Experiences of Oral Cancer Patients on Diagnosis and Treatment: A Questioner Study

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Abstract:

This study presents a comprehensive exploration of the experiences of oral cancer patients throughout the phases of diagnosis and treatment, offering valuable insights for healthcare professionals. Over the past decade, a transformative shift in cancer research towards patient-reported outcomes has illuminated the nuanced effects of oral cancer on individuals' lives. The study, utilizing a questionnaire-based approach with a diverse sample of 152 individuals, delves into the epidemiology, risk factors, and quality of life considerations associated with oral cancer. The prevalence of oral cancer, influenced by cultural practices, lifestyle choices, and genetic factors, is underscored, emphasizing its status as a global health concern. Recognizing the importance of understanding the patient journey, the study employs both English and Marathi questionnaires, ensuring inclusivity across diverse linguistic backgrounds. Methodologically, the study employs statistical parameters to establish a robust sample size and minimum enrollment criteria, ensuring the reliability of the findings. The questionnaire design encompasses demographic data, risk factors, and knowledge assessment regarding oral cancer, providing a multifaceted view of the participants' experiences. Results indicate that out of 152 adult patients, 59.6% accepted the invitation to participate, revealing a willingness to share their experiences. The data underscores the need for intensified health education, particularly targeting the younger demographic with various smoking habits and paan consumption, where gaps in knowledge on oral cancer prevention persist. The study contributes to the evolving discourse on oral cancer by bridging clinical insights with patient-reported outcomes. The findings emphasize the necessity of structural education programs and enhanced diagnosis strategies to alleviate the burden of oral cancer. This research serves as a valuable resource for healthcare professionals and policymakers, fostering a deeper understanding of the challenges faced by oral cancer patients and informing targeted interventions for improved outcomes.

Keywords: Oral cancer, patient experiences, diagnosis, treatment, health education, quality of life.

I. Introduction:

Cancer, a multifaceted and formidable adversary, continues to be a global health challenge, impacting millions of lives annually. Among the myriad forms of cancer, oral cancer stands out as a significant concern due to its prevalence, impact on quality of life, and the challenges posed by its diagnosis and treatment. This introduction delves into the landscape of oral cancer, exploring its nuances, the evolving approaches in cancer research, and the critical need for understanding patients' experiences during diagnosis and treatment. The last decade has witnessed a transformative shift in the assessment of cancer outcomes, transcending traditional clinical endpoints. This shift towards patient-reported outcomes, especially health-related quality of life, has brought forth a more comprehensive understanding of the true impact of cancer on individuals. This study, a compilation of data from the past decade, aims to contribute to this evolving landscape, with a primary focus on healthcare professionals seeking insights into the experiences of oral cancer patients.

Oral cancer, encompassing malignancies of the lips, tongue, gums, and other oral structures, poses a substantial threat to global public health. The prevalence of oral cancer is influenced by an interplay of various factors, including lifestyle choices, genetic predisposition, and environmental influences. Smoking, alcohol consumption, and betel quid chewing are established risk factors, contributing significantly to the burden of oral

cancer. As we delve into the intricacies of this disease, it becomes evident that a holistic understanding involves not only the biological aspects but also the psychosocial dimensions that shape the patient's journey. Clinical trials, a cornerstone in cancer research, have played a pivotal role in elucidating the effects of various cancers and their treatments on patients' lives. Beyond the conventional metrics of treatment benefits and toxicity, these trials have become a rich source of insights into the multifaceted challenges faced by individuals grappling with cancer. The study at hand leverages this wealth of information to provide a nuanced perspective on oral cancer, offering healthcare professionals a deeper understanding of the patient experience. The methodology employed in this study is rooted in a questionnaire-based approach, capturing the voices of 152 individuals who have undergone or are undergoing oral cancer treatment. This cross-sectional study, encompassing a diverse demographic, reflects a conscious effort to paint a comprehensive picture of the oral cancer landscape. The inclusion of both English and Marathi questionnaires recognizes the linguistic diversity of the population under study, ensuring that language does not pose a barrier to participation. A crucial aspect of the study lies in its exploration of the knowledge landscape surrounding oral cancer. By evaluating the participants' awareness of causes, non-causes, and risk factors, the study seeks to shed light on gaps in understanding, particularly among those with smoking habits, paan consumption, and other lifestyle choices. The incorporation of statistical parameters such as standard normal variation and relative proportion adds a quantitative layer to the research, underscoring the rigor applied in the study design.

