

# Why don't dentists talk to patients about oral cancer?

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VERIFIABLE CPD PAPER

## IN BRIEF

- Recognises the importance of dentists raising awareness of oral cancer through discussions with their patients, particularly those who are at higher risk.
- Suggests that guidelines and practice standards, the presence of risk factors and good dentist-patient relationships can help facilitate these discussions.
- Discusses that barriers include the fear of invoking undue anxiety, time constraints and insufficient knowledge and training.

RESEARCH

**Objectives** Up to half of oral cancer patients are diagnosed with advanced lesions. One route to early diagnosis could involve dentists raising awareness of oral cancer through discussions with patients, emphasising prompt help-seeking. This study explores opinions and practices of dentists regarding discussing oral cancer with patients including views on barriers and facilitators. **Design** Qualitative in-depth interviews. **Setting** Dentists working in general dental practices in the United Kingdom were interviewed in 2013. **Subjects and methods** In-depth interviews with dentists ( $n = 16$ ) were conducted. Interviews were audio-recorded and transcribed. Data was analysed using framework analysis. **Results** Dentists recognised the importance of raising awareness but identified several barriers to discussions including system factors (for example, time constraints and a lack of financial incentive), patient factors (for example, fear of invoking undue anxiety) and dentist factors (for example, a lack of sufficient knowledge, training and self-confidence). Facilitators included developing practice standards and good dentist-patient relationships. **Conclusion** Identified barriers may hold back efforts to raise awareness of oral cancer and could be targeted in future initiatives to encourage early detection.

## INTRODUCTION

Although still relatively rare, oral cancer is increasing in incidence in the United Kingdom.<sup>1</sup> Up to half of oral cancer patients are diagnosed with advanced lesions,<sup>2</sup> when treatment is debilitating<sup>3</sup> and five-year survival rates are low.<sup>4,5</sup> Detecting oral cancer at an early stage is key to improving survival and reducing morbidity.<sup>6</sup> One route to early diagnosis could involve raising awareness of the risk factors and both signs and symptoms of potentially malignant oral disorders among high-risk groups, and encouraging prompt help-seeking.<sup>7,8</sup>

The dental practice offers one setting in which awareness of oral cancer could be raised. Petersen<sup>9</sup> suggests dentists often have more time with patients than other clinicians, so they can integrate preventative health advice into their routine. During a dental check-up, a soft tissue examination is routinely carried out and the British Dental Association advises patients should

be told that such an oral cancer check is being carried out.<sup>10</sup> However, only 7.1% of patients reported their dentist or physician spoke about oral cancer<sup>11</sup> and 86% of dental patients were unaware they are routinely screened for signs of oral cancer during a dental visit, with those at higher risk being less aware.<sup>12</sup> Dentists may be reluctant to tell their patients they are being screened and often avoid using the word 'cancer', for fear of alarming patients.<sup>13</sup> Yet this may be unwarranted as patients appear to be in favour of discussing oral cancer with their dentists.<sup>12,13</sup> Overall, reasons why dentists do not appear to discuss oral cancer with patients are unclear. The current research aims to conduct an in-depth study to explore opinions and practices of dentists with regards to discussing oral cancer with their patients; asking whether dentists talked to their patients about screening, used the word 'cancer', and the barriers and facilitators to such discussions.

## MATERIALS AND METHODS

This was a qualitative study involving semi-structured interviews. Data and quotes were anonymised such that no individual is identifiable. Ethical approval was received from King's College London Biomedical Sciences, Dentistry, Medicine and Natural and Mathematical Sciences Research Ethics Subcommittee (BDM/11/12-74) and Research

Governance from Southwark Primary Care Trust (RDSLSL639). The study is in compliance with the Helsinki Declaration.

