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High-Risk Families and Early Detection: Screening Awareness and Compliance in First-Degree Relatives of Oral Squamous Cell Carcinoma

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ABSTRACT

Background: Oral squamous cell carcinoma (OSCC) is a leading malignancy worldwide, strongly linked to tobacco, betel quid, and alcohol consumption. First-degree relatives (FDRs) of OSCC patients are considered a high-risk group due to shared genetic susceptibility and environmental exposures.

Objectives: The objectives of this study were to assess awareness of OSCC and its risk factors among first-degree relatives of OSCC patients, to evaluate compliance with recommended oral cancer screening practices, and to identify barriers and facilitators influencing participation in screening programs.

Methods: This cross-sectional descriptive study included 110 first-degree relatives (parents, siblings, and children) of histopathologically confirmed OSCC patients. Data were collected using a structured questionnaire assessing awareness, screening compliance, and perceived barriers and facilitators.

Results: The mean age of participants was 39.8 ± 12.5 years; males comprised 56.4%. Children formed the largest group of relatives (40%). Overall, 60.9% had heard of oral cancer, while 47.3% recognized tobacco, 34.5% betel quid/areca nut, and 28.2% alcohol as risk factors. Awareness of early warning signs was reported by 34.5%. Only 21.8% had ever undergone screening and 10.9% received periodic check-ups, though 67.3% expressed willingness for future screening. Education level was significantly associated with both awareness ($p = 0.01$) and compliance ($p = 0.03$). Major barriers included lack of awareness (38.2%), financial constraints (25.5%), and fear of diagnosis (18.2%), while family history (40.0%) and physician recommendation (34.5%) were key facilitators. Awareness was strongly associated with willingness for screening (80.6% vs. 46.5%, $p = 0.002$).

Conclusion: It is concluded that first-degree relatives of OSCC patients have limited awareness and poor compliance with screening, despite high willingness for future participation. Education is the strongest determinant of preventive behavior, while barriers are primarily informational and financial.

Keywords: *Oral squamous cell carcinoma, first-degree relatives, awareness, screening compliance, barriers*

1. INTRODUCTION

Oral squamous cell carcinoma (OSCC) accounts for the vast majority of oral malignancies and continues to present a significant global health challenge. Despite being largely preventable, it remains one of the top ten cancers worldwide in terms of incidence and mortality [1]. According to global cancer statistics, OSCC affects nearly 377,000 people annually, with over 170,000 deaths reported each year. The disease burden is particularly severe in South and Southeast Asia, where cultural and social practices such as chewing betel quid, smokeless tobacco use, and alcohol consumption contribute to an elevated risk profile [2]. Even in developed countries, OSCC remains a major concern, often associated with smoking and alcohol consumption, alongside emerging associations with human papillomavirus (HPV) infection [3]. The prognosis of OSCC is closely tied to the stage at diagnosis. Five-year survival rates approach 80–85% for early-stage tumors but drop to below 40% for advanced-stage disease [4]. Unfortunately, a substantial proportion of patients present late due to a combination of lack of awareness, absence of symptoms in early disease, and poor access to preventive care. This underscores the importance of early detection and screening, particularly in individuals at elevated risk [5].

One high-risk subgroup comprises first-degree relatives (FDRs) of OSCC patients. Familial aggregation studies have consistently demonstrated that FDRs carry a higher risk of developing OSCC and related premalignant lesions [6]. This excess risk arises from a combination of shared lifestyle factors and genetic predisposition. Families often share high-risk practices such as chewing areca nut, smoking, or alcohol use, all of which significantly contribute to oral carcinogenesis. Beyond environmental exposures, genetic susceptibility is increasingly recognized as a key driver [7]. Mutations and polymorphisms in genes regulating carcinogen metabolism, DNA repair, cell cycle control, and immune regulation have been implicated in familial clusters of OSCC. Such genetic vulnerabilities may amplify the impact of shared exposures, placing FDRs at substantially higher risk compared to the general population [8].

