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Assessment of the Quality of Treatment Provided to Oral Cancer Patients in Pakistan: A Multi-Centre Study

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ABSTRACT

Objective: To determine the expectation and satisfaction of oral oncology patients with their management by evaluating the quality of patient communication, physical and emotional support and the factors that results in treatment delays.

Materials and Methods: A cross-sectional study was conducted in multiple oncology centres across Pakistan from 15-July-2020 to 15-October-2020. Seventy patients who had undergone surgical excision for their oral tumours and were receiving radiotherapy or chemotherapy with curative intent filled out a content validated questionnaire. Patients who had unresectable tumours or were receiving palliative care were excluded.

Results: A total of 70 oral cancer patients were recruited. Fifty-one (72.9%) patients were under treatment for less than 1 month while 19 (27.1%) were being treated for 1 to 3 months. With regards to information needs related to diagnosis, 82.9% were being informed clearly. The majority of patients were satisfied with treatment planning information needs. Regarding the prognosis of cancer; 8 (11.4%) of the patients had to inquire about the prognosis themselves, 14 (20%) were informed by the health care provider and 48 (68.6%) got the information on a mutual basis. For attention to care; 64.3% responded that general practitioner and family both were helpful. The timelines and delays in appointment and referral were reported by 95.7% of patients.

Conclusion: The majority of our patients were satisfied with information needs, communication, personalized care, the responsibility of care, psychosocial support and equitability through their treatment, however, the patients were unsatisfied with coordination, timeliness of care, and attention to care and reimbursement.

Keywords: Continuous Quality Management, Health Care System, Oral Cancer, Psychosocial Support

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INTRODUCTION

Head and neck cancer affects more than 650,000 patients yearly, making it the 7th most common malignancy in the world. The annual mortality rate linked with this type of cancer exceeds 0.3 million.[1] Oral squamous cell carcinoma (OSSC) accounts for 95% of all oral malignancies seen in South, and South East Asia.[2] This high prevalence is attributed to the use of betel-quid, smokeless tobacco, cigarette smoking and alcohol in the region.2 OSCC accounts for 8.6% of new cancer cases, and 7.2% of cancer-related mortality in Pakistan.[3] The 5-year survival rate for OSCC is less than 50%.[4]

Management of OSCC depends on the patient's/ physicians' preferences, age, lifestyle, and socioeconomic status.[5] Surgery is the preferred treatment for OSCC, however, ionizing radiation and chemotherapy are slowly becoming important adjuvant options.[6]

Management of OSCC can have a significant aesthetic, functional and emotional impact. It can be associated with decreased quality of life for patients and their caregivers.[7] This quality of life can be measured by considering multidimensional parameters like mental and physical health, general and social wellbeing, and healthcare satisfaction.[8]

A patient coming in with a diagnosis of OSCC is terrified of his treatment outcome, concerned about treatment cost and confused about treatment plans.[9] Similarly, financial toxicity is a worrisome factor for the cancer patient. The abandonment, delay, and discontinuation of treatment form part of the arsenal of strategies that patients with cancer use to cope with the financial burden of treatment.[10] Responsibility for ensuring a smooth treatment experience for such patients lies with the multi-disciplinary oncology team managing such patients. Literature is deficient in highlighting the satisfaction of cancer patients regarding the quality of treatment.

The dearth of tertiary healthcare facilities and personnel, cancer centres and radiation therapy centres in Pakistan make cancer management challenging.[11] This coupled with referral delays, ineffective patient communication and expensive treatments can complicate the patient experience.[12] Since limited data is available from Pakistan on the treatment experience of patients with OSCC, this investigation aims to determine the challenges faced by Pakistani patients during oral cancer treatment; so appropriate measures can be taken to improve the patient experience. The factors of care have been divided into information needs, communication, personalized care, the responsibility of care, psychosocial support, equitability, coordination, timeliness of care, attention to care and reimbursement of finances.

MATERIALS AND METHODS

A cross-sectional analytical study had been conducted in four Institutes of Nuclear Medicine & Oncology from 15th July 2020 to 15th October 2020 in Rawalpindi and Lahore. Ethical approval was taken from Ethical Review Board at Riphah International University (Ref. No. IIDC/IRC/2020/07/002) before the initiation of data collection and permission was taken from the respective institutes to access patients in their oncology departments. A sample size of 70 was collected by using non-probability convenience sampling technique. Patients suffering from oral cancer, between 18-80 years of age, who underwent surgical excision with or without radiotherapy and/or chemotherapy with curative intent and were finished with the initial cancer treatment were included in the study. Patients treated with palliative intent or who didn't give consent to participate in the study were excluded from the study.

With the consent of the subject, a complete history was taken and a pre-drafted proforma was filled that included questions about demographics, treatment modality, and timeline of treatment. In addition, questions about the patient's perception about his/her well-being, level of satisfaction during the treatment, economic burden, assessment of information delivered, delays faced during diagnosis and start of treatment and attitude/behaviour of the medical team. The content of the questionnaire was derived from a qualitative inquiry.[12] Informed consent was obtained from the patients before handing out questionnaires to patients. Help was provided in clarifying information.