Participants were selected from performers' list of NHS dentists based in primary care practices across South East London. Before starting the interview, participants asked questions, and then asked to sign an informed consent form. Three questions were asked to check whether or not they screened all their patients for oral cancer, informed their patients of screening and used the term 'oral cancer' when informing patients. Their answers were recorded in a short questionnaire before each interview began. A topic guide was used to ensure the interview was guided. All interviews were audio-recorded and transcribed verbatim. Interviews continued until data saturation was reached.

Data were analysed using framework analysis.<sup>14</sup> Initial themes and concepts were identified by the researcher; these were discussed with the research team as well as coding and charting in order to achieve consensus on data interpretation.

## RESULTS

Seventeen dentists returned the forms and 16 were interviewed between June and September 2012. The 17th dentist was not interviewed as their form was received after saturation was deemed to have been reached.

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### Refereed Paper

Accepted 8 April 2015

DOI: 10.1038/sj.bdj.2015.343

©British Dental Journal 2015; 218: 537-541

## Sample characteristics

Table 1 displays the characteristics of dentists and answers to questions asked at the start of the interview. Interviewees' answers to questions did not always match what they said subsequently during the interview. There were nine male and seven female dentists who had been in practice for an average of 24 years and carried out a varying mix of private and NHS activities. Two dentists were participating in the pilot programme for the new dental contracts at the time. This is a government initiated scheme testing ideas for a new dental contract based on registration, capitation and quality. It aims to provide appropriate, high quality clinical service emphasising prevention and patient self-care. The pilot aims to develop a model of care that is appropriate to maintaining and improving the oral health of the population of England rather than simply paying for treatment.<sup>16</sup>

## Communicating about screening and using the term 'cancer'

All participants reported routinely performing visual soft tissue examinations. Availability of time and patients' risk determined how thorough these examinations were.

Some noted not talking about screening beforehand, but once done, a decision is made whether or not to inform the patient they have been screened. Others reported they inform patients screening will take place. However, there was tension around saying 'cancer' for those who chose to inform patients of screening, with several dentists opting to say they were screening for 'anything untoward' or 'abnormalities' instead.

*'I think it is a very erm, strong word and patients associate it with death or that basically long term they're not going to survive. So I, I try and avoid using it as much as possible'* (4, 9 years in practice).

Figure 1 depicts these decisional processes along with the factors that influence them. Barriers and facilitators are outlined below.

### Barriers to communication

**Time constraints:** Participants complained of increasing pressure on their time during an appointment. Telling a patient they are being screened may require additional time to answer questions, leading to reduced time for treatment or other discussions with a knock-on effect on subsequent appointments. This issue seems to be particular to NHS patient appointments.

*'I think for NHS practitioners the time pressure is appalling, you don't have enough time to do a proper charting, measure somebody's gums, clean their teeth, talk to them about any concerns they've got, make a treatment.*

Table 1 Characteristics of study participants

Gender	Years in practice	Screens patients?	Discusses screening?	Uses the term 'oral cancer'?
M*	9	Yes	Yes	Yes
F	4	Yes	Yes	Yes
F	30	Yes	Yes	No
F	11	Yes	Yes	No
M	27	Yes	No	No
F	34	Yes	Yes	Yes
F	17	Yes	No	No
M	13	Yes	No	No
M	32	Yes	No	No
M	51	Yes	No	No
M	29	Yes	No	No
M*	10	Yes	Yes	No
F	32	Yes	Yes	Yes
M	43	Yes	No	No
F	15	Yes	No	No
M	33	Yes	Yes	Yes

M: Male; F: Female

\*Involved in new NHS dental contract pilot schemes

*there's no time'* (8, 32 years in practice).

However, dentists who were taking part in the pilot programmes for the new NHS contracts<sup>15,16</sup> found it was easier to have discussions as they had more time allocated for an initial oral health assessment.

*'At the moment the pilot while we're on it, we are finding we have a bit more time to talk to patients, because it is focused a lot more on prevention...'* (4, 9 years in practice).

