Challenges to Oral Cancer Prevention in the South Asian Population: A Scoping Review

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Abstract

Oral cancer is a public health concern due to late diagnosis, which subsequently results in considerable morbidity and mortality. Globally, South Asian countries present with some of the highest rates of oral cancer. With migration, similar disparities have been observed in Canada where the South Asian community is the largest ethnic group. The underlying cause has been attributed to the common usage of smokeless tobacco amongst South Asians. However, oral cancer is amongst the few cancers that are preventable due to known modifiable risk factors, knowledge of clinical history, and early screenings at dental clinics. A scoping review was conducted to improve the understanding of knowledge, attitudes, and behaviours (KAB) related to oral cancer among South Asians. A total of 37 studies were included with culture being identified as a gap in research. This capstone utilizes a theoretical framework based on the Social Ecological Model (SEM) to facilitate current efforts for oral cancer prevention amongst South Asians.

Keywords: oral cancer screening; KAB oral cancer; smokeless tobacco; oral cancer prevention
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1. OVERVIEW

Oral cancer is one of the most common cancers in the world, globally imposing a substantial disease burden (FDI World Dental Federation, 2014). In 2012, an estimated 300,273 new cases of oral cancer were diagnosed (Ferlay et al., 2013). In the same year, around 145,353 deaths from oral cancer occurred, contributing to almost 1.9% of cancer mortality worldwide (Ferlay et al., 2013; Ferlay et al., 2014). The 5-year survival rate for most oral cancers has remained at approximately 50% due to late diagnosis as most of the cases of oral cancer are detected in advanced stages III or IV (Warnakulasuriya, 2009; Bittar, 2010).

Late diagnosis of oral cancer not only leads to increased mortality but also exacerbates morbidity requiring aggressive treatments (Currie, 2011). Early detection, however, could improve the prognosis with the 5-year survival rates being as high as 80% (Silverman, 1988). This is possible because oral cancer is unique in terms of prevention, where the oral cavity is easily accessible through visual examination and the major risk factors associated with oral cancer, both the habits of tobacco and alcohol consumption, are preventable.

In British Columbia (BC), the BC Cancer Agency (BCCA) operates to improve cancer care and research for a comprehensive list of cancers (BCCA, 2015). Oral cancer is one of the areas where the agency strives to advance prevention strategies that can address the needs of the communities most
vulnerable to oral cancer in BC. As populations differ in their incidence and prevalence rates of oral cancer and are comprised of communities that are culturally distinct with underlying risk factors, prevention strategies require research into the assessment and analysis of such variations. As such, oral cancer has been identified to disproportionately affect South Asians within Canada. Though biomedical and technological advances in the field of oral cancer have been prioritised, little is known about the awareness and perceptions towards oral cancer amongst South Asian (SA) communities in BC. For prevention programs to be equitable and sustainable, it is important to visualize at-risk SA communities at the centre of being impacted through programs and policies involving oral cancer. This capstone will, therefore, focus upon reviewing literature and analyzing relevant data in order to strengthen current prevention efforts within SA communities.

This paper begins with a brief background on oral cancer in SA communities, while also situating prevention in oral cancer according to different levels of prevention. The purpose, objectives, and methods which focus on the scoping review are then elaborated. As such, the findings of this review are summarized as commonly occurring themes in results. The discussion and recommendations emphasize upon the importance of these findings, research gaps, and their relevance to public health in which a theoretical framework based on the Social Ecological Model (SEM) is presented. Following this, limitations of this capstone are discussed.
2. BACKGROUND

2.1. Epidemiology of Oral Cancer

Oral cancer is an emerging public health concern with variability in disease patterns amongst populations. Geographic variability is apparent as the Indian subcontinent represents about one-third of the oral cancer disease burden with relatively high prevalence, incidence, and mortality rates for oral cancer (Subramanian et al., 2009; Boyle & Levine, 2008; Ferlay et al., 2014). Age-adjusted incidence rates for oral cancer also vary from over 20 per 100,000 population in India to 10 per 100,000 in US (Sankaranarayanan, Masuyer, Swaminathan, Ferlay & Whelan, 1998). This variation is due to differences in prevalence of risk habits, such as chewing betel quid with tobacco or areca nut that are associated with increased risk of developing oral cancer (IARC Working Group on the Evaluation of Carcinogenic Risks to Humans, 2004). Several epidemiological studies have reported at least 20-40% of the population in India, Pakistan, Bangladesh, and Nepal to be betel quid chewers (Gupta & Ray, 2004; World Health Organization [WHO], 2009). Following migration, this habit of chewing betel quid has been suggested to have remained prevalent amongst South Asians in North America (Avon, 2004).

With that perspective, the SA community is the largest ethnic group in Canada and has a higher incidence rate for oral cavity cancer in BC (Statistics Canada, 2011; Auluck, Bajdik, Poh, Zhang & Rosin, 2010). The age-adjusted
incidence rates for SA men at 5.6 (95% CI: 2.1-9.8) and for women at 4.4 (95% CI: 1.8-7.8) are higher when compared to the general population at 4.3 (95% CI: 3.8-4.7) for men and 2.7 (95% CI: 2.3-3.0) for women (Auluck et al., 2010). In 2011, South Asians accounted for 25% of the total visible minority population and 4.8% of Canada’s total population (Statistics Canada, 2011). Such results have been consistently increasing following each census with Statistics Canada (2007) defining the number of people in Canada of SA origin as “growing considerably faster than the overall population”. It is likely that following the rise in immigration from high-risk countries such as India, the number of cases of oral cancer will also increase in Canada (Laronde, Hislop, Elwood, & Rosin, 2008).

Nevertheless, oral cancer is amongst the few cancers that are potentially preventable due to modifiable risk factors, knowledge of early clinical history of premalignant lesions, accessible screenings at dental clinics with increased potential for early detection, and the existence of a strong research base in BC that supports the development of prevention strategies for oral cancer. Regular dental visits have been found to influence early diagnosis of oral cancer in BC (Elwood & Gallagher, 1985). Given that South Asians are more susceptible to oral cancer, prevention in this field is better achieved through the adoption of a health equity lens. This requires exploring the factors that predispose SA communities to a greater risk of developing oral cancer and further developing prevention strategies to be context specific.
2.2. Risk factors

Oral cancer is a multifactorial disease comprising mainly of exogenous risk factors such as tobacco and alcohol that are responsible for the development of about 90% of oral cancers, and endogenous risk factors such as genetic predisposition and nutrition (Bittar, 2010; WHO, 2005). Ethnicity also contributes towards the initiation of selective habits (Bittar, 2010). In particular, the use of oral chewing products increases the risk of developing oral malignancies such as those being observed in SA countries (Subapriya, Thangavelu, Mathavan, Ramachandran & Nagini, 2007). Several studies have also described increased oral cancer incidence arising from oral chewing habits amongst SA migrant groups and minority ethnic populations (Warnakulasuriya, 2009).

