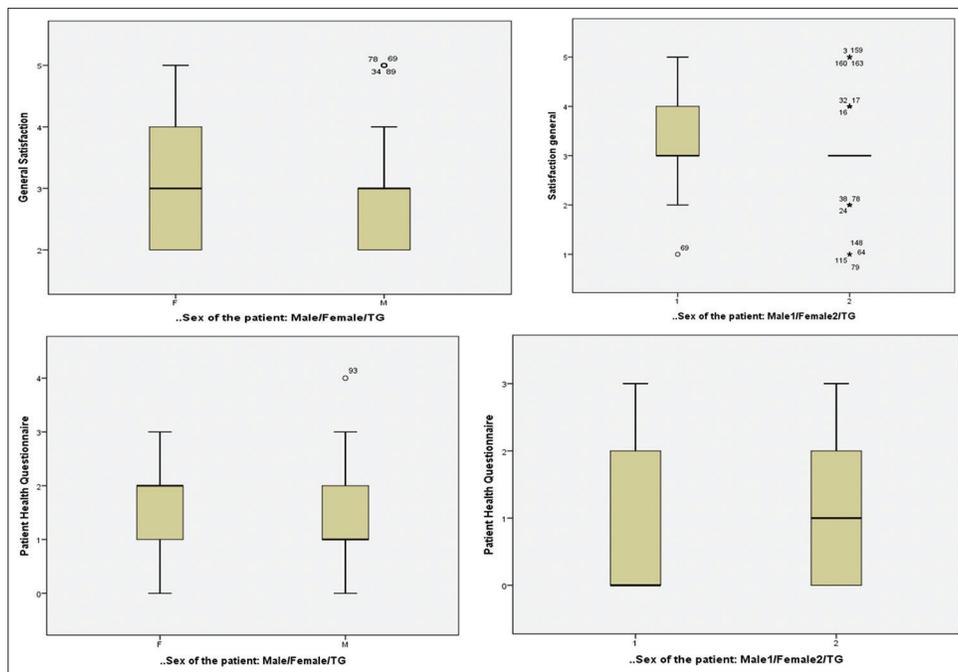


Figure 1: Box and plot depiction of the satisfaction scores and the PHQ scores.

services, staff including physicians, nurses, counselors and for diagnostics and management in Table 2. It was found that 81% were satisfied for both general services and staff and nearly 40% with treatment and diagnosis. The elderly >49 years were the most (20%) among the dissatisfied ones with general services, whereas the children <18 years were maximumly satisfied (100%) with staff available, although they were the ones who were maximumly dissatisfied with the treatment options. All of these were significant at a statistical $P < 0.05$. Educated metrics and below tend to be more satisfied (88%) as compared to the other education categories. This was also true for staff satisfaction (93%) and treatment satisfaction (54%) all at $P < 0.05$. Similarly, those who were not self-referred (42%) and those below the poverty line (41%) tend to be significantly better satisfied with the diagnosis and treatment options as compared to their counterparts.

Satisfaction of patients indoors as shown in Table 3 was based on satisfaction with general services, and staff including physicians, nurses, counselors and for diagnostics and management. It was found that a mere 20% were satisfied for the general services, whereas 83% were satisfied for staff and nearly 41% with treatment and diagnostics. The females were found to be more satisfied with the general services (34%) and treatment (67%), whereas it was the males who were more satisfied with the staff (90%), all at statistically significant values. The children <18 years were the most dissatisfied ones with general services (85%) and treatment (29%), whereas the elderly >50 years were maximum satisfied with the general services and staff. All of these were significant

at a statistical $P < 0.05$. Educated patients metric and below tend to be more satisfied (40%) as compared to the other education categories. This was also true for staff satisfaction and treatment satisfaction (56%) all at $P < 0.05$. Similarly, those who were self-referred and those above the poverty line tend to be significantly better satisfied with the general services as well as the diagnosis and treatment options as compared to their counterparts. Patient type, whether new or follow-up, did not make any significant differences in opinion. However, those who had visited >2 times showed a greater percentage of significant satisfaction association for general services (32%), staff (84%) and for treatment (61%) as compared to those visiting less frequently. Considering insured patients versus the uninsured ones, it was found that insured ones were more satisfied with the general services (26%), staff (83%) and treatment (53%) at high level of statistical significance, thereby supporting our hypothesis.