**Lack of financial incentive:** Participants felt they will be unrewarded for the time and effort to educate patients about oral cancer. Some noted financial incentives might offset the issue of time, which was seen as a real threat to discussions.

*'I would love to give my patients the time I would love to give it, but it's the economics of the situation and wanting us to see so many patients. It takes time and it takes money, and those are the two issues that are, that are the tension within delivering a good health service...'* (3, 29 years in practice).

**Patient characteristics:** Older patients were thought to be less likely to want to have a discussion or take on board any advice offered by the dentist compared with younger patients.

*'If you tell a 70-year-old man to stop smoking as he's going to get cancer and he' will say 'I've lived 70 years with smoking it's not hurt me, why should I stop now?'. A 20-year-old*

*will respond better'* (1, 11 years in practice).

**Knowledge, training and experience:** Dentists' confidence to talk to patients about oral cancer was closely linked to their knowledge, previous training and experience of oral cancer in practice. Dentists who felt unknowledgeable or insufficiently trained seemed less likely to want to have discussions with their patients, anticipating situations in which they might be unable to answer questions.

*'Well, I don't have enough knowledge. Or expertise in that area. That's the main thing. So I would say I would not like to use those words 'I am screening you for oral cancer' with the level of knowledge I have ...'* (13, 32 years in practice).

On the contrary, dentists who had been on courses related to oral cancer, smoking cessation or had postgraduate training in hospitals where they had seen oral cancer patients found they understood their patients better and felt more confident to have discussions about the disease and risk.

If dentists had never come across patients with oral cancer in their years in practice, there were feelings of low prevalence and therefore other issues were more important.

*'My experience is that oral cancer presenting itself initially in general practice is exceedingly rare. and when you see some pathology that looks sinister in the mouth*

90% of it plus is not oral cancer' (13, 32 years in practice).

*Perceived negative reactions from patients:* There was a general perception that patients would react negatively to any mention of 'cancer' because it is emotive and likely to cause undue anxiety especially for those more prone to worry. Some dentists opined that patients generally associate cancer with death, therefore talking about it would be 'alarmist'. It was thought that coming to the dentist is stressful enough and saying 'cancer' would make it more stressful.

*'Because I feel a lot of people get scared, put off and stressed when someone uses the word cancer, rightly so'* (1, 11 years in practice).

Furthermore, patients' access to the internet and discussions about oral cancer would invoke unguided searches for additional information, and patients would return to the dentist quite disturbed by whatever information they find.

*'The thing is people are on the internet and they come back and I see here and they see sort of, you know here's the risk factor for cancer, oral cancer and they get very disturbed by this'* (14, 43 years in practice).

These fears appear to be contradicted by other dentists who find their patients are happy to be informed they have been screened.

*'They're very interested, er they're very pleased that I take it seriously and they're always, they're usually pretty pleased that I'm bothering, bothering to look'* (8, 32 years in practice).