Betel quid, also known as paan, is a popular oral chewing product amongst South Asians. This usually comprises of betel leaf, areca nut, and slaked lime, with or without smokeless tobacco. Both smokeless tobacco and areca nut are addictive and carcinogenic. Smokeless tobacco or tambaku contains 28 carcinogens, which mostly comprises of tobacco-specific N-nitrosamines (Brunnemann & Hoffmann, 1992). Areca nut or supari contains alkaloids, mainly arecoline which is converted into N-nitroso compounds in the presence of slaked lime (Dave, Trivedi & Adhvaryu, 1992; Nair, Bartsch & Nair, 2004). These constituents, both individually and as part of a quid, are readily available in BC at SA shops and grocery stores. While sale of tobacco is
regulated in BC, oral chewing products escape such scrutiny with prices ranging from $1.25 to $1.75 per quid (Auluck, 2012).

2.3. Utilization of Services

Evidence from numerous studies suggests a low uptake of cancer services in general by SA communities in contrast to other groups in the population (Randhawa & Owens, 2004; Canadian Cancer Society, 2013). Additionally, screening practices for various cancers among SA communities, particularly women have also been found to be lower than in other populations (Islam & Zojwalla, 2002; Lofters, Hwang, Moineddin, & Glazier, 2010). These reduced numbers can be attributed, in part, to the unmet needs of the SA communities in terms of provision of cancer information, resulting in lower awareness of risk factors, signs and symptoms of cancer, and cancer services (Cancer Research UK, 2008). Thereby, a “one size fits all” model of approach in disseminating information is unlikely to meet the needs of an ethnic group with strong cultural perceptions (Thompson & Van Der Molen, 2009). These beliefs include stigma towards cancer, fatalism, and the importance of family in decision-making to play a significant role in the uptake of screening services and the development of appropriate information resources (Watts, Merrell, Murphy & Williams, 2004). In summary, research in SA communities indicates that barriers to screening include limited knowledge on cancer, communication gap, and inadequate access to cancer services as well as cultural beliefs and practices (Islam & Zojwalla, 2002; Thompson & Van Der Molen, 2009).
Minorities such as the SA community face similar barriers in accessing appropriate oral cancer care and information including socio-economic barriers, geographic barriers, barriers related to a lack of education, and barriers related to cultural differences and discrimination in care (Gany, Shah & Changrani, 2006). For instance, a study reported that knowledge and attitudes towards oral cancer including the use of alcohol, tobacco, and paan varied across the SA community even between 1st and 2nd generation males (Vora, Yeoman & Hayter, 2000). This is due to the reason that the SA population is not a homogenous group but consists of distinct communities with their own cultural beliefs and habits. Moreover, immigrants with limited English proficiency risk being excluded from conventional cancer research programs (Gany et al., 2006). Even in data collection, cancer data is not gathered by immigrant variables such as language preference, country of origin, and length of stay which could impact utilization of screening services (Gany et al., 2006).

2.4. A Public Health approach to Oral Cancer

Prevention is the basis of public health practices. Generally, this is categorized into 4 different levels: primordial, primary, secondary, and tertiary prevention. These levels as depicted in Figure 1, provide a suitable context to understand prevention in the field of oral cancer. Traditionally, oral cancer prevention efforts have been treatment-oriented. Although, upstream approaches are gaining momentum, these often fail to account for the socio-cultural inequities
related to oral cancer which affect certain communities like SA communities more so than others. This capstone focuses on reviewing relevant data to enhance oral cancer prevention for South Asians in the area of primordial, primary, and secondary prevention. Literature related to risk factor behaviour and screening are a focal point in this analysis as this reduces the development of oral cancer and related mortality (Sankaranarayanan et al., 2005).

This capstone also utilizes a behavioural theory to understanding various factors that influence risk behaviours and screening for oral cancer. Theories form an essential part of health promotion and public health. These are a
blueprint to examining a health problem, program planning, and evaluation as they address the *what, why,* and *how* questions (National Cancer Institute [NCI], 2005). Theory also provides for a strong framework to identify and understand factors that influence behaviours in order to change them (NCI, 2005). Contemporary theories usually comprise of 3 constructs to health behaviour change: knowledge, attitudes or perceptions, and behaviour. The theoretical framework that emerged after conduction of the scoping review is elaborated in recommendations.

### 3. PURPOSE

The overall goal is to improve the understanding of knowledge, attitudes, and behaviours (KAB) related to oral cancer and associated risk factors among SA communities. The specific objectives are as follows:

- To develop an understanding of oral cancer risk behaviours and uptake of oral cancer screening in SA communities.
- To design a KAB questionnaire that captures information specific to oral cancer among SA communities in BC.

### 4. METHODS OF DATA COLLECTION

Scoping reviews, also known as scoping studies, are being utilized in health research as a popular method to characterize literature (Pham et al.,
They are used to map current literature on a particular topic of interest with various underlying purposes that can also include the value of undertaking a full systematic review (Arksey and O’Malley, 2005). Unlike systematic reviews, however, scoping reviews provide a more descriptive overview of literature (Pham et al., 2014). Scoping reviews also accept a variety of studies by not differentiating them based on methodological differences and study designs (Pham et al., 2014). Thus, a scoping review in this capstone was undertaken to examine the extent of current research, map key concepts, summarize findings, and identify research gaps in the area of oral cancer screening and risk behaviours for SA communities.

Overall, a scoping review is summarized to either be considered as part of an ongoing review process or as a separate method on its own (Arksey and O’Malley, 2005). This capstone focuses on the latter, where the scoping review was conducted with the intent of planning a survey; there is no population-based survey in BC at present to gather baseline oral cancer KAB data. Relevant studies were included in this scoping review. The methodology was based on the framework outlined by Arksey and O’Malley (2005) and recommendations made by Levac, Colquhoun, and O’Brien (2010). This review, therefore includes 5 stages: identifying the research question, identifying relevant studies, study selection, charting the data, and collating, summarizing, and reporting the results (Arksey & O’Malley, 2005).
The research question guiding this scoping review was, “what are the factors towards uptake of oral cancer screening services in the South Asian population?” An initial search yielded few articles specific to South Asians, hence the terminology was expanded to include ethnic minorities. Even so, studies on minority populations were not excluded from this scoping review as they contained rich data with relevance to KAB. The literature search was conducted from May 1st to August 7th 2015, thus articles published after this date were not considered in this review. Articles were retrieved from 5 electronic databases: Medline with full text via EBSCO, EMBASE via Ovid, ScienceDirect, CINAHL with full text, and PsycINFO. No limits on publication date were placed on the electronic database search engine and repetitive articles were excluded from the review process.

