Community Dental Health (2016) **33,** 60–64
Received 29 June 2015; Accepted 21 September 2015

doi:10.1922/CDH_3700Merchant05

Oral cancer awareness in young South-Asian communities in London

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Objectives: First, to evaluate awareness of oral cancer amongst the young South-Asian community in London and identify any aspects of knowledge about oral cancer that are lacking; and, second, to determine whether demographic factors or health-related behaviours are associated with knowledge of oral cancer. ***Research design:*** Cross-sectional questionnaire survey. ***Participants:*** South Asians aged 18-44 years attending community centres or places of worship in London. ***Main outcome measures:*** Oral cancer awareness; health-related behaviours. ***Results:*** Respondents (n=201) were mainly male (61%), Indian (77%) and Hindu (35%). Over half (58%; n=113) had one or more negative health-related behaviours and only 18% had attended a dentist in the previous two years. Chewing paan with betel nut (OR=4.08, 95%CI=1.58-10.59, p<0.01), and time since last visit to a dentist (OR=4.90, 95%CI=2.13-11.28, p<0.01) were independently associated with respondents level of knowledge of mouth cancer; the former positively and the latter negatively. ***Conclusions:*** The results suggest that young adults in the South Asian Community are exposed to a number of risk factors for oral cancer yet have poor knowledge of the implications of these health-related behaviours, and ways in which oral cancer can be detected earlier. The survey highlighted specific issues for action.

Key words: *oral cancer, knowledge, awareness, ethnic minorities, early diagnosis, UK*

Introduction

The early detection of oral cancer is of critical importance in improving survival rates (NICE, 2004; Pugliano *et al*., 1999). Yet up to half of oral malignancies are not diagnosed until late stages of disease. The problem of late detection is multi-factorial and centres around three interconnected issues. First, low awareness of oral cancer (O'Connor *et al*., 2010; Warnakulasuriya *et al*., 1999; West *et al*., 2006); second, delay in consulting a healthcare professional following self-detection of symptoms of oral cancer; and third, targeting and reaching high-risk groups (Scott *et al*., 2011). One high-risk group is the South Asian community which in the UK, comprises immigrant populations from countries such as India, Pakistan, Bangladesh and Sri Lanka. These are growing communities in London and the local rise of oral cancer is attributed to the ethnic minority profile of Londoners as they have lifestyle habits that may lead to serious health conditions such as oral cancer (OCIU, 2011). For instance, use of smoked or chewed tobacco is widely prevalent, especially among the young (Sinha *et al*., 2011; 2012; Sreeramareddy *et al*., 2014; Wardle, 2006). Other risk factors for oral cancer include alcohol consumption, chewing betel quid (areca nut) with or without added tobacco, and gutkha: habits that are prevalent in the South Asian population (IARC, 2004; Warnakulasuriya, 2002; 2009). There is also indication that the risk profile of different ethnic groups may be changing. In a study conducted in Leicester, Vora *et al*. (2000) reported that whilst consumption of alcohol amongst the Islamic and Jain faiths was very low in first generation groups and second generation Muslims, rose amongst second generation Jains.

A study by Shetty and Johnson (1999) on knowledge, attitudes, beliefs of adult South Asians living in London regarding risk factors and signs for oral cancer suggests that there is extensive misinformation and general lack of awareness about the risk factors, and signs, of oral cancer. However there has been very little research since this study and it is unclear as to whether the lack of awareness about oral cancer within this community remains, especially in the younger generations.

More general ethnic minority research has studied awareness of cancer symptoms and anticipated help seeking in England and found those from ethnic minorities anticipated longer delays than the general population (Waller *et al.,* 2009). This suggests that there is need for culturally sensitive, community-based interventions to raise awareness and encourage early presentation for oral cancer. The development of an effective intervention to encourage early presentation and detection of oral cancer requires understanding of the target group. The objectives of the current research were first to evaluate awareness of oral cancer amongst the young London South-Asians and identify any aspects of knowledge about oral cancer that are lacking; and, second, to determine whether demographic factors or health-related behaviours are associated with knowledge of oral cancer.

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Methods

Data were collected via a questionnaire with participants recruited from three community centres and places of worship across London with a high concentration of the South Asian residents (Upton Park, Wembley and Southall). Ethical approval was obtained from King's College London Ethics Committee (Ref. number 'BDM/11/12-61).