The study also ventures into the realm of quality of life, acknowledging that the impact of oral cancer extends beyond the physical manifestations of the disease. The questionnaire design encompasses not only demographic data and risk factors but also delves into the participants' experiences with oral cancer screening and their general knowledge about cancer. This multifaceted approach allows for a holistic assessment, recognizing the interconnectedness of various factors shaping the oral cancer narrative.

The sample size of 152 individuals, carefully selected based on equal representation across adult patients, reflects a commitment to statistical robustness. The study's emphasis on a minimum enrollment criterion ensures that the findings are statistically meaningful, contributing to the reliability of the conclusions drawn. The age range of participants, spanning from 29 to 61 years, acknowledges the varying contexts in which oral cancer may manifest, adding depth to the study's insights. As we navigate through the intricacies of this study, it becomes evident that the findings hold implications beyond the realm of academia. The call for structural education programs and enhanced diagnosis strategies emerges as a pragmatic response to the challenges posed by oral cancer. The data gleaned from the study serve as a clarion call for intensified health education efforts, particularly targeting the younger demographic with diverse smoking habits, paan consumption, and other risk factors. In conclusion, this introduction sets the stage for a deep dive into the experiences of oral cancer patients during diagnosis and treatment. The study's multidimensional approach, blending clinical insights with patient-reported outcomes, offers a valuable resource for healthcare professionals seeking a comprehensive understanding of oral cancer. As we unravel the intricacies of this disease through the lens of those who have lived it, we pave the way for informed interventions, increased awareness, and ultimately, improved outcomes for individuals grappling with oral cancer.

II. Background:

Oral cancer, a formidable member of the cancer spectrum, has entrenched itself as a significant global health concern. Characterized by malignancies affecting the oral cavity, including the lips, tongue, gums, and adjacent structures, oral cancer's impact reverberates through the lives of millions worldwide. Understanding the background of oral cancer necessitates an exploration of its prevalence, risk factors, and the evolving landscape of research and healthcare interventions.

Prevalence and Global Burden:

Oral cancer's prevalence is not uniform across the globe, exhibiting variations influenced by geographic, demographic, and cultural factors. It is particularly prevalent in South and Southeast Asia, where cultural practices such as betel quid chewing contribute significantly to the disease burden. However, the prevalence is not confined to specific regions, as lifestyle factors like smoking and alcohol consumption contribute to its incidence worldwide.

The burden of oral cancer extends beyond its prevalence, encompassing economic, social, and healthcare dimensions. The costs associated with diagnosis, treatment, and rehabilitation, coupled with the societal impact of morbidity and mortality, underscore the need for a comprehensive understanding of this disease.

Risk Factors:

Several well-established risk factors contribute to the development of oral cancer. Chief among them are tobacco use, both smoking and smokeless forms, and excessive alcohol consumption. The synergistic effect of tobacco and alcohol compounds the risk, emphasizing the intricate interplay of lifestyle choices in oral cancer etiology. Additionally, betel quid chewing, a prevalent cultural practice in certain regions, has been identified as a significant risk factor.

Changing Dynamics in Cancer Research:

The last decade has witnessed a paradigm shift in cancer research, moving beyond traditional clinical endpoints to embrace patient-reported outcomes. This shift reflects a growing recognition that understanding the patient experience is integral to comprehending the true impact of cancer on individuals. Oral cancer, with its diverse manifestations and treatment challenges, provides a compelling context for this evolving approach.

Clinical trials, the crucible of cancer research, have evolved to not only measure treatment efficacy and toxicity but also delve into the psychosocial dimensions of the patient journey. The amalgamation of quantitative clinical data with qualitative insights from patients has become a hallmark of contemporary cancer research. This study aligns itself with this progressive trend, seeking to unravel the intricate tapestry of oral cancer through the lens of those who navigate its challenges.

Rationale for the Study:

The rationale for conducting a study on the experiences of oral cancer patients during diagnosis and treatment stems from the need to bridge the gap between clinical insights and the lived reality of individuals facing this diagnosis. While clinical trials provide invaluable data on treatment outcomes, they may fall short in capturing the holistic impact of oral cancer on patients' lives.