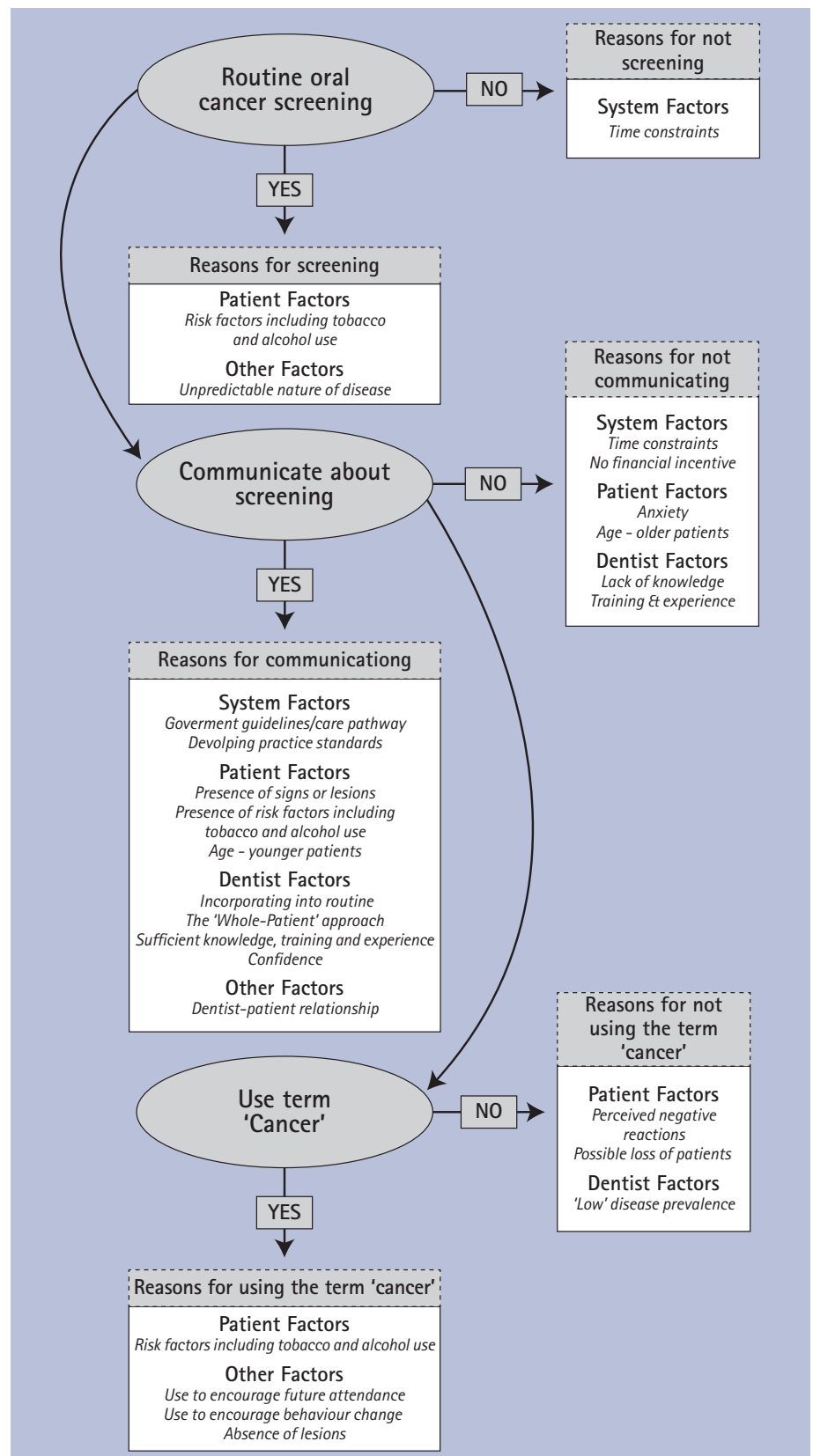
*Possible loss of patients:* There was concern that negative reactions from patients may lead to loss of patients who may not want to return for further appointments because of this alarm or panic that may be invoked.

*'They may not come to you again because of that word, you understand? So, I don't mention that I screen them for cancer, but I just use layman language, if there's an abnormality, that's the word I use'* (12, 13 years in practice)

### Facilitators to communication

Factors that encouraged dentists to tell their patients about screening and discuss oral cancer included the presence of risk factors, signs or lesions, government or practice guidelines and good dentist-patient relationship.

*Presence of signs or lesions:* Participants said they are more willing to inform a patient of screening if they find a lesion they were concerned about. Using the term 'cancer' to stress the seriousness of a situation and encourage patients to attend a referral or follow-up appointment.