The search query initially consisted of 68 key terms which were later reduced to 25 relevant keywords. These keywords included: barrier*, factor*, acceptability, perception*, cultural belief*, attitude*, knowledge*, lack of knowledge, awareness, socioeconomic status, risk factor*, smok*, psychological, oral cancer, mouth neoplasm*, prevent*, screening*, program*, screening practice*, oral cancer screening*, south asia*, south asian population, south asian communit*, ethnic group*, minorit*. Search queries were modified for applicability to each electronic database and appropriate subject headings were selected (see Appendix A).
Eligibility criteria, both inclusion and exclusion, of articles was set to further guide the search strategy. Articles were eligible for inclusion if they broadly described the research question, specific to factors affecting oral cancer screening amongst SA or ethnic minority populations. Articles described below in points 5 and 6 of the exclusion criteria were excluded for not confining to the objectives of this capstone (see Table 1). While both seem to be relevant to prevention, neither would be conducive to the development of a KAB questionnaire for the SA population.

1. Articles published in languages other than English or without translation.
2. News articles, opinion articles, editorial reviews, and commentaries.
3. Articles without abstracts.
4. Articles on treatment or stage of diagnosis or survival without a focus on levels of prevention for oral cancer.
5. Articles assessing healthcare providers’ attitudes or knowledge towards screening of oral cancer including those that compare between perceptions of community leaders, healthcare providers, and participants on oral cancer.
6. Articles on analysis and evaluation of oral cancer education material.
7. Articles that just focus on epidemiology, HPV, and genes in oral cancer.

Table 1: Exclusion criteria of the scoping review
5. RESULTS

5.1. Study Selection

Overall, 1643 articles were identified in the search. After screening the titles and abstracts, 73 articles were retrieved for full text relevancy. After the inclusion of additional 24 articles through reference lists and other journals, the list amounted to 97. Then, 60 of the total 97 papers were excluded for not
conforming to the eligibility criteria. Finally, 37 papers were chosen for this scoping review.

Figure 2 outlines the article selection process. After searching in 5 databases, the titles and abstracts of the resultant articles were screened for identification of relevant terms. Duplicate articles were removed through Mendeley citation software. Based on the eligibility criteria, abstracts of the remaining articles were then assessed. The same criteria were used to identify papers in academic journals and grey literature, yielding additional publications that were also included. References in each of the selected articles were further screened for relevant papers. The final selected articles were then screened for full text relevancy. Study characteristics such as author(s), year of publication, aim, sample population, study design, and key findings were extracted and recorded in Microsoft Excel (see Appendix B).

The articles were broadly categorized into 3 emerging themes, namely knowledge, attitudes, and behaviour, which continually appeared in the review process. Figure 3 depicts the distribution of articles as per themes. As all 3 themes are constructs that influence behaviour change, many studies reflected similar pattern. Though this scoping review categorizes different aspects of articles into 3 themes, linkages between these when articulated in any article are also provided.
Knowledge includes awareness about oral cancer and the influence of socioeconomic status (SES). Attitude encompasses perceptions about oral cancer, its risk factors, and oral cancer screening. Behaviour compiles both the risk factors for oral cancer and dental visits. Risk factors relates to consumption and frequency of alcohol, cigarettes, and smokeless tobacco. Dental hygiene includes frequency of patient visits to a healthcare provider for routine services and opting to undergo an oral cancer examination. The KAB questionnaire that emerged from this synthesis is attached at the end of this report (see Appendix C).

Figure 3: Distribution of articles by themes identified in full review.
5.2. Study Characteristics

Variation in study design was observed across all studies, which included 18 quantitative (questionnaires), 9 qualitative (focus group discussions or interviews), and 3 mixed method studies (quantitative and qualitative components). The remaining 7 papers were reviews (systematic or literature reviews). Computer-assisted telephone interviewing (CATI) was used in 3 studies, leading to low response rates for all except one such study.

Research focusing solely on SA communities included 22 studies. About 12 of these studies focus on SA immigrants in other continents, while the remaining 10 were of SA origin. Most of the articles were from US, UK, and India. Half of the articles from US closely align progress with the Healthy People initiative. Some studies derived samples from national surveys of their respective countries, while other studies took samples from cohorts of larger studies.

From the 1990s, an increase in trend of papers relevant to oral cancer risk behaviours and screening in ethnic minorities is noticeable (see Figure 4). Articles increased from their initial number of 4 in the 1990s to 18 articles being published from 2010 onwards.
All studies with the exception of reviews, gathered data on the gender variable through two response options: male or female. No additional categories were listed in any of these studies. While these studies also provided details on gender differences within their target population, some studies provided no such details.

5.3. Knowledge

Majority of the studies measured knowledge about oral cancer within their study samples. This theme broadly encompasses awareness on oral cancer in terms of having heard the term, risk factors, sources of information, signs and symptoms, preventability, screening, and treatment. Numerous studies focused
on demographic variables, particularly those determining SES in relation to knowledge.

5.3.1. Awareness on Knowledge Parameters

Several studies attempted to establish a basic understanding and awareness of the term “oral cancer”. About 6 of these studies reported high number of participants who had heard the term “oral cancer” with the exception of 3 studies, which reported relatively lower awareness of the term. Considerably lower rates were observed for awareness on oral potentially malignant disorders in 3 studies, which measured awareness on precancerous oral lesions. Furthermore, some studies simplified the terminology to “mouth cancer” or “mouth and throat cancer” as participants could not understand the terms “oral and pharyngeal cancer” or “head and neck cancer”. Dodd, Riley, and Logan (2012) further simplified the terms, where “screening” was replaced with “exam”, “HPV” was replaced with “human papilloma virus” and “older age” was replaced with “over the age of 60” based on participant input on their questionnaire.

Many studies estimated awareness about risk factors for oral cancer amongst their target population. Some studies included reporting of a knowledge score based on a general list of risk factors, estimating misinformation about risk factors for oral cancer, and gathering the participants’ sources of information for their awareness on oral cancer. Smoking with tobacco was the most widely recognised habit associated with oral cancer in most studies, while alcohol was
less known. Overall 10 studies focused on awareness of smokeless tobacco as a risk factor for oral cancer: 6 studies reported higher awareness rates and 4 studies reported limited awareness of its effects in the oral cavity. Amarasinghe, Usgodaarachchi, Johnson, Laloo, and Warnakulasuriya (2010) specifically reported that 76% of the participants in their study lacked awareness on the effects of areca nut usage.

Knowledge about the signs of oral cancer generally appears to be varying across studies that assessed this parameter. In other studies, parameters for evaluation of knowledge were based on awareness about oral cancer being preventable, screening, and the availability of treatment. Few studies gathered data on whether the participants had a family history of cancer or knew someone with oral cancer.

About 8 studies completed analysis on gender and achieved differing results in terms of its association with knowledge. About half of these studies indicated that women were relatively more aware than men about oral cancer. The remaining studies reported no significant difference in awareness between males and females.