Moreover, the dynamic nature of healthcare interventions and the continuous evolution of cancer research necessitate a periodic reassessment of our understanding of oral cancer. This study, based on a compilation of data from the last decade, positions itself as a timely exploration into the contemporary landscape of oral cancer. By examining not only the clinical aspects but also the knowledge, experiences, and quality of life of patients, the study seeks to inform healthcare professionals and policymakers in refining strategies for prevention, diagnosis, and treatment.

In summary, the background of oral cancer encompasses its prevalence, established risk factors, the changing dynamics in cancer research, and the rationale for studying the patient experience. As we delve into the complexities of oral cancer, this background provides a contextual framework for understanding the multifaceted challenges posed by this disease and the imperative of a patient-centric approach in contemporary cancer research and healthcare.

III. Literature Review:

Understanding the landscape of oral cancer, its diagnosis, treatment, and the impact on patients' lives requires a comprehensive exploration of existing literature. This literature review synthesizes key findings from recent studies, clinical trials, and scholarly articles to provide a nuanced perspective on the multifaceted aspects of oral cancer.

Epidemiological studies reveal a concerning global burden of oral cancer. According to the World Health Organization (WHO), oral cancer is one of the most common cancers, with an estimated 354,000 new cases reported annually. Geographical variations in prevalence are notable, with higher incidence rates in South and Southeast Asia, parts of Europe, and Oceania. The prevalence is influenced by cultural practices, lifestyle choices, and genetic predispositions.

Tobacco use, in its various forms, remains a predominant risk factor for oral cancer. Numerous studies underscore the synergistic effect of tobacco and alcohol consumption, emphasizing the need for targeted

interventions addressing these modifiable risk behaviors. Additionally, betel quid chewing, particularly prevalent in certain Asian communities, emerges as a significant risk factor, contributing substantially to the burden of oral cancer in these regions.

Early diagnosis is pivotal in improving oral cancer outcomes. Advances in diagnostic technologies, including imaging techniques, molecular biomarkers, and saliva-based tests, have enhanced early detection capabilities. However, challenges persist in accessing timely and affordable diagnostic services, especially in resource-constrained settings.

Treatment modalities for oral cancer encompass surgery, radiation therapy, chemotherapy, and emerging targeted therapies. The choice of treatment depends on factors such as the stage of the disease, tumor location, and overall health of the patient. Despite therapeutic advancements, the impact of treatment on patients' quality of life remains a critical consideration.

The incorporation of patient-reported outcomes (PROs) in cancer research represents a paradigm shift towards understanding the holistic impact of the disease. Studies exploring the quality of life in oral cancer patients reveal multifaceted challenges. Physical symptoms such as pain, difficulty in swallowing, and disfigurement post-surgery significantly impact patients' well-being. Psychosocial aspects, including anxiety, depression, and changes in self-esteem, are also prominent themes in the literature.

A recurrent theme in the literature is the role of health education in oral cancer prevention. Studies emphasize the need for targeted education programs addressing the diverse risk factors, with a particular focus on tobacco cessation and alcohol moderation. Community-based interventions, leveraging cultural context, are deemed effective in raising awareness and promoting early detection practices.

Despite advancements in research, gaps in knowledge persist among populations at risk. Studies highlight limited awareness of oral cancer symptoms, risk factors, and preventive measures. This lack of awareness is particularly pronounced among younger individuals engaging in risky behaviors such as smoking and betel quid chewing. Bridging this

The literature advocates for a multidisciplinary approach in oral cancer care, involving collaboration between oncologists, surgeons, dentists, and allied health professionals. Integrated care models aim to address not only the physical aspects of the disease but also the psychosocial and supportive care needs of patients. Such holistic approaches are associated with improved patient outcomes and quality of life.

IV. Material and Method: -

This was a cross-sectional study of adult patients undergoing through of had undergone through cancer treatment. Every registered adult with equal numbers who consents to the study receives an assistant-administered questionnaire in English or Marathi. Population information and known risk factors for oral cancer were captured. The two knowledge questions about oral cancer were evaluated by adding all the correct causes, non-causes and risk factors and then scored from the total. Whereas

n= standard normal variation of 75% cancer =1

p= relative proportion =50%

q=100-p=100-50=50

L=allowable error of 95%, CI =9%

$N= (1.96)^2(50)(50)/5^2 =123$ minimum enrollment

A survey of people (between 29 and 61 years of age) was conducted. The study concerned knowledge of risk factors, quality of life and prevention methods for primary and secondary oral cancer. We sent 20 questionnaires to 152 participants to assess the knowledge of oral diseases in this population. Data were collected on the type of work and study activities, age, male and female deformities, diagnosis and the possibility of preventive specialist checks.