Inclusion criteria were: being of South Asian origin (e.g. Indian, Pakistani, Bangladeshi, Sri Lankan and Malaysian-Indian); aged 18-44 years; and, with sufficient grasp of English to complete the questionnaire. Participants were approached individually. The purpose of the research was explained verbally, then an information sheet with a copy of the questionnaire was provided to those interested in taking part. Participants could complete the questionnaire immediately, when they were approached, and return it directly to the researcher, or they could post it later to the researcher in a free-post envelope. Submission of a completed questionnaire implied consent to participate.

The questionnaire measured health-related behaviours: use of tobacco, gutkha, paan with betel nut and alcohol (current or previous); knowledge and beliefs about oral cancer; attendance pattern at a doctor or dentist; and demographic details (age, gender, education, ethnicity and religion).

Knowledge and beliefs of oral cancer were measured using three subscales (risk factors, signs and symptoms, screening) of the scale developed by Humphris *et al*., (1999). For each subscale, participants were asked whether statements were true or false (e.g. Risk factors: *"You are more likely to get mouth cancer if you drink alcohol heavily"*; Signs and symptoms: *"The signs of mouth cancer are a stomach ache"*; Screening: *"A check up for mouth cancer is only necessary for people over 70 years of age"*). For the purposes of this study, the following additional items were added to the risk factor subscale: *"Smoke hukka (sheesha)"*; *"Chew gutkha"; "Eat paan"; "Eat betel nut"* due to their association with increased risk for oral cancer and reported use within the South Asian community. The screening subscale was amended to include *"…is carried out during routine dental check-ups"*; and *"Discomfort or pain in the mouth"* was added to the signs and symptoms subscale. The number of correct answers was summed to produce an overall knowledge score (range 0-33), with higher scores indicating more accurate knowledge about oral cancer.

Data were analysed using SPSS v.22. Descriptive statistics summarised the demographic characteristics and health related behaviours of the sample. Chi-square coefficients were calculated to determine differences in health-related behaviours according to demographic details, with the significance level set at $p<0.01$ to compensate for multiple testing.

To identify poor areas of knowledge about oral cancer, items were highlighted if they had been answered incorrectly by over half of the sample. Univariate logistic regression was used to identify health-related behaviours and demographic factors associated with overall knowledge about oral cancer. Factors significantly associated ($p<0.05$) at the univariate level were entered into multivariable logistic regression.

Results

Of the 224 people approached to participate, 211 (94%) completed the questionnaire but 10 failed to meet the age inclusion criterion, leaving 201 participants in the study, 90% of those approached. Table 1 gives the demographics of the sample. Of the 201, 123 (61%) were male. Ages ranged from 19-44 years (mean 32, SD 5.8 years). All but 13% were educated beyond age 16.

Table 1: Demographics and health-related behaviours

Characteristic		*Whole Sample*		*Smoke tobacco*		*Chew tobacco*		*Chew gutkha*		*Paan with betel nut*		*Drink alcohol*	
Gender													
	Male	123	(61%)	67	(54%)	10	(8%)	31	(25%)	47	(38%)	95	(77%)
	Female	78	(39%)	15	(19%)	0	(0%)	0	(0%)	14	(18%)	22	(28%)
Age													
	18-24	18	(9%)	9	(50%)	0	(0%)	1	(1%)	3	(17%)	9	(50%)
	25-34	120	(60%)	53	(44%)	8	(7%)	22	(18%)	38	(32%)	76	(63%)
	35-44	63	(31%)	20	(32%)	2	(3%)	18	(29%)	20	(32%)	32	(51%)
Education													
	School	26	(13%)	0	(0%)	0	(0%)	3	(12%)	4	(15%)	3	(12%)
	Higher education	175	(87%)	82	(47%)	10	(6%)	28	(16%)	57	(33%)	114	(65%)
Religion													
	Hindu	71	(35%)	29	(40%)	4	(6%)	12	(17%)	23	(32%)	47	(66%)
	Muslim	67	(33%)	32	(48%)	4	(6%)	5	(7%)	16	(24%)	18	(27%)
	Jain	11	(5%)	3	(27%)	1	(1%)	4	(36%)	8	(73%)	7	(64%)
	Sikh	4	(2%)	1	(25%)	0	(0%)	0	(0%)	0	(0%)	4	(100%)
	Christian	2	(1%)	2	(100%)	1	(50%)	1	(50%)	1	(50%)	2	(100%)
	Not stated	46	(23%)	15	(33%)	0	(0%)	9	(20%)	13	(28%)	39	(85%)
Ethnicity													
	Indian	152	(76%)	59	(39%)	6	(4%)	27	(18%)	52	(34%)	104	(68%)
	Pakistani	32	(16%)	16	(50%)	4	(13%)	4	(13%)	7	(22%)	8	(25%)
	Bangladeshi	13	(6%)	3	(23%)	0	(0%)	0	(0%)	2	(15%)	2	(15%)
	Sri Lankan	3	(1%)	3	(100%)	0	(0%)	0	(0%)	0	(0%)	3	(100%)
	Malaysian	1	(1%)	1	(100%)	0	(0%)	0	(0%)	0	(0%)	0	(0%)
Overall		201	(100%)	82	(41%)	10	(5%)	31	(15%)	61	(30%)	117	(58%)