Data was entered and analysed using IBM SPSS Statistics for Windows, Version 22.0. (IBM Corp., Armonk, NY, US). A descriptive analysis of patients' demographics was performed. Frequencies and percentages of the patients' responses were found to measure the quality of treatment and patients' satisfaction in general. The reliability test Cronbach's alpha was also calculated to analyse the reliability of the items of the questionnaire.

RESULTS

The reliability of Cronbach's alpha for the questionnaire was calculated at 0.65. A total of 70 oral cancer patients were recruited for evaluating their treatment quality. Fifty-one (72.9%) patients were male while 19 (27.1%) were female. The mean age of the subjects was 58.21±8.19 years. Twenty-four (34.3%) had less than secondary school education, 36 (51.4%) had completed secondary schooling while only 10 (14.3%) had studied beyond secondary school. Twenty-one (30%) had received their first diagnosis between a 6 month to 1 year period, 39 (55.7%) were diagnosed 1 to 2 years prior, while 10 (14.3%) were diagnosed within the 2-to-5-year bracket. Fifty-one (72.9%) patients were under treatment for less than 1 month while 19 (27.1%) were being treated for 1 to 3 months. There were 6 (8.6%) patients who received radiotherapy only, 28 (40%) had surgery before radiotherapy, 2 (2.9%) had surgery followed by chemotherapy, 25 (35.7%) had surgery followed by both radiotherapy and chemotherapy, and 9 (12.9%) underwent radiotherapy and chemotherapy only.

Patients' responses towards the health care providers and the treatment quality are documented in Table 1. Regarding the prognosis of cancer, 8 (11.4%) of the patients had to inquire about the prognosis themselves, 14 (20%) were informed by the health care provider and 48 (68.6%) got the information on a mutual basis. For attention to care, 1 (1.4%) of patients responded that a general practitioner was the most helpful person in dealing with their illness, 19 (27.1%) friends and family, 5 (7.1%) general practitioners, specialist doctors and family and 45 (64.3%) responded that general practitioner and family both were helpful.

Table 1: Responses of the oral cancer patients towards the health care providers and the treatment quality

S.No	THEMES	YES n (%)	NO n (%)
	Diagnosis		
1	Were you sensitively told of your diagnosis?	59 (84.3)	11 (15.7)
2	When you were first told of your illness, were you referred to a provider who could help with anxieties and fears?	45 (64.3)	25 (35.7)
3	Have you been informed about your condition?	58 (82.9)	11 (15.7)
	Treatment Planning		
4	Did someone discuss different treatments for your cancer with you?	67 (95.7)	3 (4.3)
5	Were you given enough information about therapies for treating cancer?	61 (87.1)	9 (12.9)
6	If you had to travel for any tests or treatments, did your care providers consider your travel concerns when planning for your treatment?	51 (72.9)	19 (27.1)
7	Were the test reports clearly explained to you?	51 (72.9)	19 (27.1)
8	Were you informed about the side effects of your treatment?	64 (91.4)	6 (8.6)
9	Did the care provider help you with the decision-making process?	53 (75.7)	17 (24.3)
	Communication		
10	Did you clearly understand the instructions or information given at diagnosis and during treatment decision-making?	43 (61.4)	27 (38.6)

11	Were the doctors available in case of urgency during treatment?	29 (41.4)	41 (58.6)
	Coordination of Care		
12	Was there a lack of a single source of information on treatment history, tests, and billing?	60 (85.7)	10 (14.3)
13	Do you notice teamwork among your care providers?	27 (38.6)	43 (61.4)
14	Were the referrals convenient, if any?	19 (27.1)	51 (72.9)
	Timeliness of Care		
15	Were there any problems with appointment systems or waiting times leading to missed appointments?	52 (74.3)	18 (25.7)
16	Delays during the diagnostic period increased distress?	65 (92.9)	5 (7.1)
17	Did long wait times added to patient stress?	67 (95.7)	3 (4.3)
	Responsibility for Care		
18	Was it clear to you who is responsible for which part of care?	46 (65.7)	24 (34.3)
	Personalized Care		
19	Were you being cared for as a person rather than just as a patient and did the provider and staff know you by name?	52 (74.3)	18 (25.7)
	Psychosocial Support		
20	Did you receive peer and professional psychosocial and emotional support for patients?	42 (60)	28 (40)
	Lack of Attention to Care		
21	Providers did not pay enough attention to the individual’s care and patients have an insufficient amount of time with the provider?	20 (28.6)	50 (71.4)
	Equitability		
22	Did you receive any racial and ethnic discrimination?	1 (1.4)	69 (98.6)
23	Were you discriminated against based on socio-economic status?	15 (21.4)	55 (78.6)
24	Did you face any geographic disparities in access?	1 (1.4)	69 (98.6)
	Reimbursement/Finances		
25	Did you face problems because of a lack of health insurance?	53 (75.7)	17 (24.3)
26	Was there any financial burden because of the hospital?	48 (68.6)	22 (31.4)