5.3.2. Influence of SES

SES was based on a number of variables such as age, education, race, income, health insurance, occupation, and sometimes immigration status, and area of residence. Some studies reported that adults less than 30 years of age
were more aware, while adults greater than 40 or 60 years of age were less aware about oral cancer. Level of education was proportional to overall awareness in 5 studies, while 2 studies reported no difference. In a few studies, awareness about oral cancer screening and the possibility of being already screened increased with higher education levels.

Few studies gathered health insurance status either as a general category such as “health insurance” or separated as “dental” or “medical” and sometimes further categorized as “private”. Other studies specifically aligned family income levels with relevance to national poverty rate of their country. Some studies have included area of residence in estimating SES by outlining the observed differences in urban vs rural areas. Significant differences with higher scores in all categories for urban than rural were found in 2 such studies.

Amongst the 12 studies that focused on SA immigrants with the exception of 5 studies that were reviews, only 5 of them gathered data on immigration variables from their participants. These variables were immigration status, country of birth, length of stay, and generation type. Johnson, McDonald, and Corsten (2012) reported race, income, immigration, and health insurance to be significantly correlated to oral cancer awareness and screening.

5.4. Attitudes

Attitudes as a theme was always reported in combination with either knowledge, behaviour or both. Some studies linked knowledge or attitudes to
acceptance of screening as a behaviour. Factors that influence screening include knowledge about oral cancer, fear of dentists, anxiety related to screening, preference for care provision, no recommendation from healthcare provider, convenience of clinic locations, transportation, and financial cost (Paudyal, Flohr, & Llewellyn, 2014; Dodd, Watson, Choi, Tomar & Logan, 2008; Howell, Sheperd & Logan, 2013; Shepperd, Howell & Logan, 2014). In terms of care provision, participants preferred having primary care physicians perform the oral cancer examination rather than dentists (Paudyal et al., 2014).

In terms of risk perception, greater feelings of susceptibility to oral cancer were expressed by half of the subjects in a study by Tan, Ng, and Esa (2001). Dodd et al. (2008), however, found more females feeling at risk in their study, while Hay et al. (2002) found more males feeling susceptible to oral cancer. Hay et al. (2002) also reported that Asians felt less at risk of developing oral cancer when compared to other racial groups. In the same study, current smokers perceived themselves to be at a higher risk while alcohol use was unrelated to oral cancer risk perception (Hay et al., 2002).

### 5.5. Behaviour

This theme comprises of studies that gathered data on risk factors for oral cancer in terms of initiation, frequency, prevalence, and history of usage, while also estimating the uptake of screening services and regular dental visits. Few
Some studies estimated age of initiation for betel quid chewing which was reported to be at 13-17 years.

Some studies explored the process of initiation of habits that are known risk factors for oral cancer. The reasons for initiation of chewing smokeless tobacco in these studies were due to social acceptability and company, observing elders, family tradition, wedding rituals, religious ceremonies, perceived health benefits, easy accessibility, addiction, stress, boredom, to relax, low cost, marketing, and lack of prohibitive legislation. Chewing betel quid was linked to culture with some studies noting that this habit provided a mechanism for South Asians to continue and maintain cultural traditions and practices. Messina et al. (2013) noted this to be of particular importance for older people of the SA community in England. Other studies indicated that limited awareness and misconceptions such as calcium being a perceived benefit of chewing smokeless tobacco might also be influential on continuation of this habit. Banerjee et al. (2014) noted that women were interested in betel quid because of the red colour that was observed on lips after chewing betel quid.

Some studies noted differences in prevalence of tobacco and alcohol use among religious subgroups in the SA community. Vora et al. (2000) considered the religious subgroups such as Hindus, Sikhs, Muslims, and Jains within SA communities, where significant differences were found in males from these subgroups with regards to habits and oral cancer awareness. About 10% of both 1st and 2nd generation Hindu males combined all three risk habits of alcohol,
tobacco, and paan consumption (Vora et al., 2000). Auluck, Hislop, Poh, Zhang, and Rosin (2009) further suggest that the risk of interaction in chewing betel quid, alcohol, and tobacco consumption may very well be underestimated in SA communities.

Risk factor prevalence in some studies also varied with respect to gender. Messina et al. (2013) cited that chewing smokeless tobacco was more appropriate for females within SA communities. This is supportive of findings in some studies of this scoping review where more females than males added tobacco to their quid even though men were more likely to smoke tobacco.

Studies that focused on screening reported lower number of participants having had an oral cancer examination. Calhoun, Kolker, McGowan, Sohn, and Ismail (2009) reported 70% of participants being uncertain of whether they ever received an oral cancer examination. Oh, Kumar, and Cruz (2008) also observed that even though 80.4% of adults had heard about oral cancer, about 74.3% had never heard about an oral cancer examination. Of those studies that recorded sources of examination, most respondents reported having received their examination from dentists.

6. DISCUSSION

This scoping review has considered the available evidence on KAB related to oral cancer within SA communities. In general, studies included in this
review differ not only in their context but also in terms of the factors considered in their study designs. Most studies gathered KAB data from their study samples with knowledge being a common theme. This indicates that any attempts for future program and policies must first gather baseline awareness on oral cancer from SA communities in BC. This would be useful in development of awareness material as it relates to primary prevention. Furthermore, usage of simpler terms such as “mouth cancer” for “oral and pharyngeal cancer” in data collection tools would be of particular importance.

Generally, smoking with tobacco was identified as the most recognized risk habit for developing oral cancer, while alcohol largely remains a lesser known risk factor. Several studies reported limited understanding of health risks on chewing smokeless tobacco within the SA population, though fewer studies attempted to measure awareness on areca nut alone. Further research in risk factor awareness should consider incorporation of not just conventional risk factors for oral cancer, but also those that are culturally relevant for South Asians. This would in turn provide a stronger basis for primordial prevention in placing health warnings on cultural tobacco products.

SES is a challenge and its relationship with oral cancer is well documented. While all papers apart from reviews gathered data on SES variables, education was the most frequently reported upon. Though each study utilized different variables such as age, education, income, occupation, health insurance, and ethnicity, gathering data by immigration variables is of relevance.
to prevention strategies for SA communities. This is because chewing tobacco products in the SA community is linked to culture.

Several studies have noted the social acceptability of chewing betel quid within SA communities at weddings, company of friends, and religious ceremonies. Retaining the habit of chewing betel quid is reported in SA migrant studies where participants viewed this habit as a mechanism to continue cultural traditions. Thereby, culture plays an essential part in initiation, continuation, and even cessation of betel quid practices. Future research and prevention strategies should comprehensively identify and include this cultural context in their focus to facilitate behaviour change. In this regard, relaying information particular to oral cancer in a culturally sensitive and appropriate manner becomes crucial.

