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Attendance and Compliance at an Oral Cancer Screening Programme in a General Medical Practice

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The purpose of this study was to measure the attendance and compliance rates in a demonstration invitational screening programme for oral cancer. 4348 subjects aged 40 years or over registered at an inner city medical practice in north London were invited for screening by post. The socioeconomic profile of the group was determined by analysis of residential areas. Screening was conducted by one of several dentists and a referral pathway was established for patients requiring follow-up. Attendance rates for screening and referral for follow-up were measured. The response rate was 985/3826 (25.7%) after removing 522 subjects whose invitations could not be delivered or who refused appointments. No reply was obtained for 2841 patients. Attendance for referral of lesions considered to have malignant potential was 67% (8/12), compared to 92% (11/12) for patients requiring referral for incidental benign lesions. The low compliance suggests that oral cancer screening may not be able to achieve the desired benefits of reducing morbidity and mortality, and establishment of such a programme may not, therefore, be cost-effective. Further research is required into how to identify people in high risk groups and motivate them to present themselves for screening.

Keywords: cancer screening, compliance, invitational screening, oral cancer, oral precancer

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INTRODUCTION

THERE ARE almost 2000 cases of oral cancer each year in England and Wales [1] and over 50% die of their disease within 5 years. The survival rate is comparable to that of invasive cancer of the uterine cervix and melanoma [2], and has not changed for over 25 years although reconstructive surgery and rehabilitation have improved quality of life [3]. One of the main reasons for the poor survival is that over 60% of oral cancer patients present with lesions greater than 2 cm in diameter when prognosis is known to be significantly worse than for smaller lesions [4]. The morbidity associated with treatment of larger lesions is also greater. In the developing world most lesions of oral cancer are preceded by a precancerous stage [5] but there is a lack of knowledge with regard to malignant transformation and progression rates in a Western population (reviewed by Speight and Morgan [6]).

Screening for oral cancer is simple and involves a systematic visual examination of the soft tissues of the mouth [7]. The aim of screening is to detect lesions more frequently during the pre-invasive stage or at an earlier stage of invasive disease than is usual in clinical practice [8]. Since oral cancer would seem to meet many of the criteria for screening as described by Wilson and Jungner [9, 10], and because early diagnosis is associated with improved prognosis, it would seem appropriate to evaluate its suitability for screening. The U.K. Working Group on Screening for Oral Cancer and Precancer recently considered many of these aspects and have made recommendations for further research [11].

The present study, conducted within a general medical practice, is part of a larger demonstration study to evaluate an oral cancer screening programme [12] and was designed to measure compliance rates and to consider the acceptability and feasibility of invitational screening for oral cancer, important factors to consider in evaluating a screening programme [13].

METHODS

The target population was identified from among the registered patients of a large inner city medical practice. All the patients approached were aged 40 years or over since over 95% of oral cancers occur in this age group [14]. Each patient's name, date of birth and address were obtained from the records of the relevant Family Health Services Authority (FHSA). There were 4348 eligible patient names on the list. The distribution of age is shown in Table 1. All patients were invited to attend for mouth screening by postal invitation which included a fixed appointment at the medical practice. This was part of a large health centre with a community dental clinic on site. Patients were also offered an alternative open screening appointment during the day at a nearby dental

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Table 1. Distribution of subjects obtained from the FHSA register and acceptance of invitations to screening (first and second rounds combined)

Age group (years)	Total	Acceptance	Response rate %
40–44	609	139	22.8
45–54	1069	246	23.0
55–64	939	260	27.7
65–74	873	211	24.2
75–84	562	109	19.4
85–94	241	18	7.5
95–104	50	2	4.0
105–114	4	0	0
115–124	1	0	0
All groups	4348	985	25.7*

First mailing = 659; second mailing = 326; total = 985.
*Corrected for 522 notified non-attenders (985/3826).

hospital, an open evening at the medical practice or the opportunity to change the time by telephone, if their appointment was not convenient. To minimise anxiety [15] the letter was sent from the medical practice and explained that the subject's name had been obtained from their general practitioner as part of a mouth screening study for all patients aged 40 years or over. The letter also included an information leaflet explaining the screening process and outlining the benefits of a healthy mouth and the importance of early diagnosis of oral cancer.

After the first round of invitations had been completed a second invitation was sent out in a slightly different format to the 3167 subjects who had failed to respond to the initial invitation. These remaining subjects were randomly divided into two approximately equal groups. One received only a reminder and an appointment card, whereas the other group received an appointment and an additional information leaflet. This was published by the British Dental Health Foundation (BDHF) [16], and contained more explicit information about mouth cancer, including risk factors and the importance of early diagnosis. The frequency of attenders and non-attenders in each group was compared to see if the information leaflet had any effect on compliance. The decision to have two rounds of invitations was to allow for holidays and to follow the customary format of other screening programmes.