**Fig. 1 Oral cancer communication model showing the processes undertaken in communicating about oral cancer and oral cancer screening in general dental practice**

*'I try and avoid it as much as possible but I would in certain cases if I have to be black and white about it, I will say to them, 'Now look, you drink a lot, you're a heavy smoker, you're high at risk of cancer so let's just get it checked out'* (4, 9 years in practice).

In contrast, others would use the term 'cancer' if there is no lesion or reason for concern. If the dentist did find a lesion, they would be unwilling to use the word 'cancer' in case patients think it is a diagnosis.

*Presence of risk factors:* If a patient's history showed they were engaged in behaviours such as tobacco and alcohol use, chewing of betel nut, dentists were more likely to inform such patients that they had been screened or discuss the patient's risk for oral cancer and other diseases.

*'Predisposing factors we tend to mention cancer, if they haven't got it we mention the cancer word, yes, that's a decision we made between us because we felt that people who had predisposing factors should be aware they have'* (9, 34 years in practice).

Participants admitted to sometimes saying 'cancer' to 'scare' patients into making healthier choices. A practice referred to as 'scaremongering' by others.

*Government or practice guidelines:* Dentists involved in piloting the new contracts found that having government guidelines requiring them to discuss prevention (including oral cancer prevention) as part of oral health assessment of new patients meant it had become incorporated into their routine practice.

*'...and part of the pilot scheme it's included in the actual software that basically as soon as you erm, talk about sort of smoking or alcohol then we have got specific boxes ticked up to say we've discussed oral cancer'* (4, 9 years in practice).

Some participants noted that it is easier to follow a standard when there is uniformity across the board. Specifically, in a situation where all the dentists in a practice had agreed on how to deal with oral cancer screening and communication with patients, dentists expressed confidence in what to say and do.

*Dentist-patient relationship:* Dentists with a relatively stable patient-base who had established relationships with patients seemed to find it easier to have 'sensitive' discussions with their patients compared to newly qualified dentists with a less well-established patient-base.

*'You have to sort of build a rapport with the patients, so if I have been seeing this patient for three or four years it will be easier for me to use the 'C' word than if I'm seeing them for the first...whereas with the youngest associate she will have a lot of new patients'* (11, 17 years in practice).

## DISCUSSION

Oral cancer can have devastating consequences including disfigurement and death. Early detection is a key determinant of good prognosis, yet many patients are unaware of oral cancer and wait many months after noticing symptoms before presenting to a healthcare professional.<sup>17</sup> It is important to work with dentists and other stakeholders to

find ways to raise awareness among those who are most at risk<sup>18</sup> and address barriers to effective communication ensuring the dental team is confident in their ability to encourage early presentation.

One key finding from this study is that whereas Petersen<sup>9</sup> suggested that compared to other healthcare professionals, dentists have more time to include preventative messages into their routine practice, participants in this study found the opposite to be true and they view time constraints as a major barrier to having discussions about oral cancer. The only participants who did not raise this issue were those who were taking part in the government's pilot programmes for the new dental contracts. While these participants acknowledged time pressures, dentists in the pilots felt they had sufficient time for discussions about oral cancer as part of an overall patient assessment, and the pilots placed an expectation on them to support patients around prevention. Thus there is potential for the new contracts to provide scope for dentists to play a more active role in primary and secondary preventive initiatives and move beyond just treating disease.

Dentists are also of the opinion that attaching a financial incentive to having discussions about oral cancer may provide motivation for them to spend the time and effort required. This is in line with a study by Clarkson *et al.*<sup>19</sup> that found a fee-for-service intervention was most cost-effective at increasing provision of targeted services (fissure sealants) by dentists. However, further research is required to develop an evidence-base for this system.