The qualitative findings indicated that the majority of patients expressed positive attitudes toward patient care and staff behaviour. They appreciated the doctor's treatment, counseling and rounds. However, the majority expressed concern about issues such as wait time, registration and waiting area. Many patients and staff believed that it was difficult to maintain proper hygiene in hospitals due to the increased patient load. Few patients and their attendants made specific mention of the general wards' lack of cleanliness and their reluctance to stay there. As a result, the majority chose to stay in nearby lodges and wait their turn for beds in cabins or the palliative care unit. Many expressed gratitude for the food supply and quality. Because

Table 1: Association of patient traits with depression as per the Patient Health Questionnaire-9.

	Outdoor				Indoor			
	Mild depression n (%)	Moderate depression n (%)	Severe depression n (%)	Total n (%)	Mild Disorder n (%)	Mod depression n (%)	Severe Depression n (%)	Total n (%)
Total (% Across)	240 (71)	93 (28)	4 (1)	337 (100)	133 (66)	64 (39)	4 (1.9)	201 (100)
Sex								
Male	101 (73)	34 (24)	4 (3)	139 (100)	87 (71.9)	31 (25.6)	3 (2.5)	121 (100)
Female	139 (70)	59 (30)	0	198 (100)	46 (57.5)	33 (41.2)	1 (1.2)	80 (100)
χ^2 , df, P: 6.6, 2, 0.03								χ^2 , df, P: 207, 2, 0.001
Age								
<18	7 (53.8)	6 (46.2)	0	13 (100)	4 (57.1)	2 (28.6)	1 (14)	7 (100)
19–48	117 (67.2)	55 (31.6)	2 (1.1)	174 (100)	60 (60.6)	38 (38.4)	1 (1)	99 (100)
>49	116 (77.3)	32 (21.3)	2 (1.3)	150 (100)	69 (72.6)	24 (25.3)	2 (2)	95 (100)
χ^2 , df, P: 344, 4, 0.000								χ^2 , df, P: 211, 4, 0.003
Marital status								
M	218 (71.7)	83 (27.3)	3 (1)	304 (100)	121 (65.8)	60 (32.6)	3 (1.6)	184 (100)
UM	22 (66.7)	10 (30.3)	1 (3)	33 (100)	12 (70.6)	4 (23.5)	1 (5.9)	17 (100)
χ^2 , df, P: 1.2, 2, 0.3								χ^2 , df, P: 1.8, 2, 0.2
SES								
APL	150 (75.4)	47 (23.6)	2 (1)	199 (100)	81 (70.4)	33 (28.7)	1 (0.9)	115 (100)
BPL	90 (65.2)	46 (33.3)	2 (1.4)	138 (100)	52 (60.5)	31 (36)	3 (3.5)	86 (100)
χ^2 , df, P: 4, 2, 0.1								χ^2 , df, P: 3.2, 2, 0.1
Highest education of family								
Metric	42 (73.7)	14 (24.6)	1 (1.8)	57 (100)	13 (72.2)	5 (27.8)	0	18 (100)
Grad and less	155 (68.9)	68 (30.2)	2 (0.9)	225 (100)	58 (69.9)	24 (28.9)	1 (1.2)	83 (100)
Grad and up	43 (78.2)	11 (20)	1 (1.8)	55 (100)	62 (62)	35 (35)	3 (3)	100 (100)
χ^2 , df, P: 3.1, 4, 0.5								χ^2 , df, P: 204, 4, 0.05
Patient type								
New	189 (67.5)	88 (31.4)	3 (1.1)	280 (100)	88 (69.8)	37 (29.4)	1 (0.8)	126 (100)
Follow-up	51 (89.5)	5 (8.8)	1 (1.8)	57 (100)	45 (60)	27 (36)	3 (4)	75 (100)
χ^2 , df, P: 12.6, 2, 0.002								χ^2 , df, P: 3.7, 2, 0.1
Referral								
Self	34 (73.9)	12 (26.1)	0	46 (100)	29 (78.4)	8 (21.6)	0	37 (100)
Others	206 (70.8)	81 (27.8)	4 (1.4)	291 (100)	104 (63.4)	56 (34.1)	4 (2.4)	164 (100)
χ^2 , df, P: 0.7, 2, 0.6								χ^2 , df, P: 3.4, 2, 0.2
Insurance status								
Yes	6 (26.1)	15 (65.2)	2 (8.7)	23 (100)	69 (56.6)	50 (41)	3 (2.5)	122 (100)
No	184 (69.7)	78 (29.5)	2 (0.8)	264 (100)	64 (81)	14 (17.7)	1 (1.3)	79 (100)
NA	50 (100)	0	0	50 (100)				
χ^2 , df, P: 55.7, 6, 0.00								χ^2 , df, P: 28.6, 4, 0.000
Frequency of visit								
<2	192 (67.6)	89 (31.3)	3 (1.1)	284 (100)	77 (64.7)	40 (33.6)	2 (1.7)	119 (100)
>2	48 (90.6)	4 (7.5)	1 (1.9)	53 (100)	56 (68.3)	24 (29.3)	2 (2.4)	82 (100)
χ^2 , df, P value: 12.7, 2, 0.002								χ^2 , df, P: 16.8, 2, 0.018
Accompany								
Family	159 (78.7)	39 (19.3)	4 (2)	202 (100)	105 (65.2)	54 (33.5)	2 (1.2)	161 (100)
Others	81 (60)	54 (40)	0	135 (100)	27 (69.2)	10 (25.6)	2 (5.1)	39 (100)
χ^2 , df, P: 357, 2, 0.000								χ^2 , df, P: 25.1, 2, 0.01