The screening procedure and the referral process has been described in detail elsewhere [12]. Briefly, all patients received an interview questionnaire about their lifestyle habits. Informed consent was obtained and any questions were answered regarding the nature of the screening process [17]. Each subject was examined independently by a dentally trained screener and a specialist. There was a total of four screeners but only one specialist who examined all the subjects. The specialist provided the definitive diagnosis for each subject. Evaluation of the concurrent validity of the screening test has been described previously [12].

If a subject was considered to be negative according to the definitive diagnosis (no precancer or cancerous lesions were detected), they were told immediately. All smokers and heavy drinkers were advised of the risk of oral cancer from their habits. All patients requiring treatment or further follow-up were advised of this and given an appointment to attend at the dental hospital where they were reviewed by the specialist and a consultant oral physician. The group requiring referral contained both positive subjects and subjects classified as negative for oral cancer and precancer, but who required treatment for benign pathology. No follow-up was arranged for subjects screened negative but all participants were advised to attend their dentist on a regular basis.

The postcodes of all patients were analysed by "ACORN" which is a commercially available service which provides a classification of residential neighbourhoods [18, 19]. This information was used to obtain a socio-economic profile of the invited practice population. The frequency distribution in each ACORN group for non-attenders and attenders was compared statistically.

RESULTS

Uptake of screening

Of the 4348 invitations sent out, there were 522 notified non-attenders and 2841 subjects who did not respond at all. Of the 3826 eligible attenders 985 (25.7%) accepted the invitation for mouth screening. There was no significant difference between the numbers or proportions of males (479; 21%) and females (506; 24%) who attended. The breakdown of attendance by age group is shown in Table 1. The 522 notified non-attenders are detailed in Table 2, these included those who could not be contacted and those who refused for reasons of ill-health, immobility or other, unspecified, reasons.

ACORN classified the patients of the medical practice into four (A, C, E, F) of the six (A–F) possible classifications (Table 3), with over 98% of the population being in either group C or F. Groups A and E were excluded from any analysis since the numbers of patients in each group were small. The true proportion of attenders in each ACORN group

Table 2. Details of the notified non-attenders

Reason	Number
Return to sender	329
Dead	36
Other reasons*	65
Not interested	65
Visits dentist	27
Total	522

*Other reasons includes patients who could not attend due to ill health or immobility.

Table 3. ACORN classification of the invited subjects compared to that of the United Kingdom

ACORN	Defining factors	Study %	U.K. %
A	Thriving, wealthy achievers, prosperous pensioners	0.2	19
B	Expanding, affluent families	0	10.4
C	Rising, prosperous urbanites	46.5	9
D	Settling, skilled workers, mature home-owners	0	24.5
E	Aspiring, white collar, better off ethnic areas	0.7	13.9
F	Striving, low income, high unemployment	52.3	23.1

after correction of notified non-attenders was 20.3% (411/2022) in C and 24.8% (566/2274) in F. Although this was found to be statistically significant (SND = 3.56, 95% C.I., 2.1–7.1%; $P < 0.001$), the actual numerical difference between the groups was only 155 patients.

The inclusion of an information leaflet about oral cancer with the second mailing appeared to be of no benefit, 136 (9%) patients attended from the group who received both a card and a leaflet, and 190 (12%) from the group sent only an appointment card. When these groups were compared it was found that the group receiving both the card and the leaflet had a significantly poorer attendance than the card alone (SND = 3.19, 95% C.I., 1.3–5.6%; $P < 0.001$).

Referral for further assessment

All subjects were screened as positive or negative. The criteria for a positive screen have been defined previously [10, 12] as the presence of a white or red patch, or an ulcer of more than 2 weeks duration. The following lesions with such a clinical appearance were included as positive: lichen planus, discoid lupus erythematosus, leukoplakia, erythroplakia or squamous cell carcinoma. Negative subjects were those whose mouths were normal or who might have benign pathology with no recognised malignant potential. All subjects who were considered to require further follow-up or treatment were referred to an oral medicine clinic to be seen as soon as possible. 12 patients were referred with positive lesions. 4 subjects failed to attend; 2 with leukoplakia and 2 with erosive lichen planus. 12 subjects required referral for benign pathology including 1 lipoma, 1 sebaceous cyst, 1 trigeminal neuralgia, 2 polyps and 7 denture related conditions. Of the 12 subjects, only 1 (referred for a denture related condition) failed to attend.