Prevalence of risk habits also varies according to religious and ethnic subgroup identity (Ahluwalia, 2005). Mukherjea and Modayil (2005) noted that Hindus and Muslims were more than 6 times as likely as Sikhs to currently use smokeless tobacco. This is consistent with findings of several studies where Hindus had a higher incidence of oral cancer than Muslims while Christians had the lowest incidence (Ahluwalia, 2005). Given the influence of religion, some studies also advocate for the involvement of religious leaders in discussions to facilitate uptake of oral cancer screening for secondary prevention.

Studies that attempted to analyze risk habits with awareness often ended with differing results. The perceived gap here could be due to lack of data on the
influence of religious and ethnic subgroups. Gathering data by immigrant variables is likely to be key as variations in terms religion and ethnicity could be impacting behaviour and attitudes towards screening in the SA population.

In studies that focused on barriers or facilitators to screening, influential factors were noted to be knowledge, fear, anxiety, cost, preference in care provision, and recommendation from healthcare provider. Although knowledge has extensively been emphasized upon, other factors such as psychosocial factors and issues in provider trust must be further explored.

7. RECOMMENDATIONS

Given the findings of this capstone, interventions in oral cancer prevention must account for the social, cultural, and environmental factors that influence South Asians. This perspective is best emphasized upon in the Social Ecological Model (SEM) which considers the interaction and interdependence within all levels—individual, community, institution, and society. The SEM has two underpinning concepts, multiple levels of influence and reciprocal causation, which help in determining interventions (NCI, 2005). Various factors can be organized in accordance to their levels of influence as intrapersonal factors such as individual characteristics and KAB; interpersonal factors such as family, friends, and support systems; institutional factors such as settings, rules, and regulations; community factors such as social norms and standards; and public policy such as local, state, and federal laws (NCI, 2005).
The factors that influence South Asians in terms of risk factor behaviour and screening for oral cancer can best be described using the SEM. Table 2 represents the adapted model, wherein the roles of multiple factors can be understood. This framework is meant as a guide to not just identifying and linking factors within multiple levels but also to visualize intervention points and enhance prevention efforts. The SEM has the advantage of providing the social and environmental context as opposed to other models where the individual appears to exist external to their context. Even though constructs within other models are evolving, none has been updated to fully account for the factors present in the SEM. As context is integral to health behaviour, interventions that adopt a holistic view rather than an individualistic lens in this regard are bound to be more successful.
### CONCEPT

#### Intrapersonal level
- **Demographics:**
  - SES: age, level of education, income, health insurance status
  - Immigration variables: immigration status, country of birth, length of stay, and generation type
  - Other: ethnicity, religion
- **Knowledge:** oral cancer, its signs and symptoms, risk factors, and screening
- **Attitudes:** risk perception, oral cancer screening (fear, anxiety, and healthcare provider preference), perceived benefits of betel quid
- **Behaviour:** history of betel quid chewing, smoking, and alcohol consumption

#### Interpersonal level
- Social acceptability of chewing betel quid
- Social norms
- Maintenance of traditional habits

#### Community level

<table>
<thead>
<tr>
<th>Institutional factors</th>
<th>Community factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Availability of tobacco and alcohol</td>
<td>Social gatherings: weddings, religious ceremonies</td>
</tr>
<tr>
<td>Low cost betel quid outlets</td>
<td>Tobacco control coalition</td>
</tr>
<tr>
<td>Health insurance plans (public/private)</td>
<td>Risk behaviour prevalence differs by religion</td>
</tr>
<tr>
<td>Promotional marketing on tobacco and alcohol</td>
<td>Conventional screening locations</td>
</tr>
<tr>
<td>Convenient screening locations</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Public Policy</th>
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</thead>
<tbody>
<tr>
<td>Financial cost of screening</td>
</tr>
<tr>
<td>Recommendation from healthcare provider</td>
</tr>
<tr>
<td>Legislation on tobacco and alcohol</td>
</tr>
<tr>
<td>Health warnings on cultural tobacco products</td>
</tr>
</tbody>
</table>

**Table 2:** SEM for oral cancer prevention
8. LIMITATIONS

Scoping reviews in general do not assess quality of included studies in terms of their methodology. A clear eligibility criterion, search strategy, and summary is provided in an attempt to enable reproducibility and overcome this issue. Also, this capstone makes recommendations based on the present scoping review. However, qualitative assessments within SA communities are needed to build on a contextual understanding of oral cancer in BC.

9. CONCLUSION

This capstone utilizes a systematic protocol to map current literature for KAB related to oral cancer among SA communities. The findings of the scoping review were organized into 3 broad themes, knowledge, attitudes, and behaviours, which were used to develop a KAB questionnaire for SA communities in BC. The significance of these findings in terms of primordial, primary, and secondary prevention is discussed with particular emphasis given to cultural context. In view of this, a conceptual framework based on the SEM was developed. Factors influencing oral cancer risk behaviours and screening in SA communities were aligned to multiple levels within SEM. This visual depiction highlights the importance of identifying and understanding the linkages of factors within a cultural context for SA communities. Thus, the factors explored in this capstone can facilitate in the development of better tools and also identify suitable intervention areas in oral cancer prevention.
REFERENCES


35


Appendix A. List of search string combinations

<table>
<thead>
<tr>
<th>DATABASE</th>
<th>SEARCH STRING COMBINATIONS</th>
</tr>
</thead>
</table>
| **Medline with Full Text via EBSCO** | (MH "Mouth Neoplasms+/EP/EH/ET/HI/PC") OR (MH "Head and Neck Neoplasms+/EP/EH/ET/PC") OR (MH "Early Detection of Cancer/TD") AND factor* AND "oral cancer" OR "mouth neoplasm" AND prevent* AND "south asia" AND "ethnic group"
 |                                                                                | (MH "Mouth Neoplasms+") OR (MH "Head and Neck Neoplasms+") OR (MH "Early Detection of Cancer") AND "cultural belief" OR perception* AND "oral cancer" AND screening*
 |                                                                                | (MH "Mouth Neoplasms+") OR (MH "Head and Neck Neoplasms+") OR (MH "Early Detection of Cancer") AND "oral cancer screening practice" AND "south asia" OR "south asian community"
 |                                                                                | (MH "Mouth Neoplasms+") OR (MH "Head and Neck Neoplasms+") OR (MH "Early Detection of Cancer") AND "socioeconomic status" AND "oral cancer" AND prevent AND program AND minorit* OR "south asian population"
 |                                                                                | (MH "Mouth Neoplasms+") OR (MH "Head and Neck Neoplasms+") OR (MH "Early Detection of Cancer") AND acceptability AND "oral cancer screening"
 | **PsycINFO**                    | DE "Oral Health" OR DE "Dental Health" AND psychological AND "oral cancer screening"
 | **ScienceDirect**               | TITLE-ABSTR-KEY(barrier*) and TITLE-ABSTR-KEY("oral cancer screening")
 | **CINHAL with full text**       | (MH "Mouth Neoplasms+") OR (MH "Early Detection of Cancer") OR (MH "Head and Neck Neoplasms+") AND "lack of knowledge" AND "risk factor" OR smok* AND "oral cancer" AND prevent AND program AND "south asian population"
 | **EMBASE via Ovid**             | ((awareness or "risk factor") and "oral cancer screening").af. |
Appendix B: Summary of articles included in full review