χ^2 : Chi-square, df: Degree of Freedom, P: Probability value, APL: Above poverty line, BPL: Below poverty line, SES: Socioeconomic status, M: Married, UM: Unmarried, Grad: Graduation

the hospital serves residents of nearby states, where chapattis are a staple, they complained when they were done only rice. Almost all participants expressed concern about the

scarcity of diagnostics, blood, and medications, which they had to obtain from outside sources. Consultants' perspectives revealed an acute staff shortage, the need to capacitate

Table 2: Satisfaction of outdoor patients and its associates.

	General service		Staff		Diagnosis and treatment		
	Yes	No	Yes	No	Yes	No	Total
Total	272 (80.7)	65 (19.3)	272 (80.7)	65 (19.3)	132 (39.2)	205 (60.8)	337 (100)
Gender							
Male	113 (81.3)	26 (18.7)	118 (84.9)	21 (15.1)	59 (42.4)	80 (57.6)	139 (100)
Female	159 (80.3)	39 (19.7)	154 (77.8)	44 (22.2)	73 (36.9)	125 (63.1)	198 (100)
χ^2 , df, P: 0.05, 1, 0.4			χ^2 , df, P: 2.6, 1, 0.06		χ^2 , df, P: 1.1, 1, 0.1		
Age							
<18 years	11 (84.6)	2 (15.4)	13 (100)	0	4 (30.8)	9 (69.2)	13 (100)
19–49 years	141 (81)	33 (19)	137 (78.7)	37 (21.3)	69 (39.7)	105 (60.3)	174 (100)
>49 years	120 (80)	30 (20)	122 (81.3)	28 (18.7)	59 (39.3)	91 (60.7)	150 (100)
χ^2 , df, P: 338, 6, 0.000			χ^2 , df, P: 341, 6, 0.000		χ^2 , df, P: 338, 6, 0.000		
Marital status							
Single	23 (69.7)	10 (30.3)	26 (78.8)	7 (21.2)	6 (18.2)	27 (81.8)	33 (100)
Married	249 (81.9)	55 (18.1)	246 (80.9)	58 (19.1)	126 (41.4)	178 (58.6)	304 (100)
χ^2 , df, P: 2.8, 1, 0.07			χ^2 , df, P: 0.1, 1, 0.4		χ^2 , df, P: 6.7, 1, 0.006		
Highest Education in family							
Metric	50 (87.7)	7 (12.3)	53 (93)	4 (7)	31 (54.4)	26 (45.6)	57 (100)
Grad and below	178 (79.1)	47 (20.9)	176 (78.2)	49 (21.8)	85 (37.8)	140 (62.2)	225 (100)
Above grad	44 (80)	11 (20)	43 (78.2)	12 (21.8)	16 (29.1)	39 (70.9)	55 (100)
χ^2 , df, P: 2.1, 2, 0.3			χ^2 , df, P: 6.6, 2, 0.03		χ^2 , df, P: 8.1, 2, 0.01		
Economic status							
APL	161 (80.9)	38 (19.1)	158 (79.4)	41 (20.6)	75 (37.7)	124 (62.3)	199 (100)
BPL	111 (80.4)	27 (19.6)	114 (82.6)	24 (17.4)	57 (41.3)	81 (58.7)	138 (100)
χ^2 , df, P: 0.01, 1, 0.9			χ^2 , df, P: 0.5, 1, 0.4		χ^2 , df, P: 0.4, 1, 0.5		
Referral							
Self	33 (71.7)	13 (28.3)	36 (78.3)	10 (21.7)	11 (23.9)	35 (76.1)	46 (100)
Other	239 (82.1)	52 (17.9)	236 (81.1)	55 (18.9)	121 (41.6)	170 (58.4)	291 (100)
χ^2 , df, P: 2.7, 1, 0.09			χ^2 , df, P: 0.2, 1, 0.6		χ^2 , df, P: 5.2, 1, 0.02		
Patient type							
New	226 (80.7)	54 (19.3)	224 (80)	56 (20)	105 (37.5)	175 (62.5)	280 (100)
Follow-up	46 (80.7)	11 (19.3)	48 (84.2)	9 (15.8)	27 (47.4)	30 (52.6)	57 (100)
χ^2 , df, P: 0.00, 1, 0.9			χ^2 , df, P: 0.5, 1, 0.4		χ^2 , df, P: 1.9, 1, 0.1		
Frequency of visit							
<2	229 (80.6)	55 (19.4)	228 (80.3)	56 (19.7)	105 (37)	179 (63)	284 (100)
>2	43 (81.1)	10 (18.9)	44 (83)	9 (17)	27 (50.9)	26 (49.1)	53 (100)
χ^2 , df, P: 0.01, 1, 0.9			χ^2 , df, P: 10.5, 1, 0.03		χ^2 , df, P: 3.6, 1, 0.05		
Accompany							
Family	161 (79.7)	41 (20.3)	171 (84.7)	31 (15.3)	72 (35.6)	130 (64.4)	202 (100)
Others	111 (82.2)	24 (17.8)	101 (74.8)	34 (25.2)	60 (44.4)	75 (55.6)	135 (100)
χ^2 , df, P: 338, 1, 0.005			χ^2 , df, P: 343, 1, 0.000		χ^2 , df, P: 340, 1, 0.001		
Insured							
Yes	18 (78.3)	5 (21.7)	19 (82.6)	4 (17.4)	10 (43.5)	13 (56.5)	23 (100)
No	254 (80.9)	60 (19.1)	253 (80.6)	61 (19.4)	122 (38.9)	192 (61.1)	314 (100)
χ^2 , df, P: 16.8, 2, 0.006			χ^2 , df, P: 16.6, 2, 0.007		χ^2 , df, P: 16.4, 1		