In addition to genetic and behavioral factors, psychosocial and cultural influences play an important role in disease risk and screening practices among FDRs. For example, in many South Asian communities, chewing betel quid or smokeless tobacco is normalized across generations, making behavior modification particularly challenging. Moreover, awareness regarding early warning signs of OSCC, such as persistent oral ulcers, leukoplakia, or erythroplakia, remains limited in both patients and their families. Stigma, fatalism, and lack of knowledge about screening programs further reduce the likelihood of early detection [9]. Targeted screening of FDRs offers a promising strategy for addressing this high-risk group. Screening can take the form of visual oral examination, adjunctive use of toluidine blue or autofluorescence, and, increasingly, the use of salivary biomarkers and molecular assays [10]. Evidence suggests that screening focused on high-risk populations is more cost-effective than population-wide programs, especially in resource-limited settings. For FDRs of OSCC patients, periodic screening not only facilitates early detection but also provides an opportunity for preventive counseling, habit cessation, and risk education [11-13].

Despite the potential benefits, screening awareness and compliance remain major challenges. Studies have shown that awareness of oral cancer is low even among families directly affected by OSCC. Compliance with follow-up recommendations is often poor due to socioeconomic constraints, fear of diagnosis, and lack of trust in healthcare systems. In some cases, family members prioritize the care of the diagnosed patient and neglect their own risk, leading to missed opportunities for prevention [14]. These barriers highlight the need for tailored interventions that address both knowledge gaps and behavioral obstacles. Globally, public health strategies are increasingly shifting toward risk-based screening and personalized preventive approaches [15]. In high-prevalence countries, this includes identifying high-risk families as a priority population for targeted intervention. Integrating education programs into oncology clinics, where OSCC patients are treated, may be a feasible and effective strategy to engage their relatives. Health professionals can play a pivotal role in encouraging FDRs to participate in screening, reinforcing the message that their risk is elevated and that early detection offers a significant survival advantage [16].

Objective

The objectives of this study are:

1. To assess awareness of oral squamous cell carcinoma (OSCC) and its associated risk factors among first-degree relatives of OSCC patients.
2. To evaluate compliance with recommended oral cancer screening practices in this high-risk population.
3. To identify barriers and facilitators influencing participation in screening programs among first-degree relatives of OSCC patients.

2. METHODOLOGY

This was a cross-sectional descriptive study conducted at

Jinnah Hospital Karachi from March 2024 to February 2025. A total of 110 participants were enrolled. Study Population was first-degree relatives (parents, siblings, and children) of patients who had been diagnosed with histopathologically confirmed oral squamous cell carcinoma (OSCC). Non-probability consecutive sampling was used to recruit eligible participants.

Inclusion Criteria:

- First-degree relatives (parents, siblings, children) of OSCC patients.

- Age ≥ 18 years.
- Willing to provide informed consent.

Exclusion Criteria:

- Relatives with a prior history of oral precancerous or cancerous lesions.
- Healthcare professionals, to avoid bias due to higher baseline awareness.
- Individuals who declined consent or had incomplete data.

Data Collection Procedure:

After obtaining approval from the institutional ethics review board, participants were approached in oncology and head-and-neck outpatient clinics where OSCC patients were being treated. Informed written consent was obtained. A pretested, structured questionnaire was administered to collect information regarding sociodemographic details (age, gender, education, socioeconomic status), awareness of OSCC and its risk factors, history of personal risk habits (tobacco use, areca nut, betel quid, alcohol), and knowledge of early symptoms. Compliance with oral cancer screening practices was assessed by inquiring about prior participation in screening examinations, frequency of oral check-ups, and willingness for future screening. Additional questions identified barriers (financial, cultural, lack of awareness, fear of diagnosis) and facilitators (family history, physician recommendation, knowledge of risk) to screening participation.

Data Analysis:

Data were entered and analyzed using SPSS version 26. Continuous variables such as age were summarized using mean ± standard deviation, while categorical variables such as gender, awareness status, habits, and screening compliance were expressed as frequencies and percentages. The chi-square test was applied to assess associations between awareness, compliance, and demographic factors. A p-value of ≤0.05 was considered statistically significant.

