

Smokers and drinkers awareness of oral cancer: a qualitative study using focus groups

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Objective To examine the perceptions and understanding of oral cancer among older male drinkers and smokers in the north east of England.

Design Qualitative research using focus group discussions led by an experienced moderator.

Setting Residents of the north east of England in their community.

Subjects Male alcohol drinkers and tobacco smokers over the age of 44 years and by socio-economic grouping.

Results There is a lack of knowledge and understanding of the risk of oral cancer in this whole at-risk population sample. Even those who have direct contact with the disease profess ignorance. Information on health is perceived as confusing or distrusted. Much of this is linked to a fatalistic approach to serious illness.

Conclusions There appears to be a large information gap to bridge, and we need to further understand the target group for oral cancer health promotion; and to use that knowledge to design effective health promotion initiatives.

Lack of awareness of the risk factors for oral cancer leads to late presentation of the disease, which contributes to poor survival of patients who contract it.¹ Intra-oral cancer has a high incidence in the north east of England:² the standardised registration rate for intra-oral cancer (ICD-9 143-145) for the northern region (historical data before northern region abolished) for men is 160 and for women is 125 (England and Wales 100). On average there are about 70 new cases of intra-oral cancer (ICD-9 143-145) and about 40 of cancer of the tongue (ICD-9 142) a year in the northern region. Men are especially at risk from oral cancer,³ especially if they are smokers and alcohol drinkers.

The current study was undertaken because of the importance of primary prevention in oral cancer.^{4,5} Using qualitative research methods, the study sought to identify the health beliefs of an at-risk population in the following areas: the perceived risk to health from oral cancer; how attitudes towards oral cancer affect health risk behaviour; gaps in health education and oral cancer awareness programs; and all with a view to indicate future research priorities and help inform policy recommendations.

Methods

The research adopted a qualitative, focus group methodology. This method is well established in social scientific research, and increas-

ingly in medical and dental research.^{6,7} It is particularly suitable for identifying, exploring and explaining complex attitudes, perceptions and beliefs,⁸ explaining the level of consensus around a given topic,⁹ and can overcome some of the disadvantages of quantitative methods, especially non-sampling error such as the superficiality of response. As Kitzinger put so succinctly:

Interviews may be more appropriate for tapping into individual biographies, but focus groups are more suitable for examining how knowledge, and more importantly, ideas, develop and operate within a given cultural context. Questionnaires are more appropriate for obtaining quantitative information and explaining how many people hold a certain (pre-defined) opinion; focus groups are better for exploring exactly how those opinions are constructed. Thus while surveys repeatedly identify gaps between health knowledge and health behaviour, only qualitative methods, such as focus groups, can actually fill these gaps and explain why these occur.¹⁰

Focus group discussions involve bringing together, in an informal setting, groups of eight to ten subjects who are carefully selected in social demographic terms, and asking them to discuss areas of interest under the direction of a group moderator. The moderator encourages interaction and synergy between group members and ensures that their subjective experiences are explored in relation to the determined research objectives.

Subjects were recruited to take part in one of the focus groups (Table 1) on a door-to-door basis by trained and experienced market research interviewers (a method widely used in social science research and more frequently in health services research) according to a strict code of conduct.¹¹ Group two comprised members from socio-economic grouping ABC1, group three CDE, and group one was mixed of ABC1/C2DE. Ten subjects were invited for each group; a group comprised a minimum of eight. Both the personal invitation and the incentive ensured a high turn-out. In order to avoid any possible bias, respondents were not informed of the exact nature of the research, but were told that the discussion would be centred around the topic of 'health and illness'. Oral cancer was only mentioned at the end of the discussion if it became apparent that this topic would not arise naturally. Neither dental attendance or personal knowledge of oral cancer were to be recorded. Subjects were recruited on the following basis:

- Age (45–60-year-old range)
- Male sex
- Health status (no mouth or throat problems)
- Drinking and smoking habits (either drinkers and/or smokers)
- Place of residence (north east of England).

The three focus group discussions (Table 1 labelled in order of completion) lasting one and a half hours were held at a central location and subjects were paid a standard fee for participating. The moderator (who conducted and analysed data from all groups) used a standardised guide for the discussion, which included

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general health concepts, drinking and smoking habits and knowledge of risk factors for oral cancer. Each group discussion was recorded on audio tape for later analysis.

Results

General health

There was common agreement on issues of general health. Fitness, diet and lifestyle were regarded as important to both physical and psychological health, as was age. Smoking, (alcohol) drinking and obesity all had unhealthy connotations, although much health promotion advice was seen as scare-mongering.