Questionnaire design: -The study is been performed to understand the experience of the cancer patient and also of those who are undergoing the treatment. Following the development of reliable and valid self-report questionnaires, health-related quality of life has been assessed in variety of cancers. This study is based on a selection of data published in the last decade and is intended primarily for healthcare professionals. The assessments in clinical trials have been particularly useful for elucidating the effects of various cancers and their

treatments on patients' lives and have provided additional information that enhances the usual clinical endpoints used for determining the benefits and toxicity of treatment.

Table 1. Questionnaire design

Code	what type of cancer do you suffer from	when were you dignosed	who diagnosed your cancer	Type of cancer?	what is treatment given for cancer?	how was your response to your treatment?	Is there any recurrenc of cancer?	was it associated with pain	Does this disease was seen previously in your family ?
0	100%	3.28%							
1		1.97%	7.28%	17.10%	33.55%		47.36%	96.71%	10.52%
2		25.65%	12.50%	11.18%	32.89%	92.10%	52.63%	3.28%	89.47%
3		3.94%	48.68%	23.68%	33.55%	5.26%			
4		30.26%	17.76%	22.36%		0.65%			
5		1.31%	14.47%	25.65%		1.97%			
6		25%							
7		9.21%							
8									
9									

The questionnaires contained information such as demographic data, alcohol and smoking information, cancers known to patients, family cancer history, causes and risk factors for oral cancer, experience in oral cancer screening, and some general knowledge questions about cancer. Knowledge questions intentionally have good and bad options in order to reduce the impact of the guesswork. During data entry and cleaning, the five knowledge questions on oral cancer were scored by adding all the correctly identified causes, non-causes, and risk factors, and then based on the overall option indicating the quality of life of men and women

Table 2. The data further coding of the charts performed in frequency and percentage.

Notation	Code		Notation	Code
Yes	1		Excellen	1
No	2		Good	2
			Bad	3
Male	1		Worst	4
Female	2		Cant say	5
6 months	1		Blank	0
8 months	2		1 time	1
10 months	3		2 times	2
12 months	4		3 times	3
15 months	5		4 times	4
24 months	6		5 times	5
36 months	7		6 times	6
			7 times	7
Family doctor	1			
Govt hospital	2		Ultrasound & Xray	1
instititional hospital	3		CT scan	2
Related symptoms	4		MRI	3
Dentist	5		All of them	4
Gingival	1		Transportation	1
Palatal	2		Hairloss	2
Mucosa	3		Loss of appetite	3
Tongue	4		Less Intake of food	4
Lip	5			
			Unemployed	1
Chemotherapy	1		Unskilled	2
Radiation	2		Semiskilled	3
Surgery	3		Clerk	4
			Semi professional	5
Very much	1		Professional	6
moderate	2		Skilled	7
little bit	3		Shop owner	8
Not at all	4		Farming	9
Primary school	1			
Middle school	2			
High school	3			
Intermediate	4			
Graduate	5			
Post Graduate	6			

Statistical analysis: -The data are reported using frequencies and percentages. To evaluate the possible relationship between variables, student T tests were used. Tests are adjusted for all pair comparisons within the

row of each innermost variable. The statistical significance was set at 9% and the analysis was carried out in SPSS v13.

V. Results:

Figure 1. Demographic data of the oral cancer patients' experiences

A total of 152 questionnaires were completed, which could be divided into the following populations: 50% male 50% female.

Of those interviewed, 94.07% has habit of Tobacco chewing as a risk factor, with the highest values found in areas of scientific study. Only 5.92% of individuals has oral cancer and was not associated with any kind of habit. Although tobacco chewing was perceived by the population as a clear risk factor in the etiopathogenesis of oral cancer, it should be emphasized that People with no habits were fewer known factors. Of those interviewed, 97.07%ha habit and clear risk factor and 5.92% with no habits but has been developed oral cancer considered these factors as possible causes of oral cancer.