χ^2 : Chi-square, df: Degree of freedom, P: Probability value, Grad: Graduation

primary care facilities for the early diagnostic screening so that tertiary levels are not overburdened with patients and the establishment of a robust palliative care unit to care for end-stage patients.

In addition, the participants emphasised the importance of the proper functioning of a counseling unit, which was lacking in the institute due to staffing and time constraints.

Record-keeping was one such aspect that was necessary but time-consuming. According to numerous staff and patients, another issue is bed availability. In addition, there was a long wait time due to the high patient load. Patients also perceived a lack of adequate diagnostic facilities and medication availability. According to a patient from the palliative care unit at the hospital, a limited number of tests were

Table 3: Satisfaction of indoor patients and its associates.

	General service		Staff		Diagnosis and treatment		
	Yes	No	Yes	No	Yes	No	Total
Total	41 (20.4)	160 (79.6)	167 (83.1)	34 (16.9)	83 (41.3)	118 (58.7)	201 (100)
Gender							
Male	14 (11.6)	107 (88.4)	110 (90.9)	11 (9.1)	29 (24)	92 (76)	121 (100)
Female	27 (33.8)	53 (66.2)	57 (71.2)	23 (28.7)	54 (67.5)	26 (32.5)	80 (100)
χ^2 , df, P: 216, 1, 0.000			χ^2 , df, P: 215, 1, 0.00		χ^2 , df, P: 239, 1, 0.000		
Age							
<18 years	1 (14.3)	6 (85.7)	1 (14.3)	6 (85.7)	2 (28.6)	5 (71.4)	7 (100)
19–49 years	20 (20.2)	79 (79.8)	80 (80.8)	19 (19.2)	45 (45.5)	54 (54.5)	99 (100)
>49 years	20 (21.1)	75 (78.9)	81 (85.3)	14 (14.7)	36 (37.9)	59 (62.1)	95 (100)
χ^2 , df, P: 202, 2, 0.03			χ^2 , df, P: 202, 2, 0.02		χ^2 , df, P: 203, 2, 0.01		
Marital status							
Single	2 (11.8)	15 (88.2)	13 (76.5)	4 (23.5)	6 (35.3)	11 (64.7)	17 (100)
Married	39 (21.2)	145 (78.8)	154 (83.7)	30 (16.3)	77 (41.4)	107 (58.2)	184 (100)
χ^2 , df, P: 0.8, 1, 0.2			χ^2 , df, P: 0.5, 1, 0.4		χ^2 , df, P: 0.3, 1, 0.4		
Highest education in family							
Metric	7 (38.9)	11 (61.1)	18 (100)	0	10 (55.6)	8 (44.4)	18 (100)