Results

A total of 110 first-degree relatives (FDRs) of OSCC patients participated in the study. The mean age was 39.8 ± 12.5 years (range: 18–72 years). Males comprised 62 (56.4%) of the participants, while females accounted for 48 (43.6%). Among the relatives, 44 (40.0%) were children of OSCC patients, 38 (34.5%) were siblings, and 28 (25.5%) were parents.

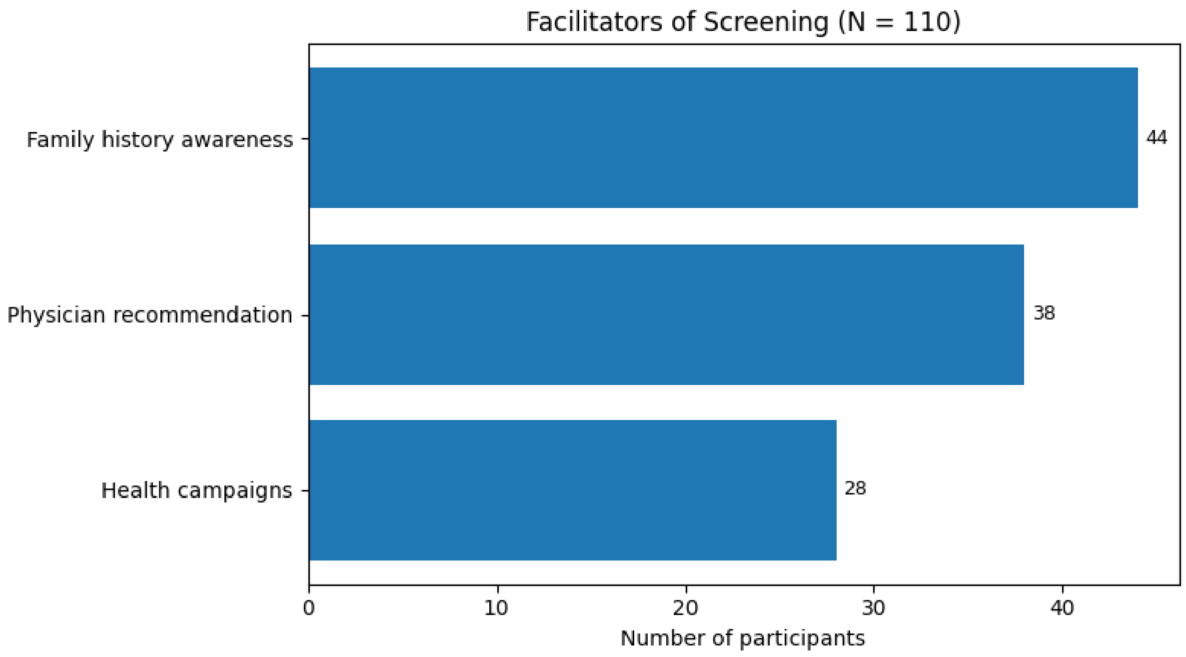
Table 1. Baseline Characteristics of First-Degree Relatives (N = 110)

Variable	n (%) / Mean ± SD
Age (years)	39.8 ± 12.5
Gender	
• Male	62 (56.4%)
• Female	48 (43.6%)
Relationship to patient	
• Children	44 (40.0%)
• Siblings	38 (34.5%)
• Parents	28 (25.5%)
Education level	
• No formal education	22 (20.0%)
• Primary/secondary	40 (36.4%)
• Higher education	48 (43.6%)

Awareness of OSCC was suboptimal in this high-risk group. Only 52 (47.3%) participants were aware that OSCC was linked to risk habits such as smoking, smokeless tobacco, and betel quid use. Awareness of early symptoms (such as persistent oral ulcers or white/red patches) was reported by 38 (34.5%). Screening compliance was low. Only 24 (21.8%) participants had ever undergone an oral examination for cancer screening, while just 12 (10.9%) reported attending periodic follow-ups. Willingness for future screening was higher, with 74 (67.3%) stating they would consider screening if advised by a healthcare professional.