Additionally, as dentists fear, there may indeed be patients who are more prone to worry, but whether this fear is real is open to debate and how much weight this carries in light of other issues like time and financial incentives is unclear. To combat patients researching the topic and accessing inappropriate resources which may cause anxiety, dentists should provide accurate and adequate information and recommend patient resources. The general unwillingness to tell patients they are being screened and avoiding the use of the term 'cancer' in order not to alarm patients was also reported in the United States by Choi *et al.*<sup>13</sup> However, research with patients indicates that this concern is unfounded as patients want to be told they are being screened and are willing to engage with healthcare professionals in discussions around cancer and prevention.<sup>12,13,20</sup> It is therefore important to reassure dentists about the benefits of communicating with patients, how best to do so. Effective communication remains at the heart of patient management.<sup>21</sup> Dentists need to be

aware of potential causes of anxiety for their patients and ensure the manner in which they deliver information and handle discussions is based on empathy and compassion. In fact, Swarthout-Roan and Singhvi<sup>22</sup> have suggested that 'operating from a framework of empathy is less taxing on the dental professional and even builds rapport with the patient'; building rapport is a good basis for trust and openness in the dentist-patient relationship which can foster good communication. This was acknowledged by dentists as a facilitator to talking to their patients about oral cancer.

Comprehensive training in communicating about oral cancer is particularly important as some dentists did not feel confident in their ability to communicate with their patients about oral cancer. This was seen in other studies<sup>23-25</sup> (where dentists did not feel confident to communicate preventive messages like smoking cessation and alcohol moderation advice). Dentists report a lack of confidence, which is in part due to a lack of or insufficient training. Communication skills training can be embedded in the curriculum of dentists-in-training.<sup>26</sup> For dentists in practice, they can gain skills through professional development courses. The early detection of oral cancer has become a recommended CPD topic for the dental team.<sup>27</sup> It is important to include a communication element in these CPD courses so that dentists are able to make the most of the opportunity to raise awareness among their patients. This is supported by Silverman<sup>28</sup> and by Dave<sup>29</sup> although it is important to stress that the provision of a checklist as recommended by Dave<sup>29</sup> (which includes a risk factor assessment and a list of soft tissue sites within the mouth for clinicians to examine) if used on its own, may not be sufficient. Communication training remains vital.

## Study limitations

Qualitative research aims to identify the range of views of a specific group of individuals rather than produce generalised data, yet it should be remembered that as this study was based on voluntary participation, participants may significantly differ from those who did not take part. However, findings in this study are similar to findings of other studies.<sup>13,25,30-32</sup>

Care was taken to ensure the researcher did not influence participants, by asking open, non-leading questions and ensuring no self-disclosure, but it is possible that the researcher's own background, views and beliefs may have played a part when analysing and interpreting data and the views of participants. The use of 'respondent

validation<sup>14</sup> is one way of ensuring that the meaning and interpretation of data is how it was meant by participants.

Although not regarded as a study limitation, it should be noted that the study sample size is adequate for a qualitative interview study. Qualitative research provides detailed understanding of social structures, behaviours and cultures offering an opportunity for clarification. Ritchie and Spencer 2003<sup>14</sup> highlight three main reasons why sample size in qualitative studies is relatively small for reasons including diminishing returns where additional data does not add new evidence (saturation), no requirement to draw statistical inference with required precision and sample sizes need to be kept reasonably small scale in order to properly analyse large amount of rich data generated. Furthermore, where expert groups are involved sample sizes tend to be smaller, as it is assumed there is greater homogeneity.<sup>33</sup>

In conclusion, dentists recognised the importance of raising awareness of oral cancer through discussions. However, they identified barriers such as insufficient time, lack of training and not wanting to make patients anxious. It is these barriers that may hold back efforts to raise awareness of oral cancer and could be targeted in future initiatives to encourage early detection of oral cancer.

*The authors would like to thank all the dentists that took part in this study. Oluwatumise Awojobi undertook this research project as a graduate research student who was funded through a King's College London internal scholarship. No additional external funding was received for the project. Suzanne Scott and Tim Newton are Higher Education Funding Committee England (HEFCE) funded academic staff at King's College London. The authors declare no conflict of interest with regards to this research work.*

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