'You hear all these discussions on about suntan and other things on health and all that; I mean before long we'll stop doing everything ... take food, the eating habits of everybody have changed drastically over the last 20 years ... they're trying to get people to stop eating beef or whatever I think a lot of it is scare-mongering.' [Verbatim quotation from discussion transcription]

Though most subjects felt they had some control over their lifestyles, they did not actively try to prevent ill-health, but would wait until symptoms occurred before seeking help. While there was agreement on the inadvisability of smoking (about half the groups smoked), alcohol drinking was better tolerated. There was more of a consensus on how little should be smoked than how much alcohol was safe.

'Its not a very healthy thing to do. I don't think anyone would want to do it if they could pack it in.'

'Everybody's metabolism's not the same. Someone can come out and have 2 pints and someone can come out and have 18 pints and be as sober as a judge.'

Information on health

Although the accessibility of health information was not perceived as a problem, various criticisms were expressed within the groups. For example:

'One week they're telling us one thing and then it seems the next week, but its probably years, they're telling us another thing that's what they said was once good for us is now bad for us and vice versa. So we're not really quite sure what's good and what's bad so we continue to smoke and drink.'

Others expressed distrust:

'Lets face it, the doctors are just simply humans who've read a few more books than we have. That's being very unkind to them but its also very true that they're not immortal, they don't have any great powers, they've just read a few more books and sat a few more exams over a period of 5 to 6 years which is probably less than a vet does for treating animals. And yet we put them on pedestals as having the knowledge to cure all, but really they don't. They don't have all the wisdom in the world.'

As a result of these doubts, many rely on their own resources:

'There is no quality advice ... so you find your own solutions.'

'We're all different and things affect us differently ... you're not dealing with a definite science are you?'

Advancing years were also seen as encouraging inertia:

'I wouldn't change my ways now cos it would probably do the opposite. If I went straight onto rabbit food all the time and stuff like that I think it would have an adverse effect on us.'

Oral cancer

When the discussion turned to diseases which might affect the mouth or throat, only thrush, foot and mouth disease, and colds were mentioned. Despite the fact that a couple of individuals within the three groups had relatives and friends who had suffered from oral cancer, there was a distinct lack of knowledge about oral cancer risk factors:

'The prevention of the disease comes in the fact of knowing what

Table 1 Composition of the all-male focus groups by age and occupation

Group 1		
Respondent	Age range	Occupation
1	45-50	Retired Sales Executive
2	45-50	Butcher
3	45-50	Factory Worker
4	45-50	Factory Worker
5	45-50	Factory Worker
6	45-50	Joiner
7	45-50	Shipping Manager
8	45-50	Electrician
9	45-50	Security Guard
10	45-50	Early Retired Teacher
Group 2		
Respondent	Age range	Occupation
1	45-60	Electrical Supervisor
2	45-60	Clerical Officer
3	45-60	Retired Company Director
4	45-60	Sales Manager
5	45-60	Civil Servant
6	45-60	Antique Dealer
7	45-60	Retired Electrical Engineer
8	45-60	Maintenance Manager
Group 3		
Respondent	Age range	Occupation
1	45-60	Unemployed Grass Cutter
2	45-60	Grass Cutter
3	45-60	Retired Night Worker
4	45-60	Self-employed Handyman
5	45-60	Postman
6	45-60	Postman
7	45-60	Disabled
8	45-60	Disabled
9	45-60	Track man

causes it and if you're getting a lot of conflicting information or getting second hand information through your local press, magazines etc., you don't really know. In fact, if I wanted to make sure that I didn't get cancer then the only certain thing for me would be to starve to death. It seems to me that everything you eat can cause cancer. Feeding 250 pounds of Brand X [a brand of potato snack food] to a rat gives it cancer of the big toe, so that can cause cancer ... so how do you prevent these diseases? There isn't really a way. You just seem to be unlucky if you get them.' [subject's emphasis]

'A lot of cancers are hereditary. Anything can bring on cancer, it doesn't have to be smoking. Somebody can fall over and it can cause cancer in a bone ... it's in virtually everybody, it just needs something to trigger, to start it off. It can be anything, you can get a bad cold and start with cancer.'

For these men in the discussion groups, the concept of cancer was kept 'hidden' and not discussed during their everyday lives. Cancer was thought to be a disease that still holds a huge stigma for everyone and it was much easier to forget its existence unless forced to confront it through personal experience.