<table>
<thead>
<tr>
<th>AUTHOR, YEAR</th>
<th>METHOD, POPULATION &amp; LOCATION</th>
<th>OBJECTIVES</th>
<th>KEY FINDINGS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agrawal, Pandey, Jain &amp; Maitin, 2012</td>
<td>Cross-sectional survey (quantitative)</td>
<td>To assess awareness of oral cancer, its early signs and risk factors</td>
<td>General awareness on oral cancer, its signs and risk factors were proportional to the level of education. Individuals who were &lt; 30 years of age were also more aware. Urban population scored higher than rural in general awareness, though no difference was seen for signs or risk factors. Age, education, sex, and place of residence were predictors of awareness on oral cancer, signs and symptoms.</td>
</tr>
<tr>
<td>Auluck, Hislop, Poh Zhang &amp; Rosin, 2009</td>
<td>Literature review South Asian immigrants in western countries</td>
<td>To provide an outline of beliefs, knowledge, and practices regarding betel quid To outline implications for oral cancer screening</td>
<td>Risk of combining the habits of chewing betel quid, tobacco and alcohol consumption may be underestimated in South Asian communities. Reasons for chewing areca nut are social acceptability, religious beliefs, health benefits, and addiction. There is also lack of awareness of areca nut as an independent risk factor for oral cancer. Age of initiation is usually between 13-15 years. Betel quid is now being swallowed instead of being spitted out. Low cost betel quid substitutes are being advertised. Majority of South Asian immigrants are staying in rural areas of Vancouver.</td>
</tr>
<tr>
<td>Calhoun, Kolker, McGowan, Sohn &amp; Ismail, 2009</td>
<td>Mixed (questionnaire &amp; focus group discussions) African-Americans in US</td>
<td>To assess TFM coalition members' knowledge of oral cancer To determine their awareness towards the role of healthcare providers in tobacco cessation</td>
<td>Low awareness on oral cancer mortality and screening in the community. High risk factor awareness was noticed, although alcohol as a risk factor was less known. Participants were supportive of healthcare providers to conduct oral cancer examination. However, 70% of participants were not sure of having received an oral cancer examination.</td>
</tr>
<tr>
<td>Horowitz, Moon, Goodman &amp; Yellowitz, 1998</td>
<td>Cross-sectional survey (CATI) Mixed population of</td>
<td>To determine knowledge of risk factors, signs and symptoms of oral cancer</td>
<td>About 85% had heard about oral cancer but just 21% had heard of oral cancer. Awareness on signs was low. Females were more aware than males on risk factor awareness. Misinformation on risk factors for oral cancer</td>
</tr>
<tr>
<td>Study</td>
<td>Population/Methodology</td>
<td>Research Question</td>
<td>Findings</td>
</tr>
<tr>
<td>-------------------------------</td>
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</tr>
<tr>
<td>Johnson, McDonald &amp; Corsten, 2012</td>
<td>Cross-sectional survey (quantitative) Mixed population of US</td>
<td>To determine the correlation of SES with awareness of oral cancer screening. To determine the correlation SES with likelihood of having had an oral cancer exam.</td>
<td>SES influences awareness of oral cancer and uptake of screening. Level of education is associated with less likelihood of having had oral cancer screening. Immigrants are less likely to be aware about screening than non-immigrants. Race and ethnicity are predictors of oral cancer exam. Minorities are less likely to have undergone oral cancer screening.</td>
</tr>
<tr>
<td>Klassen, Juon, Alberg, Reid &amp; Meissner, 2003</td>
<td>Cross-sectional survey (qualitative) African-American women in US</td>
<td>To examine the relationship between psychosocial factors, smoking history, and dental use.</td>
<td>Compared dental use with other health provider services. In this case dental use is suggestive of having access to screening. Lack of recent dental care among current and former smokers. Of these those who were older were less likely to have had dental care. Health insurance is predictive of dental use. Advocates for integrated screening programs with other cancers for at-risk women.</td>
</tr>
<tr>
<td>Paudyal, Flohr &amp; Llewellyn, 2014</td>
<td>Systematic review Studies with ethnic minorities</td>
<td>To determine the acceptability of oral cancer screening outside of dental care settings.</td>
<td>Influencing factors for acceptance of screening were: knowledge, anxiety, preference for care provision, and financial cost. Acceptance of screening is high in those patients who receive oral cancer education. Recommends Mouth Self Examination (MSE) as a screening method, however results of success vary across studies.</td>
</tr>
<tr>
<td>Ahluwalia, 2005</td>
<td>Literature review South Asian immigrants in US</td>
<td>To present an overview of risk factors for oral cancer among South Asian immigrants. To describe a pilot study that assesses oral cancer risk behaviours in South Asian seniors.</td>
<td>Risk factor prevalence varies by religion and ethnicity. Areca products are of significance for Hindus. Hindus also have a higher incidence rate for oral cancer than Muslims or Christians. First generation immigrants are more likely to continue cultural habits.</td>
</tr>
<tr>
<td>Study Authors</td>
<td>Study Design</td>
<td>Study Details</td>
<td>Findings</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
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<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Amarasinghe, Usgadoarachchi, Johnson, Laloo &amp; Warnakulasuriya, 2010</td>
<td>Cross-sectional survey (qualitative)</td>
<td>Sri Lankans in Sri Lanka</td>
<td>To assess the awareness of oral cancer, oral potentially malignant disorders (OPMD), and risk factors. Awareness of oral cancer was high, whereas OPMD was low. Awareness on symptoms was low for both oral cancer and OPMD. Awareness differed with ethnicity, SES, and place of residence. More participants were aware about tobacco and alcohol as risk factors than betel quid. Awareness was even lower for areca nut. Majority of smokers and alcohol consumers were unaware of their habits being risk factors. Betel quid chewers were aware, indicating that factors other knowledge were reinforcing the habit. Those with a family history of cancer were more aware about oral cancer but not about OPMD. Recommend a common risk factor approach to oral cancer prevention.</td>
</tr>
<tr>
<td>Ariyawardana &amp; Vithanaarachchi, 2005</td>
<td>Cross-sectional survey (quantitative)</td>
<td>Sri Lankans in Sri Lanka</td>
<td>To assess awareness about oral cancer and precancer among patients in a dental hospital. High awareness on oral cancer and betel quid as a risk factor was noted. Knowledge on tobacco and alcohol as risk factors was poor.</td>
</tr>
<tr>
<td>Banerjee et al., 2014</td>
<td>Mixed (focus group discussion &amp; survey)</td>
<td>South Asian immigrants in US</td>
<td>To examine smokeless tobacco initiation and use patterns. To examine perceptions related to tobacco control and cessation. Initiation factors were ease of availability of betel quid, social networks, perceived benefits, and curiosity. Age of initiation was between 14-17 years. Betel quid is being swallowed and not spitted out. Efforts in tobacco control must take into account the cultural beliefs and norms.</td>
</tr>
<tr>
<td>Changrani, Gany, Cruz, Kerr &amp; Katz, 2006</td>
<td>Cross-sectional survey (quantitative)</td>
<td>South Asian immigrants in US</td>
<td>To explore migration of smokeless tobacco habits and use. Prevalence of paan was 45% in Indian-Gujaratis and 70% in Bangladeshis. However, Indian-Gujaratis identify gutka as a risk factor, whereas Bangladeshis identify paan as a risk factor for oral cancer.</td>
</tr>
<tr>
<td>Dodd, Watson, Choi, Tomar &amp; Logan, 2008</td>
<td>Focus group discussion (qualitative)</td>