Table 2. Awareness of OSCC and its Risk Factors (N = 110)

Awareness Parameter	**n (%)**
Heard of oral cancer	67 (60.9%)
Aware of tobacco as a risk factor	52 (47.3%)
Aware of betel quid/areca nut as a risk	38 (34.5%)
Aware of alcohol as a risk factor	31 (28.2%)
Knowledge of early warning symptoms	38 (34.5%)
Believe OSCC can be prevented by screening	40 (36.4%)
Screening Practice	
Ever screened for oral cancer	24 (21.8%)
Periodic oral check-ups	12 (10.9%)
Willingness for future screening	74 (67.3%)
Reluctance/fear toward screening	36 (32.7%)

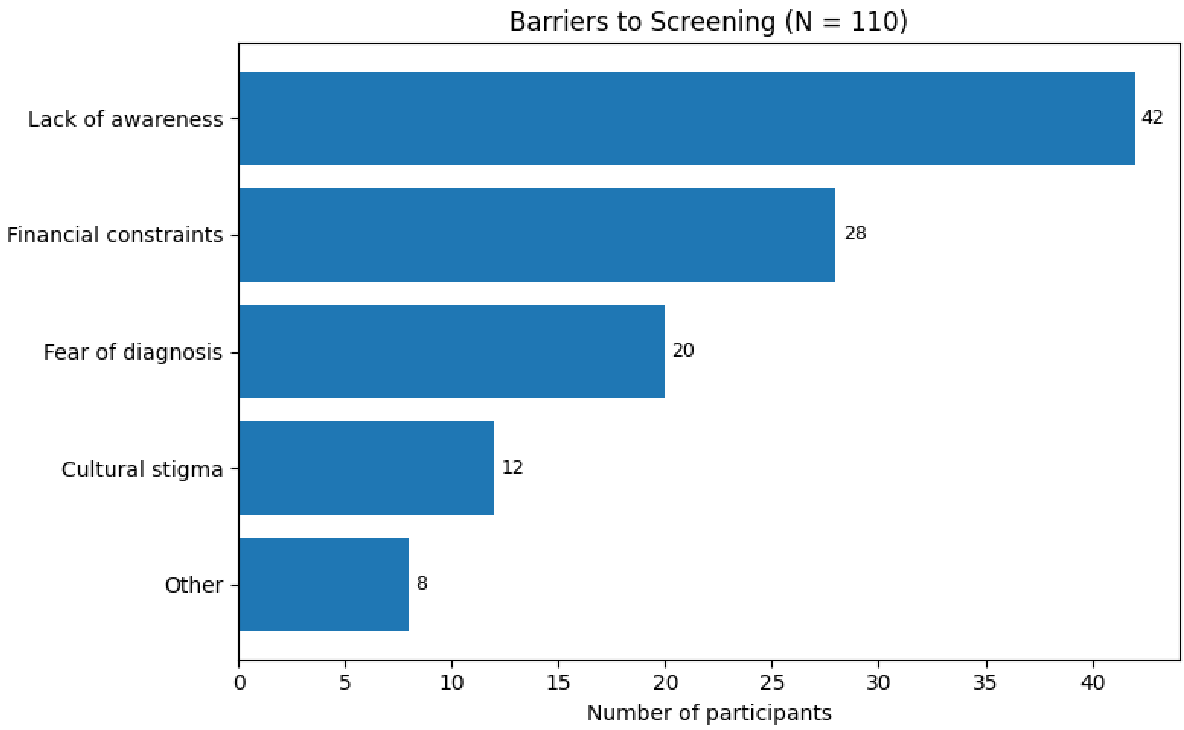


The most commonly reported barriers to screening were lack of awareness (42; 38.2%), financial constraints (28; 25.5%), fear of diagnosis (20; 18.2%), and cultural beliefs or stigma (12; 10.9%). Facilitators included family history awareness (44; 40.0%), physician recommendation (38; 34.5%), and community health campaigns (28; 25.5%).