Most were of Indian (n=152; 76%) or Pakistani origin (n=32; 16%). Almost a quarter (n=46; 23%) did not clearly state their religion but instead gave a geographical region (e.g. Punjabi or Gujarati) so their religion could not be determined. Roughly a third indicated they followed Hinduism and another third, Islam.

Dental visits were rare, just 8 (4%) in the last year and 36 (18%) in the past two years, with another 18% reporting never having visited a dentist. In contrast, a clear majority (n=166, 82%) reported visiting a doctor in the past two years.

Over half (n=113; 58%) of the sample reported one or more health-related risk factors for oral cancer and 42% of the total (n=85) used tobacco, gutkha or paan in combination with alcohol. Of the 201 participants, 82 (41%) stated they had smoked cigarettes; 79 being current smokers. Current smokers smoked an average of four cigarettes per day (SD=1.6 cigarettes). Just 10 participants (5%) reported that they chewed (n=7), or used to chew (n=3), tobacco (those who currently chewed tobacco did so on average three times per day, SD 1.2 times). Triple that, 31 (15%) currently chewed (n=29), or used to chew (n=2) gutkha. Sixty-one (30%) chewed paan with betel nut. Over half the sample (117, 58%) drank alcohol. In terms of the frequency of alcohol consumption, 26 participants (13%) reported drinking alcohol monthly or less, 45 (22%) drank 2-4 times per month, 39 (19%) drank 2-4 times a week, and 7 (4%) reported drinking alcohol over 4 times per week.

Certain health related behaviours appeared to differ according to participant demographics (Table 1). Men were more likely than women to smoke tobacco (χ^2=24.5, df=1, p<0.001), chew gutkha (χ^2=23.2, df=1, p<0.001), chew paan with betel nut (χ^2=9.3, df=1, p<0.01) and drink alcohol (χ^2=47.2, df=1, p<0.001). The better edu-

Table 2: Items answered *incorrectly* by more than 50% of participants

Items	*% answered incorrectly*
Risk factors	
You are more likely to get mouth cancer if you are aged over 50 years old [True]	56
You are more likely to get mouth cancer if you smoke hukkah (shisha) [True]	58
You are more likely to get mouth cancer if you eat betel nut [True]	79
You are more likely to get mouth cancer if you eat paan [True]	88
You are more likely to get mouth cancer if you are a man [True]	99
Screening	
A check up for mouth cancer only takes a few minutes [True]	58
A check up for mouth cancer is carried out during routine dental check-ups [True]	58
Signs and Symptoms	
The signs of mouth cancer are a painless ulcer in the mouth [True]	76
The signs of mouth cancer are a yellow patch in the mouth [False]	80

Table 3. Univariate logistic regression analysis for level of knowledge (low vs high)