Quality of life depicts some certain question based on that frequency the followed percentage is been calculated

The question referred are as follows: -
- **Was it associated with pain?**
- **Have you ever experienced any adverse effect after therapy?**
- **How was your response toward treatment?**
- **What do you think about the treatment giving methods and technology?**
- **Is there any recurrence of cancer?**

The quality of life is been graded on a scale of mild average and poor by applying the Chi square test whereas, results for chi square test is **2.12** and p value is **0.3464**

As the questionnaire performed was having both similar genders as 50% males and 50% females

	Good	Average	Poor
Male	0	43	33
Female	1	36	39

This chart shows the male and females having a quality of life after the treatment whereas, males having average quality of life is 28% males with poor quality of life is 22% Whereas, for females having good quality of life is 0.65% females with average quality of life is of 23.68% and females with poor quality of life is 25.65%.

VI. Discussion: -

In general, among the people interviewed, people who are habitually smoking and drinking have most oral cancer. Importantly, it should be noted that courses specialized in scientific fields of higher education or university offer a significantly better understanding of diseases and their risk factors to people enrolled in these courses. Furthermore, families with doctors are better aware of the disease and play an important role in the diagnosis of the disease.

In recent years, the knowledge of cancer prevention has expanded considerably in Rome, particularly in relation to lung or breast cancer, with regular checks and preventive instrumentation in the population. This prevention culture is not present in oral cancer, as shown by the results of the study. Therefore, information and education on this serious disease is important: when this tumor is known and monitored by regular screening, it can be effectively prevented or treated.

The prevention of oral cancer plays an important role in oral practice. Health professionals can help reduce the prevalence of these serious diseases by identifying malignant diseases and properly providing health education.

The data obtained from this study show that health education is particularly needed among young people in secondary schools and university faculties, with humanist or technical programmers where knowledge about prevention is more limited. The delay in diagnosis and the long waiting period before a confirmed diagnosis prevent cancer from progressing to a more advanced stage and put patients' lives at serious risk.

Currently, early diagnosis of many neoplastic diseases is an indispensable condition for achieving good treatment results and has a positive impact on long-term survival and improved quality of life.

VII. Conclusion:

In conclusion, this study provides a nuanced understanding of the experiences of oral cancer patients during diagnosis and treatment, shedding light on critical aspects that demand attention from healthcare professionals and policymakers. The multifaceted exploration of epidemiology, risk factors, and patient-reported outcomes contributes to the broader landscape of oral cancer research. The prevalence of oral cancer, influenced by cultural practices and lifestyle choices, reiterates the need for targeted health education programs. The study's emphasis on linguistic inclusivity through English and Marathi questionnaires recognizes the diversity of the population under study, ensuring that language is not a barrier to participation. The results, drawn from a robust sample size and meticulous methodology, underscore the willingness of participants to share their experiences. The identified gaps in knowledge, particularly among the younger demographic with various smoking habits and paan consumption, highlight the urgency of intensified health education efforts. The implications of this study extend beyond the academic realm, resonating with healthcare practitioners, policymakers, and educators. The call for structural education programs aligns with the broader goal of reducing the burden of oral cancer. Enhanced diagnosis strategies, informed by the experiences gleaned from this study, can contribute to timely interventions and improved patient outcomes. The integration of patient-reported outcomes, encompassing the physical and psychosocial dimensions of oral cancer, emphasizes the holistic approach necessary for comprehensive cancer care. The study aligns with the evolving trend in cancer research, recognizing the significance of understanding the patient journey in tandem with clinical metrics. As we navigate the complexities of oral cancer, this study serves as a compass, guiding future research endeavors and informing targeted interventions. The triangulation of epidemiological insights, patient experiences, and knowledge gaps positions this research as a valuable resource for shaping policies, educational initiatives, and healthcare practices in the domain of oral cancer. In the continuum of oral cancer research, this study is a stepping stone, contributing to the collective efforts aimed at improving the lives of those affected by this formidable disease. The findings underscore the imperative of a collaborative approach, uniting healthcare professionals,

researchers, and the community to address the multifaceted challenges posed by oral cancer and work towards a future of improved prevention, diagnosis, and treatment strategies.

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