Table 3. Barriers and Facilitators to Screening (N = 110)

Factor	**n (%)**
Barriers	
• Lack of awareness	42 (38.2%)
• Financial constraints	28 (25.5%)
• Fear of diagnosis	20 (18.2%)

• Cultural beliefs/stigma	12 (10.9%)
• Other	8 (7.2%)
Facilitators	
• Family history awareness	44 (40.0%)
• Physician recommendation	38 (34.5%)
• Health campaigns	28 (25.5%)



Out of 110 participants, overall willingness to undergo future oral cancer screening was 67.3%. Gender was not significantly associated with willingness (p = 0.39). Among males, 40 (64.5%) expressed willingness compared to 34 (70.8%) of females. Education level demonstrated a significant effect (p = 0.01). Only 10 (45.5%) of those with no formal education were willing to be screened, while willingness was higher among those with primary or secondary education (26; 65.0%), and highest among participants with higher education (38; 79.2%). Relationship to the OSCC patient was not statistically significant (p = 0.22), though willingness was slightly higher among children (72.7%) compared to siblings (65.8%) and parents (60.7%).

Table 4. Willingness for Future Screening by Demographic Variables (N = 110)

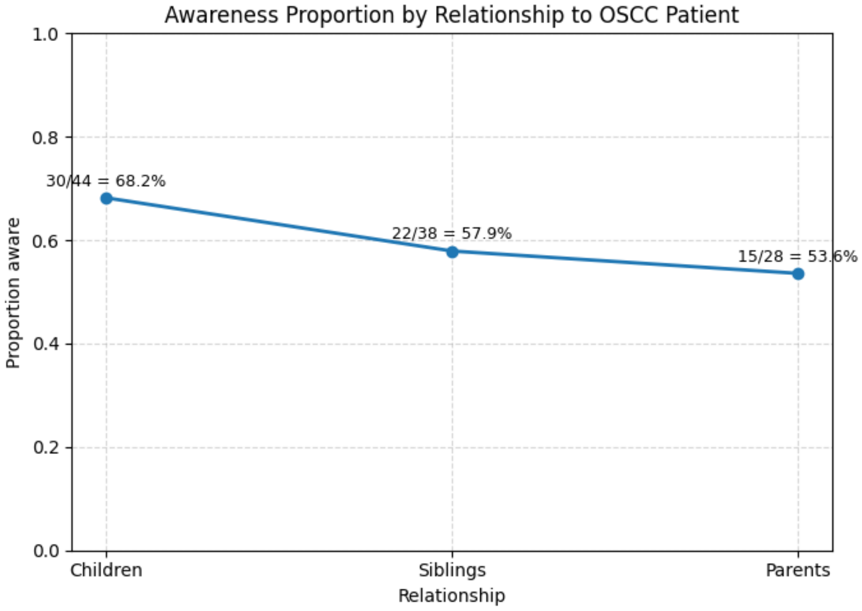
Variable	**Willing n (%)**	**Not willing n (%)**	**p-value**
Gender			
• Male (n=62)	40 (64.5%)	22 (35.5%)	0.39
• Female (n=48)	34 (70.8%)	14 (29.2%)	
Education level			
• No formal education (n=22)	10 (45.5%)	12 (54.5%)	0.01*
• Primary/secondary (n=40)	26 (65.0%)	14 (35.0%)	
• Higher education (n=48)	38 (79.2%)	10 (20.8%)	

Relationship to patient			
• Children (n=44)	32 (72.7%)	12 (27.3%)	0.22
• Siblings (n=38)	25 (65.8%)	13 (34.2%)	
• Parents (n=28)	17 (60.7%)	11 (39.3%)	

Awareness of OSCC was strongly associated with willingness for future screening (p = 0.002). Among the 67 participants who were aware of OSCC, 54 (80.6%) expressed willingness, compared to only 20 (46.5%) of the 43 who were not aware. Conversely, more than half of the unaware group (53.5%) were unwilling to participate in screening.