DISCUSSION

Oncology patients have to work closely with their physicians to decide the best mode of treatment.[13] For this quality of information delivery from physician to the patient is crucial for patients with a diagnosis of oral squamous cell carcinoma. Our study showed that in Pakistani oncology wards the patient's information needs regarding the diagnosis, prognosis and treatment planning were satisfied. Instructions and information were communicated to them clearly and sensitively. Similar results were found in the study done by Coronado et al. in which most of the patients felt that they have been told about their diagnosis sensitively, and their information needs were satisfied. However, our study did find that a higher number of individuals in our sample felt that the physician did not consider travelling hassles in comparison to Coronado's study.[14]

Our patients generally showed satisfaction regarding their treatment options and prognosis. A majority of our patients were given open information regarding their diagnosis and prognosis similar to a study from the United Kingdom.[15] This is encouraging because a study from Japan reported showed that around 86% of cancer patients want a realistic picture of their diagnosis and prognosis.[16]

Our study demonstrated that over 50% of the patients had complaints about the non-availability of doctors at times of urgency during treatment. This can be a huge source of distress for the patient because he loses confidence in the physician. The patient is already under stress due to fear of disability, mutilation, pain, death, lack of trust in hospital and hospital staff, loss of wholeness, social setback and denial of reality.[17,18] Adding negative verbal or non-verbal behaviour of the doctor would discourage patients to participate in their care further. A study on patient reported outcomes also revealed that due to time constraints the face to face patient doctor contacts are limited which contributes to the communication gap between the patient and the doctor leading the lack of interest of patient in his treatment planning.[19]

Our patients did notice a lack of patient-centred care. This was a result of each area involved in the treatment process functioning independently. Referrals were not made convenient. This of course adds to the pain and agony of cancer patients. A British survey of NHS cancer patients who reported difficulties showed a similar lack of coordination of care.[20] Cancer treatment is a multidisciplinary process, the absence of a team effort can have dire consequences on the physical and emotional wellbeing of the patient.12 This goes beyond common practices and doctor egos.

Patient delay is the time interval between the identification of a patient's symptoms and his return to seeking treatment. This is often related to education, household income, and family support. Referral Delay is the time between different doctors sees the patients under the umbrella of the oncologist. System delay is the time interval between the time of biopsy, receiving results from the lab and making a conclusive diagnosis.[21] The treatment delay is a combination of these factors. Delays were also a concern for our patients. These delays add to the distress of already worried patients. Wagner's study also termed delays as distressing experiences for the patients and their families.[12]

Our patients were well made aware of who was responsible for which part of their treatment. They appreciated the personalized care that was provided to them; however, most were not satisfied with the attention to care they received from their physicians. They felt as if they were not given enough time with the provider directly. Our patients felt that the general practitioners were most helpful. A study from the UK showed that patients found their family most helpful during their illness.[15]

Patients having diverse social networks rely on family, friends and care providers for support to cope with such devastating illnesses.[12] Such support is necessary through psychosocial issues that arise during treatment. A literature review stressed the importance of psychosocial support and timeliness of care.[22] A study on patients with breast cancer experiencing radiotherapy away from home also supported the comfort of family and friends.[23] Our subjects documented that they had adequate psychosocial and emotional support.

While the patients in our oncology clinics were being treated with equality in terms of race and ethnicity, however, low socioeconomic status can be a factor in hindering the quality of treatment. A majority of our patients complained of the financial implications of their treatment. Other studies have also shown that uninsured patients, or those with low income have delayed diagnosis and receive limited treatment options.[12,24]

The capability of the health care provider to satisfy patients' concerns through a positive attitude, and open communication is the first step in ensuring a good treatment experience. Health care providers need to be familiar with promotors and barriers to quality care. The introduction of decision support tools and cost reduction strategies is necessary to avoid distress in cancer patients.

The limitation of the study is the inclusion of limited cities of Pakistan and small sample size. Further studies involving other major cities of Pakistan with larger sample size are recommended to enhance the clinical practice and cancer patient's experience.

CONCLUSION

The majority of our patients were satisfied with information needs, communication, personalized care, the responsibility of care, psychosocial support and equitability through their treatment, however, the patients were unsatisfied with coordination, timeliness of care, attention to care and reimbursement or finances.

DISCLAIMER

None to declare.

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CONFLICT OF INTEREST

There is no conflict of interest among the authors.

ETHICAL STATEMENT

The ethical approval is provided by the Institutional Ethical Review Committee at Riphah International University (Ref. No. IIDC/IRC/2020/07/002).

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AUTHORS CONTRIBUTION

Conception and design of the study: A. Kiyani

Acquisition of data: B. K. Rana

Analysis and interpretation of data: K. Sohail

Drafting of the manuscript: B. Khalil, K. Sohail

Critical review of the manuscript: A. Kiyani

Approval of the final version of the manuscript to be published: B.K. Rana, K. Sohail, A. Kiyani

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