<td></td>
<td>To explore factors underlying perceptions of oral cancer and oral. Limited knowledge was reported for risk factors of oral cancer. This also contributed to low perceived severity of the disease.</td>
</tr>
<tr>
<td>Study</td>
<td>Population</td>
<td>Study Design</td>
<td>Methodology</td>
</tr>
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</tr>
<tr>
<td>African-Americans in US</td>
<td>cancer exam</td>
<td>Factors influencing screening were knowledge about oral cancer, belief that oral cancer is rare, fear of dentists, anxiety related to screening, preference for care provision, and financial cost. Younger females stated that they would prioritize work over screening even if screening was offered at their work site. Participants also expressed that motivational messages to be screened should come from people who had survived oral cancer and were speaking from experience.</td>
<td></td>
</tr>
<tr>
<td>Elango et al., 2009</td>
<td>Cross sectional survey (qualitative)</td>
<td>To evaluate awareness on oral cancer and its risk factors To estimate the prevalence of risk factors in a high-risk semi-urban population</td>
<td>Knowledge regarding oral cancer, etiology, and risk factors was high. About 53% perceived oral cancer to be incurable. Awareness was proportional to level of education. Smoking was the most recognized risk factor than alcohol. Majority of tobacco smokers and chewers were aware about their risk factors leading to oral cancer, while alcohol consumers were less aware.</td>
</tr>
<tr>
<td>Ghani, Doss, Jamaluddin, Kamaruzaman &amp; Zain, 2013</td>
<td>Cross-sectional survey (quantitative)</td>
<td>To assess oral cancer awareness, risk factors, and sources of information</td>
<td>Most participants recognized smoking as a risk factor for oral cancer. Variables of association to awareness include age, gender, ethnicity, marital status, education, occupation and income.</td>
</tr>
<tr>
<td>Hay et al., 2002</td>
<td>Cross-sectional survey (quantitative)</td>
<td>To assess oral cancer risk perception and risk behaviours in a free oral cancer screening</td>
<td>Current smokers felt more at risk than non-smokers, while alcohol use was unrelated. Men felt more at risk than women. Asians also felt less at risk for developing oral cancer.</td>
</tr>
<tr>
<td>Howell, Shepperd &amp; Logan, 2013</td>
<td>Focus group discussion (qualitative)</td>
<td>To explore barriers to oral cancer screening using Theory of Planned Behaviour (TPB)</td>
<td>Community participation where religious leaders were involved in discussions to list barriers. 23 barriers identified with 40 subcategories. Lack of knowledge was the most common barrier. Followed by lack of resources (money, health insurance) and fear (screening, diagnosis).</td>
</tr>
<tr>
<td>Kakde, Bhopal, Jones, 2012</td>
<td>Systematic review</td>
<td>To explore social context on smokeless</td>
<td>Smokeless tobacco use was culturally acceptable. Reasons for this were socializing</td>
</tr>
<tr>
<td>Study</td>
<td>Study Type</td>
<td>Population</td>
<td>Research Question</td>
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<tr>
<td>Khan et al., 2000</td>
<td>Cross-sectional survey (quantitative)</td>
<td>Mixed ethnic groups in UK</td>
<td>To examine the determinants of health behaviour of ethnic groups for alcohol and tobacco</td>
</tr>
<tr>
<td>Mukherjea &amp; Modiayil, 2013</td>
<td>Systematic review</td>
<td>South Asians in US</td>
<td>To assess tobacco use patterns and existing strategies</td>
</tr>
<tr>
<td>Mukherjea Morgan, Snowden, Ling &amp; Ivey, 2012</td>
<td>Focus groups</td>
<td>South Asians in US</td>
<td>To understand the cultural context of tobacco use</td>
</tr>
<tr>
<td>Pearson, Croucher, Marcenes &amp; O'Farrell, 1999</td>
<td>Cross-sectional survey (qualitative)</td>
<td>Bangladeshis in UK</td>
<td>To assess the use of dental services, barriers and attitudes to dental exams, and prevalence of tobacco and paan</td>
</tr>
<tr>
<td>Shepperd, Howell &amp; Logan, 2014</td>
<td>Cross-sectional survey (qualitative)</td>
<td>African-Americans in US</td>
<td>To examine barriers to oral cancer screening</td>
</tr>
<tr>
<td>Shodan et al., 2012</td>
<td>Cross-sectional survey (quantitative)</td>
<td>Indians in India</td>
<td>To assess oral cancer knowledge among Indian school teachers</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Study Type</td>
<td>Study Population</td>
</tr>
<tr>
<td>------------------------</td>
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</tr>
<tr>
<td>Sturgis, 2004</td>
<td></td>
<td>Literature review</td>
<td>Indians in India</td>
</tr>
<tr>
<td>Tan, Ng &amp; Esa, 2010</td>
<td></td>
<td>Cross-sectional survey (quantitative)</td>
<td>Indians in Malaysia</td>
</tr>
<tr>
<td>Dodd, Riley &amp; Logan, 2012</td>
<td></td>
<td>Mixed (focus groups &amp; CATI)</td>
<td>African-Americans in US</td>
</tr>
<tr>
<td>Tomar &amp; Logan, 2005</td>
<td></td>
<td>Cross-sectional survey (CATI)</td>
<td>Mixed population in US</td>
</tr>
<tr>
<td>Yellowitz, Goodman, Farooq, 1997</td>
<td></td>
<td>Cross-sectional survey (quantitative)</td>
<td>Mixed elderly racial groups in US</td>
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<tr>
<td>Vora, Yeoman &amp; Hayter, 2000</td>
<td></td>
<td>Cross-sectional survey (quantitative)</td>
<td>South Asians males in UK</td>
</tr>
<tr>
<td><strong>Tripathi et al., 2014</strong></td>
<td>Cross-sectional survey (quantitative)</td>
<td>Indian women in India</td>
<td>To assess problems associated with early detection of cancers in rural women</td>
</tr>
<tr>
<td><strong>Oh, Kumar &amp; Cruz (2008)</strong></td>
<td>Cross-sectional survey (quantitative)</td>
<td>Mixed Population in US</td>
<td>To assess oral cancer awareness and examination</td>
</tr>
<tr>
<td><strong>Devadiga &amp; Prasad, 2010</strong></td>
<td>Cross-sectional survey (quantitative)</td>
<td>Indians in India</td>
<td>To assess the associated knowledge in adults attending a dental hospital</td>
</tr>
<tr>
<td><strong>Shah, Qureshi &amp; Azam, 2008</strong></td>
<td>Cross-sectional survey (quantitative)</td>
<td>Pakistani children in Pakistan</td>
<td>To determine the practices and knowledge about chhalia and paan masala among school children</td>
</tr>
<tr>
<td><strong>Ahmed, Rahman &amp; Hull, 1997</strong></td>
<td>Cross-sectional survey (quantitative)</td>
<td>Bangladeshis in UK</td>
<td>To investigate the prevalence of betel quid chewing, smoking, and knowledge associated health hazards</td>
</tr>
<tr>
<td><strong>Raute et al., 2011</strong></td>
<td>Cross-sectional survey (qualitative)</td>
<td>Indians in India</td>
<td>To use ITC India Pilot Study data in examining beliefs about smokeless tobacco use, knowledge of health effects, and intentions to quit among current smokeless tobacco users. Knowledge about smokeless tobacco as a risk factor was high. Notable differences were seen in urban vs rural smokeless tobacco users. Intentions to quit usage were low.</td>
</tr>
<tr>
<td>users</td>
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<tr>
<td>Messina et al., 2013</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systematic review</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>South Asians in UK</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To explore the factors associated with smokeless tobacco use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prevalence of use is more in older individuals who began chewing betel quid in India. Reasons for initiation were stress, boredom or to relax. Misconceptions about health beliefs can also initiate betel quid usage.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More culturally acceptable for women to chew betel quid. There is also a strong desire to maintain culture through this habit.</td>
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</tbody>
</table>
Appendix C: Oral Cancer KAB questionnaire