Table 5. Association Between Awareness and Willingness for Future Screening

Awareness status (N = 110)	**Willing for screening n (%)**	**Not willing n (%)**	**p-value**
Aware of OSCC (n=67)	54 (80.6%)	13 (19.4%)	0.002*
Not aware (n=43)	20 (46.5%)	23 (53.5%)	



3. DISCUSSION

This study assessed awareness, compliance with oral cancer screening, and barriers among first-degree relatives (FDRs) of patients with oral squamous cell carcinoma (OSCC). The findings highlight considerable gaps in knowledge and screening practices within this high-risk group, despite their elevated vulnerability to developing OSCC due to shared environmental exposures and potential genetic susceptibility. Awareness of OSCC was modest in our cohort, with only 61% of participants reporting prior knowledge of oral cancer. Recognition of key risk factors such as tobacco and betel quid was under 50%, and awareness of early warning signs was even lower (34%). These findings mirror earlier reports from South Asia and other high-prevalence regions, where public knowledge of oral cancer remains limited despite its significant burden [17,18]. Education emerged as a strong determinant of awareness, consistent with prior studies showing that individuals with higher educational attainment are more likely to recognize cancer risk factors and participate in preventive practices [19]. This emphasizes the need for targeted awareness interventions that are culturally sensitive and tailored to individuals with lower literacy levels.

Compliance with oral cancer screening was notably poor, with fewer than one-fourth of participants ever undergoing an oral examination and only 11% receiving periodic check-ups. Similar low levels of compliance have been reported in other high-risk populations, suggesting systemic barriers such as limited access to healthcare, financial burden, and lack of organized screening programs [20]. In contrast, willingness for future screening was high (67%), indicating a substantial gap between knowledge and behavior. This suggests that compliance could be improved through better education and more accessible, community-based screening opportunities. Barriers to screening in this study included lack of awareness (38%), financial constraints (26%), and fear of diagnosis (18%). These findings are consistent with prior studies identifying knowledge deficits and socioeconomic barriers as major obstacles to oral cancer prevention [21,22]. Cultural stigma was also reported by a subset of participants, highlighting the influence of social attitudes in shaping health behaviors. On the other hand, facilitators such as family history awareness (40%) and physician recommendation (34.5%) strongly influenced willingness to undergo screening. Similar patterns have been reported elsewhere, where family history and direct physician advice act as powerful motivators for preventive health behaviors [23]. Importantly, awareness was significantly associated with willingness to undergo screening: 80.6% of aware participants expressed interest compared to only 46.5% of those unaware. This underscores the central role of education and awareness in driving preventive action. Comparable findings have been documented in community-based studies, where structured education campaigns and counseling significantly improved screening participation among high-risk groups [24,25]. This suggests that integrating structured awareness sessions into oncology clinics, where patients and their families are already engaged with the healthcare system, could represent a feasible and effective strategy to enhance uptake among FDRs.

This study has several important implications. First, it highlights the urgent need to integrate family-based screening strategies into existing cancer care pathways. When a patient is diagnosed with OSCC, their FDRs should be counseled about their elevated risk and actively invited to participate in screening programs. Second, physician engagement should be strengthened, as physician recommendation was identified as a major facilitator. Third, addressing systemic barriers such as cost and access will be critical, particularly in low-resource settings. Mobile screening clinics and community-based oral health programs may provide cost-effective solutions in high-incidence regions. The limitations of this study include its single-center design, relatively small sample size, and reliance on self-reported data, which may be subject to recall and social desirability bias. However, the findings align closely with regional and global evidence, reinforcing their validity. Future studies with larger, multi-center cohorts and inclusion of biomarkers or genetic testing may further clarify the risk profile and guide personalized screening strategies for FDRs of OSCC patients.

4. CONCLUSION

It is concluded that first-degree relatives of patients with oral squamous cell carcinoma (OSCC) demonstrate limited awareness regarding the disease and its risk factors, along with low compliance to recommended screening practices. Education was identified as the most significant determinant of awareness and screening behavior, while barriers such as lack of knowledge, financial difficulties, and fear of diagnosis hindered participation. Facilitators including family history and physician recommendation strongly influenced willingness to undergo screening.

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