DISCUSSION

During the period of screening almost 1000 individuals accepted the invitation for screening, giving an overall compliance rate of 25.7%. Ikeda *et al.* [20] also found low compliance following postal invitations for oral cancer screening in Japan. In their study a compliance of 12.2% was measured for postal invitations to subjects over 60 years, but compliance was in the range of 60–76% for opportunistic screening among company workers. There are no published studies in the United Kingdom for invitational screening of the mouth, although some industrial companies offer screening to their employees [21, 22]. These programmes, where screening is offered on site and encouraged by the company, achieve compliance rates of about 50% which is greater than the present figure. A similar oral cancer screening study in the United States [23], used an opportunistic method to obtain high risk subjects, but this study is not comparable with the present invitational study. Other comparable invitational screening programmes have compliance rates in the region of 70% for breast [24], 50–55% for colorectal [25], and 30% for cervical cancer [26].

Although invitational screening may result in generally low attendance rates it may achieve a wider coverage among those people who do not attend the doctor or a dentist on a regular basis. Systematic approaches to screening, either by invitation or tagging patient notes have been reported as more successful than unsystematic opportunistic programes [27]. In a computer simulation model of opportunistic screening in a general practice, it was calculated that it could take up to 12 years to screen 90% of the population [28]. The type of invitation offered may also be important. In a recent osteoporosis study [29], a fixed appointment time produced 75% attendance compared to 69% for confirmable and 54% for open appointments. Similar studies of breast cancer screening programmes have shown a 10% higher level of compliance by sending invitations with fixed appointments [30]. However, fixed appointments can result in a waste of resources due to lost appointment slots [31]. In the present study, wastage was reduced by sending large numbers of invitations for each appointment time. All letters were personally signed by the screener to encourage attendance, as recommended by Turnbull *et al.* [32], and the address of the medical centre and a contact number were given. Posters and information sheets were displayed in the waiting rooms throughout the screening period to help increase awareness of oral cancer and the mouth screening programme. In the second round, invitations were mailed to arrive at least 2 days in advance of the fixed appointment time [33].

It is of interest to note that there was a significant difference in attendance, in the second mailing, between those subjects who were, or were not given the BDHF leaflet; those who did not receive the leaflet showed a better attendance. Although the actual numerical difference was small it is possible that the leaflet, which was quite explicit about oral cancer, may deter some individuals from wanting to be screened. Further research is needed to identify the reasons for non-attendance and in particular, to further evaluate the effectiveness of different types of educational material.

A disadvantage of screening for oral cancer appears to be a lack of public knowledge of the disease and this may have contributed to the overall low compliance. In a recent investigation in the same medical practice it was found that only 65.8% of subjects questioned were aware that cancer can affect the mouth [34]. Lack of knowledge about oral cancer may also account for the lower attendance among those individuals referred with positive lesions compared to those with benign lesions. Although the numbers are small, anxiety and fear about the nature and treatment of the disease may have been the cause.

There was an obvious problem regarding the accuracy of the FHSA list of registered patients' names and addresses. The computerised system is, however, currently being modernised, and this should avoid problems such as a patient who would have been 121 years old remaining on the register. This is a particular problem in London compared to most other parts of the country and arises from high population mobility [35]. There are several studies evaluating the disadvantages and inaccuracies of using age/sex registers from family practitioner lists for screening programmes. In screening studies for cervical and breast cancer, up to 69% [36] and 35% [35] of the invitational letters have been found to be inaccurate or inappropriate. Bickler and Sutton [37] demonstrated that the accuracy could be increased from 73% to 92% by checking the family practitioner register against the electoral role and inviting only those whose names appeared on both lists.

The socio-economic status of the population selected for screening must also be taken into account. The population of the medical practice in the present study was not typical of the United Kingdom as a whole, although it may be quite representative of many inner city practices. Majeed *et al.* [38]

have shown that the uptake rates for cervical smears can vary from 16.5% to 94.1% depending upon a number of variables, including the socio-economic profile of the population and the type of medical practice. Further studies in areas with different socio-economic profiles are necessary to determine uptake rates for oral screening in other population groups. ACORN, or other similar techniques, may be of use in targeting individuals by encouraging uptake in areas where the disease is likely to be more prevalent. Cervical cancer screening, for example, shows low response rates in inner city areas [39] where the incidence of the disease is greatest.

The low compliance rate found in this study suggests that an invitational screening programme for oral cancer may not be cost-effective. Low compliance, particularly when associated with a disease of relatively low prevalence, would result in a markedly reduced detection rate in a screening programme [40]. It would seem more appropriate for screening for oral cancer to be done opportunistically during routine dental or health check-ups. However, the population coverage would depend on the age of the patients and the frequency of visits to health professionals. For example, it is known that in the over 55 year age group, the frequency of visiting the doctor is over twice that to the dentist [41]. Since only 50% of the adult population are currently registered with a dentist [42], a large proportion is not going to be screened and it is arguable that the non-attenders are likely to be those at higher risk of oral cancer. In a recent review, Smart [43] recommended that oral screening should be part of both routine dental and general health check-ups.

Before such programmes are introduced, however, it is essential to increase public awareness of oral cancer, particularly the benefits of a regular oral examination and the need to seek treatment as early as possible.

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