Grad and below	22 (26.5)	61 (73.5)	68 (81.9)	15 (18.1)	39 (47)	44 (53)	83 (100)
Above grad	12 (12)	88 (88)	81 (81)	19 (19)	34 (34)	66 (66)	100 (100)
χ^2 , df, P: 212, 2, 0.001			χ^2 , df, P: 206, 2, 0.003		χ^2 , df, P: 206, 2, 0.003		
Economic status							
APL	28 (24.3)	87 (75.7)	98 (85.2)	17 (14.8)	49 (42.6)	66 (57.4)	115 (100)
BPL	13 (15.1)	73 (84.9)	69 (80.2)	17 (19.8)	34 (39.5)	52 (60.5)	86 (100)
χ^2 , df, P: 2.5, 1, 0.07			χ^2 , df, P: 0.8, 1, 0.2		χ^2 , df, P: 0.1, 1, 0.3		
Referral							
Self	17 (45.9)	20 (54.1)	30 (81.1)	7 (18.9)	29 (78.4)	8 (21.6)	37 (100)
Other	24 (14.6)	140 (85.4)	137 (83.5)	27 (16.5)	54 (32.9)	110 (67.1)	164 (100)
χ^2 , df, P: 18.2, 1, 0.00			χ^2 , df, P: 0.1, 1, 0.4		χ^2 , df, P: 25.7, 1, 0.000		
Patient type							
New	25 (19.8)	101 (80.2)	107 (84.9)	19 (15.1)	50 (39.7)	76 (60.3)	126 (100)
Follow-up	16 (21.3)	59 (78.7)	60 (80)	15 (20)	33 (44)	42 (56)	75 (100)
χ^2 , df, P: 0.06, 1, 0.8			χ^2 , df, P: 0.8, 1, 0.3		χ^2 , df, P: 0.3, 1, 0.5		
Frequency of visit							
<2	15 (12.6)	104 (87.4)	98 (82.4)	21 (17.6)	33 (27.7)	86 (72.3)	119 (100)
>2	26 (31.7)	56 (68.3)	69 (84.1)	13 (15.9)	50 (61)	32 (39)	82 (100)
χ^2 , df, P: 212, 1, 0.000			χ^2 , df, P: 202, 1, 0.01		χ^2 , df, P: 224, 1, 0.000		
Accompanied by							
Family	31 (19.3)	130 (80.7)	136 (84.5)	25 (15.5)	62 (38.5)	99 (61.5)	161 (100)
Others	10 (25.6)	29 (74.4)	30 (76.9)	9 (23.1)	20 (51.3)	19 (48.7)	39 (100)
χ^2 , df, P: 18.9, 1, 0.01			χ^2 , df, P: 19.6, 1, 0.009		χ^2 , df, P: 20.6, 1, 0.003		
Insured							
Yes	32 (26.2)	90 (73.8)	101 (82.8)	21 (17.2)	65 (53.3)	57 (46.7)	122 (100)
No	9 (11.4)	70 (88.6)	66 (83.5)	13 (16.5)	18 (22.8)	61 (77.2)	79 (100)
χ^2 , df, P: 20.3, 1, 0.001			χ^2 , df, P: 13.8, 1, 0.01		χ^2 , df, P: 32, 1, 0.000		

χ^2 : Chi-square, df: Degree of freedom, P: Probability value

performed, and most of the tests were referred to a private hospital. The high out-of-pocket costs associated with care were a significant perceived barrier to obtaining quality care.