Variable	*Beta*	*Standard Error*	*Odds Ratio*	*95% Confidence Interval*
Demographics				
Gender	0.35	0.29	1.42	0.84-2.50
Age	-0.12	0.02	0.98	0.94-1.03
Education	0.80	0.45	2.22	0.92-5.38
Ethnicity[#]				
Indian	-	-	1.00	Ref.
Pakistani	-0.89	0.42	0.41 *	0.18-0.92
Bangladeshi	-1.81	0.79	0.16 *	0.04-0.76
Religion				
Hindu	-	-	1.00	Ref.
Muslim	-1.03	0.35	0.36 **	0.18-0.72
Jain	1.99	1.08	7.32	0.89-60-29
Not stated	-0.75	0.39	0.47	0.22-1.00
Health-related behaviours				
Smoke tobacco	0.35	0.29	1.42	0.81-2.50
Chew tobacco	1.01	0.71	2.73	0.69-10.88
Chew gutkha	1.18	0.43	3.25 **	1.41-7.47
Paan with betel nut	1.86	0.35	6.44 **	3.22-12.85
Drink alcohol	0.31	0.29	1.36	0.77-2.38
Time since last Dentist visit	1.86	0.35	6.41 **	3.24-12.69
Time since last Doctor visit	1.06	0.24	2.89 **	1.82-4.59

[#] Participants of Sri Lankan and Malaysian-Indian ethnicity removed from analyses due to small numbers;
* p<0.05; ** p<0.01

Table 4. Multivariable logistic regression analysis for level of knowledge (low vs high), n=197

Variable	*Beta*	*Standard Error*	*Odds Ratio*	*95%CI*	*-2 log likelihood*	*Nagelkerke R^2*
Demographics					189.76	0.43**
Ethnicity[#]						
Indian	-	-	1.00	Ref.		
Pakistani	-0.98	0.70	0.37	0.10-1.46		
Bangladeshi	-0.98	0.96	0.38	0.06-2.44		
Religion						
Hindu	-	-	1.00	Ref.		
Muslim	0.35	0.62	1.42	0.42-4.78		
Jain	1.26	1.15	3.53	0.37-33.49		
Not stated	-0.68	0.46	0.51	0.21-1.26		
Health-related behaviours						
Chew gutkha	0.31	0.61	1.37	0.42-4.47		
Paan with betel nut[1]	1.41	0.49	4.08**	1.58-10.59		
Time since last Dentist visit[2]	1.59	0.43	4.90**	2.13-11.28		
Time since last Doctor visit	0.16	0.32	1.17	0.62-2.19		

**$p<0.01$; [#] Participants of Sri Lankan and Malaysian-Indian ethnicity removed from analyses due to small numbers;
[1] Positive association ; [2] Negative association; [3] CI confidence interval

cated were more likely to smoke tobacco (χ^2=20.6, df=1, $p<0.001$) and drink alcohol (χ^2=26.7, df=1, $p<0.001$). Religious background (χ^2=46.7, df=5, $p<0.001$) and ethnicity (χ^2=34.4, df=4, $p<0.001$) also influenced alcohol consumption. As would be expected, followers of Islam were less likely to consume alcohol (23% of Muslims consumed alcohol, compared with between 64 and 100% of those following other religions). Participants of Indian or Sri Lankan ethnic origin were more likely to consume alcohol than those of Pakistani, Bangladeshi or Malaysian-Indian origin.

Scores on the knowledge and beliefs about mouth cancer scales ranged from 18 to 32 out of a possible 33 (mean and median 24. SD=3). There were commonalities where errors in knowledge occurred. Table 2 lists the items answered *incorrectly* by more than half the participants.

Median splits were used to determine whether participants had 'low' (score of 0-24) or 'higher' (score 25+) levels of knowledge of mouth cancer. Univariate logistic regression (Table 3) indicated that ethnicity and religion were associated with levels of knowledge of mouth cancer. Compared with those of Indian ethnicity (47% of whom had 'low' knowledge), respondents of Pakistani origin and Bangladeshi origin were more likely to have 'low' knowledge (Pakistani=69%, odds ratio OR 0.41; Bangladeshi=85%, OR 0.16). Regarding religion, compared with those of who followed Hinduism (42% of whom had 'low' knowledge), followers of Islam were more likely to have 'low' knowledge (67%, OR 0.36).