Demographic section

1. Which age group do you belong to?
   - □ 18-39 years
   - □ 40-49 years
   - □ 50-59 years
   - □ 60 years and over

2. What is your gender?
   - □ Male
   - □ Female

3. What is the highest level of education that you have completed? (Select one)
   - □ No schooling
   - □ High school graduate
   - □ Bachelor’s degree
   - □ Master’s degree
   - □ Other (Please specify): ________________

4. Which is your current work status? (Select one)
   - □ Student but not employed
☐ Homemaker

☐ Employed

☐ Self-employed

☐ Retired

5. Please indicate your total household income $__________________

6. What type of insurance do you have? (Check all that apply)

☐ No insurance

☐ Insurance that covers dental expenses

☐ Insurance that does not cover dental expenses

☐ Separate dental insurance

7. What is your current marital status? (Select one)

☐ Never married

☐ Married or living common law

☐ Separated

☐ Divorced

☐ Widowed

8. Which South Asian ethnic group do you self-identify with? (Select one)
☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Sri Lankan

☐ Other (Please specify): ________________

9. Please specify your religion, even if not practising ________________

10. What language are you most fluent with? (Select one)

☐ English

☐ Hindi

☐ Urdu

☐ Punjabi

☐ Other (Please specify): ________

11. What is your country of birth? _____________

12. If your country of birth is not Canada, please select your visa status below.

☐ Not Canadian, but living in Canada since ________ months/ years

☐ Landed immigrant, but living in Canada since __________ years
KAB section

13. Have you heard about “mouth cancer” or “cancer of the mouth and throat” before?

☐ No

☐ Yes

If yes, please select your sources. (Check all that apply)

☐ Radio

☐ Television

☐ Social media/ Internet

☐ Family member/ Relative

☐ Friend/ Colleague

☐ Other

14. Which of the following causes cancer? (Check all that apply)

☐ Smoking too many cigarettes

☐ Chewing tobacco in paan (betel quid) or gutka

☐ Drinking too much alcohol

☐ Drinking too much coffee
☐ Eating too much spicy food

☐ Don't know

15. Which is an early sign of mouth cancer? (Check all that apply)

☐ Bleeding in the mouth

☐ Burning sensation in the mouth with difficulty in mouth opening

☐ Ulcer in the mouth

☐ Ulcer or sore in the mouth that is not healing

☐ Red patches in the mouth

☐ White patches in the mouth

☐ Don't know

16. Have you ever been screened for mouth cancer, where your doctor or dentist examined your mouth by pulling on your tongue, sometimes with gauze wrapped around it?

☐ No

☐ Yes

If yes, who recommended you to be screened/ examined? (Check all that apply)

☐ Family member/ Relative

☐ Friend/ Colleague
☐ Religious figure

☐ Doctor

☐ Dentist

☐ Other

If no, what would influence your decision to be screened/ examined? (Check all that apply)

☐ Free oral cancer screening

☐ Mobile dental clinic service in my area

☐ A recommendation from a family member/ Relative

☐ A recommendation from a friend/ colleague

☐ A recommendation from a religious figure

☐ A recommendation from my doctor

☐ A recommendation from my dentist

☐ Availability of information leaflets or education material online

☐ Awareness campaigns on radio or TV

17. When did you last visit a dentist in Canada?

☐ Not at all
☐ More than a year ago

☐ Less than a year ago

If 'Not at all' or 'More than a year ago', what are the reasons for not visiting? (Check all that apply)

☐ I eat healthy food and do not feel the need to visit a dentist

☐ I have no insurance or my insurance does not cover dental expenses

☐ I did not have the time to visit a dentist

☐ The clinic location is too far from my home

☐ I prefer to visit a dentist in my home country as I trust them

☐ I prefer to visit a dentist in my home country as it is cheaper

☐ I visited a dentist out of Canada as I was on vacation travel

☐ I visited a dentist out of Canada as it was cheaper

18. What is your present tobacco smoking status? (Select one)

☐ Not a tobacco smoker

☐ Current tobacco smoker

☐ Current daily tobacco smoker

☐ Former tobacco smoker
19. Do you chew paan (betel quid) or gutka?

☐ No

☐ Yes

20. Have you ever consumed more than 2 alcoholic drinks (liquor) in a week?

☐ No

☐ Yes

21. To what extent does the following influence your decision to NOT smoke, drink, chew paan (betel quid) or gutka?

<table>
<thead>
<tr>
<th>Influence Factor</th>
<th>No influence</th>
<th>Weak influence</th>
<th>Moderate influence</th>
<th>Strong influence</th>
<th>Very strong influence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your cultural beliefs</td>
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<tr>
<td>Your social circle</td>
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<tr>
<td>Your religion</td>
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<tr>
<td>Your health</td>
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<tr>
<td>Your family</td>
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<tr>
<td>Knowing someone with any of the above habits who got cancer</td>
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</tbody>
</table>