“We are poor people. I have borrowed 20 to 25 rupees; all was spent on tests – MRI, CT scan, X-ray and ultrasound, not for treatment. The staff is friendly.” (Patient)

DISCUSSION

Since survivorship care does not have a single standard questionnaire to be implemented in a high-burden country like India, we used a modified combined version of the Iron Triangle Framework, Porter’s Hierarchy Framework and Donabedian’s Component of Care Framework which take

into count the multiple facets of survivorship care for cancer patients. After a prior pilot study and validation, the result analysis depicted findings as narrated.^[11-14]

Median satisfaction score of females is 3 in indoor patients and 3.5 for outdoor patients which was higher than that for men. Mahapatra *et al.*, in 2015, found out that the general level of satisfaction among patients was 60% with a mean of three. Further, their study went on to show that it was communication and manners which were the most satisfying with high percent scores. They had however used the PSQ-18 scale to depict the quality of care for cancer patients.^[19]

The comparatively low levels of satisfaction for general services among indoor patients might be because certain wings were still under construction and there was a gradual heap up of infrastructure and staff after its commencement. These are well explained because children are less likely to tolerate the entangles of treatment and the pain arising out of it and the elderly gradually weans off in suffering. The situation contrasted for indoor patients, where self-arrived patients showed greater satisfaction significantly. Pati *et al.* mentioned that patients appreciated being seen by a familiar person for repeat check-ups.^[20-23] Hence, a frequent referral does impede and enhances their curiosity. Moreover, when someone else refers, the build-up of expectation of perfection is gradual and so patients arrive with a sense of inflated acceptance. Patient type, whether new or follow-up, the frequency of visits did not make any significant differences in opinion. However, those visiting >2 times had a slightly greater percentage of significant satisfaction levels for staff (O-83%, I-84%) and treatment (O-52%, I-61%) as compared to those visiting less frequently. The increase in satisfaction level for staff with visit frequency shows that, in the hustle, entangles and agony of initial visits, judging the staff based on communication, character, behaviour, time, skills, or understanding might be an err on their part. As correctly highlighted in the article on “Navigation Pathway” by Pati *et al.*, the route depends on many intertwined factors such as patient perception, finance, belief in alternate therapy, family support, or referral.^[16] Mere alterations in any one or few factors might still not suffice in escalating the notion and confidence in self and providers.

When we appraise the facet of the beneficiary and his contribution toward Survivorship Care, we find that several woven factors affect his degree of mental affection. Similar studies (Shankar *et al.*, 2016 – 46%) (Saxena *et al.*, 2018) showed that about half of the patients had psychiatric morbidity either in the form of depressive disorder or in the form of anxiety or other psychiatry morbidities. These vary based on the gender, origin, address, stage and severity of cancer.^[24,25] Gopalan *et al.* found that 41.7% of subjects had a psychiatric disorder, 23% with adjustment disorder, depressed mood in 19.5% and anxiety in 3.1%. About 10.9% of subjects had a major depressive disorder. Associations with

gender, origin, severity, family history, grade of cancer and treatment being received were also established in consistence with our findings.^[24,26] New patients and the elderly have a different perception and bent of mind which makes them more vulnerable to stress. Similarly, the presence of family members or attendants plays a significant role in dealing with stress and hurdles. This stresses the fact that man, however independent, might seem always pines for a company when he is facing challenges. Thus, it also becomes important for us to target these areas of care when we advent policies for them.

A patient-centric coordinated and integrated approach to care will help us go a long way to meet the objectives of the existing national programmes setting up of palliative care units, self help anonymous, rehabilitation centres for a holistic integrative approach at the primary level of care to reduce the direct and indirect suffering of patients will reduce the cancer scare. Being a major chunk of telemedicine under the rivet of survivorship care will enable to reduce patient waiting time, queue and out of pocket expenditure. This will also reduce unnecessary consultations and referrals.

CONCLUSION

The study explores the spectrum of barriers that a cancer patient could face through the pathway to seeking care and progress toward normalcy.

Authors' contributions

All authors have made a substantial contribution to the conception, design, analysis and/or interpretation of data, drafting as well as revising an article for intellectual content.

Acknowledgment

We acknowledged all the study participants for their valuable time. We thank Subhashisa Swain for his support in data management. The authors are grateful to the AHRCC patients, their caregivers, physicians and staff, to the project team and administration of IIPH – Bhubaneswar, PHFI, the National Health Mission and Family Welfare, Government of Odisha for rendering valuable support throughout.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

Financial support and sponsorship

SHRMU, Department of Health and Family Welfare, Government of Odisha.

Conflicts of interest

There are no conflicts of interest.

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How to cite this article: Palo SK, Panda M, Sahoo KC, Mahapatra P, Pati S. Impediments of cancer survivorship and palliative care: A mixed-methods study in a tertiary health-care facility in Odisha, India. *Indian J Palliat Care* 2022;28:398-405.