'It frightened the friggin [expletive] life out of me when I went to see her the other week.' [respondent talking about his partner who has oral cancer]

It was generally agreed within the groups that cancer had to be diagnosed and treated very early in its development, otherwise it would be incurable:

'You can't do much about it, if you get it in the throat, cos it stops you eating, doesn't it?'

There was little knowledge about the specific symptoms of oral cancer, despite two of the respondents' relatives suffering from the disease.

The main symptoms discussed were:

'Lumps, growths of some sort ... or ulceration.'

Overall, there was little awareness of this type of cancer within the groups:

'It's [oral cancer] not very well known. Even when me dad had it and I tried to find out myself, as much as I could about it, it was very difficult. The only place I really got any information was the Marie Curie Nurse's set up, they actually did some fabulous leaflets on it ... and it was really very easy to understand as well.'

It was agreed within the group that lack of knowledge regarding oral cancer leads to ignorance about the symptoms and so it remains difficult to prevent or recognise signs of the disease. Although one individual mentioned that more frequent visits to the dentist would perhaps be the most helpful of preventive measures, he was strictly in a minority, since most of the others felt that the 'experts' still had very little knowledge about this particular disease. Another individual also mentioned the relationship between drinking, smoking and oral cancer, but only after directive prompting on the causes of mouth and throat cancer:

'You could stop breathing ... you've got to stop going in all public houses cos of all the smoke in there.'

Most of the men have not come across information regarding this particular type of cancer and would not actively seek advice about prevention unless they had personal experience of the disease. Any information designed to reach this group would have to account for the stigma associated with cancer in general and the lack of knowledge regarding the probable causes. Although most individuals enjoy a drink, and joke about the excesses of drinking, this appears to be an acceptable part of life, a form of 'escapism', and no-one associates this pleasurable pastime with oral cancer. Similar attitudes are prevalent with regards to smoking which, although perceived as addictive and causing lung problems, is not associated specifically with oral cancer.

Discussion

The study population were chosen because they represent an at-risk group: male smokers and drinkers from the north east of England. While there were no differences in attitudes based on socio-economic grouping in this study, it is too small to say whether this is a valid conclusion and the study does not address the issue of social stability, thought to be an important factor independent of alcohol and smoking.¹²

The subjects in this study showed a low perception of the risk of oral cancer associated with their smoking and drinking. Other studies have found this. One found only 14.9% of oral cancer patients were aware of the causative factors of oral cancer.¹³ In this case-control study, there was no significant difference in the awareness of controls; awareness was related to educational and occupational level, with the more educated and higher occupations being better informed about the causes of oral cancer. In another study,¹⁴ this time as part of a health interview survey, there was extensive misinformation and a general lack of knowledge, with, for example, only 25% of the sample able to identify one sign of oral cancer. One other notable quantitative study¹⁵ showed a similar low level of perception. Other studies have shown that smokers underestimate the risks to their health,¹⁶ or understand the well-known connections (for example lung cancer) but not the other health problems.¹⁷

Our study confirms the ignorance of the risks of oral cancer and offers some new insight into the attitudes and perceptions that accompany this. Other studies have shown how much ignorance there is;¹⁸ ours adds depth to our understanding.

Even those who have direct contact with the disease profess igno-

rance. Information on health is perceived as confusing or distrusted. Much of this is linked to a fatalistic approach to serious illness ('A lot of cancers are hereditary. Anything can bring on cancer, it doesn't have to be smoking. Somebody can fall over and it can cause cancer in a bone ... its in virtually everybody, it just needs something to trigger, to start it off. It can be anything, you can get a bad cold and start with cancer.'). which is well documented.^{19,20} More worrying perhaps is the reported ignorance of signs of oral cancer: much of our current strategy for dealing with oral cancer relies on early detection, and self awareness plays an important part in the early detection of some malignancies, such as testicular cancer. Continued ignorance of the signs of oral cancer²¹ might contribute to the continued poor prognosis for the disease.

What are the implications of these findings? There appears to be a large information gap to bridge, and we need to further understand the target group for oral cancer health promotion; to use that knowledge to design effective health promotion initiatives, for example using social marketing techniques;²² and to continue research into this neglected health promotion challenge, to test what communication strategies engage with the at-risk population and what initiatives work in bringing about changes in risk-factor behaviour. The insights gained in this study could become the first steps in a social marketing initiative to reduce risk-factor prevalence and increase the awareness of early warning signs.

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