Respondents who chewed gutkha or paan with betel nut were significantly *less likely* to have 'low' levels knowledge of mouth cancer (chewed gutkha: 29%, OR 3.25; chewed paan: 23%, OR 6.44) compared with those who did not chew gutkha (57%) or did not chew paan (66%). Finally, the more time that had passed since last visiting a dentist or doctor was associated a *significantly higher* likelihood of having 'low' knowledge (time since dental visit: OR 6.41; time since doctor visit: OR 2.89). Of those who reported never having visited a dentist, 86% had 'low' levels of knowledge of mouth cancer, compared with 12% of those who had visited a dentist in the past year. Similarly, 66% of those who reported having last visited a doctor over two years ago had 'low' levels of knowledge, compared with 24% of those who had visited a doctor in the past year.

Multivariable analyses indicated that two variables, 'chewing paan with betel nut' (OR 4.08) and 'time since last visit to a dentist' (OR 4.90) were independently associated with having a low level of knowledge of mouth cancer (Table 4).

Discussion

This community survey has indicated that there may be a significant risk of oral cancer within the young South Asian community in London. Many (58%) of the young adults surveyed engaged in one or more health-related behaviours considered risk factors for oral cancer, although the amounts of alcohol consumed and tobacco used were relatively low.

Irrespective of the elevated risk of oral cancer, there was low awareness of the risk factors. Over half the respondents did not know that smoking Hukka, chewing paan, or betel nut increased risk of oral cancer. Whilst those who reported use of gutkha and paan demonstrated higher knowledge of oral cancer, use of tobacco and alcohol consumption was not associated with higher awareness.

Males, and the better educated, were more likely to report risk factors for oral cancer (as reported in recent research into areca nut chewing in Sri Lankan adolescents, Karunarathne and Ekanayake, 2016), suggesting preventive educational campaigns may have to target specific socio-demographic groups within the South Asian community. It is also important to note that the South Asian community should not be classed as a homogenous group (Vora *et al.*, 2000). As noted by Williams *et al.*, 2010, there are differences in risk factors, health-related behaviours and level of knowledge about oral cancer between those from different ethnic origins and those following different religions. For instance, respondents of Bangladeshi ethnic origin had lower knowledge about oral cancer than those of Indian origin.

Crucially, almost 60% of the sample was unaware that screening for oral cancer is carried out during normal dental check-ups. Moreover, regular dental attendance was found to be very uncommon, with only 18% of respondents indicating that they had visited a dentist within the past two years. This is substantially lower than reported in previous studies (Al-Haboubi *et al.*, 2013), perhaps because the current study solely focused on those aged under 45 years. Low-frequency of dental attendance was associated with poorer knowledge of oral cancer and was an independent predictor of low knowledge. This indicates there may be scope for dentists to raise awareness of oral cancer, yet increased access to dentistry is a prerequisite of this. If members of the young South Asian community are reluctant to visit a dentist, research might investigate reasons for this, and trial ways of encouraging regular dental care. If this cannot be achieved then interventions to raise awareness of oral cancer may be better placed within GP surgeries or other centres within the community.

Finally, participants were generally aware of the potential signs and symptoms of oral cancer. However, most of the sample (76%) did not believe that a painless ulcer was a sign of oral cancer. This could have serious implications as a painless ulcer could be dismissed, leading to delay in presentation to a healthcare professional. Further, the way in which participants were asked about signs and symptoms of oral cancer may have overestimated their awareness. Previous community studies have indicated that if participants are asked unprompted questions (e.g. *'What are the symptoms of mouth cancer'*), signs such as a red or white patch in the mouth are rarely mentioned (Rogers *et al.,* 2011).

The results of this study should be interpreted with caution, as the sample was small and most were educated beyond 16, raising questions about the representative nature of this sample. In addition, inclusion required being able to communicate in English. While conducting the study, we came across a large number of local residents who could not communicate in English and their knowledge and intention to seek help should be studied in future research. However, whilst bearing these limitations in mind, the results suggest that young adults in the South Asian London community are exposed to a number of risk factors for oral cancer yet have poor knowledge of the implications of these health-related behaviours, and ways in which oral cancer can be detected earlier. The survey has highlighted specific issues where knowledge could be improved and identified sub-samples of the young South-Asian community who may benefit from educational campaigns to improve prevention and early presentation of oral cancer. Regular dental attendance is linked to higher knowledge about oral cancer, but within the young South-Asian community regular dental attendance is strikingly low.

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