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# **Oral Health Awareness and Care Preferences in Patients with Diabetes: A qualitative study**

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**Running Title:** Oral Health Awareness and Care Preferences in Patients with Diabetes

## **Abstract**

### *Background*

People with type 2 diabetes have an increased risk of oral health problems; however, oral health is currently not included in structured diabetes reviews and education in the UK.

### *Aim and Objectives*

This study explores the patient experience related to oral health and diabetes, especially in relation to:

- Awareness of the link between oral health and diabetes and oral self care needs
- Interaction with health professionals in dental and general practice
- Preferences for receiving oral health information and education

### *Methods*

This nested qualitative study involved semi-structured telephone interviews with a purposive sample of 20 participants from a questionnaire study on oral health awareness in patients with diabetes. Interview transcripts were analysed using a thematic framework approach.

### *Results*

Participants were mostly unaware of the link between oral health and diabetes. Those that had been made aware by a health professional were not given concrete self care advice. Interactions with dental professionals were often limited to informing the dental practice of their diagnosis and current medication. Most participants were in favour of dentists screening for diabetes, but as their general practice was the hub for diabetes care, they felt GPs or nurses should provide oral health information and discuss oral health with patients.

### *Conclusions*

Written information regarding diabetes and its possible effects on oral health needs to be more readily available to people with diabetes, especially at diagnosis. There may be a place for introducing a structured oral health question in routine diabetes reviews.

*Key words:* Oral health, Type 2 Diabetes, Qualitative Methods, Primary Care

## **Introduction**

People with diabetes are at greater risk of oral and dental health problems such as gingivitis and periodontitis compared to those without diabetes.<sup>1</sup> Inflammatory responses produced by inflamed periodontal tissues may also reduce glycaemic control, worsen cardiovascular outcomes, and increase mortality for people with diabetes<sup>2</sup> and general populations at risk of heart disease.<sup>3</sup>

There is an emerging consensus on the oral health self care requirements for people with diabetes. The International Diabetes Foundation has published a guideline recommending that primary care professionals routinely 1) enquire whether the person with diabetes follows oral self care recommended for the general population, 2) enquire whether they have noticed any signs of gum disease and 3) give general self care advice and if necessary advise to urgently seek advice from a dental professional.<sup>4</sup> However, not much is known on whether the situation in general practice, the setting in the United Kingdom and other countries for most care for patients with type 2 diabetes, does currently approach this standard. In the US, diabetes educators do not regularly discuss oral health because of lack of time and insufficient training.<sup>5</sup> In the UK, the National Service Framework for Diabetes specifies oral health as a topic to be covered in diabetes education programmes;<sup>6</sup> however, oral health is not currently included in programmes such as DESMOND.<sup>7</sup>

In order for patients with diabetes to self-manage their oral health effectively, they need to be informed about the link between diabetes and oral health and be given appropriate self care advice. Earlier research from Ireland<sup>8</sup> and the United States<sup>9</sup> suggests that oral health information for people with diabetes is given opportunistically and may come from dental or primary care teams. However, little is known about the extent to which this is occurring in the

UK. Hence, this study aimed to find out about the oral health awareness of people with type 2 diabetes, how they communicate with dentists and primary care professionals, and how they would prefer to receive care and information related to oral health.

## Methods

This nested qualitative study involved participants with type 2 diabetes from a general practice-based questionnaire study on oral health awareness<sup>10</sup> who consented to take part in an interview (see Box 1). We recruited a purposive sample of twenty participants (roughly 10% of the overall sample of 229) to ensure a range of opinions and experiences, and in order to capture diversity of age, gender and location, as experiences and opinions around oral health and dental services may vary between older and younger people<sup>11</sup> and those from affluent and deprived locations.<sup>12</sup> Participants had been sampled for diversity of their practice location (i.e. inner city, small town and rural practices with varying levels of deprivation in their catchment area). Patients who had not visited a dentist during the last year were excluded as we aimed to find out about their interactions with dental professionals about diabetes

*[Insert Box 1 here]*

The research team considered semi-structured telephone interviews would be most appropriate as they could yield rich data comparable to face-to-face interviews,<sup>13</sup> the shorter length of the average telephone interview (30 minutes) did not present a problem as the interview was focused on a specific health care experience. A researcher (VB) conducted the interviews, asking participants whether they knew about the link between oral health and diabetes and whether they had been given any concrete oral self care advice. They were also asked about their overall experience of living with diabetes, and the medical and dental care they currently received and their experiences and preferences regarding oral health care and education. The twenty recorded interviews were transcribed verbatim. Characteristics of the participants are described in **Table 1**; participant names given in this article are pseudonyms.

*[Insert Table 1 here]*

### *Data Analysis*

As our aim was to describe and interpret what is happening in a particular setting (the interface between primary care and dentistry) rather than generating more overarching theories and a *thematic framework* approach was used to analyse the data.<sup>14</sup> Firstly, JR identified the overall common and emerging themes from the interview transcripts, discussing the developing coding scheme with the research team. Themes were entered into a matrix and grouped into the overarching domains of 1) understanding and use of diabetes and oral health information, 2) experience of interacting with dental and primary care professionals and 3) the respective roles dentists, GPs or nurses and patients should play in oral health care. AL checked the coding scheme and applied this to three transcripts to validate the process. Most of the themes were researcher defined as the interview was conducted over the telephone and related to specific health concerns. However, the analysis also identified emerging themes such as the explanatory models linking diabetes and oral health which patients developed in the absence of detailed information.

## **Results**

### *Oral health awareness and diabetes*

Overall, participants were active in managing their diabetes and attended both their GP and dental practice regularly. The majority emphasized that they were happy with both the care they received from their dental practice and general practice, and that they had a good relationship with both. While most people described their diabetes as stable, one participant found it ‘difficult’ and also suffered from depression; another felt that his diabetes still was not fully under control even after taking a whole spectrum of medications. Most assessed

their overall oral health as good, although several had lost teeth which they attributed to causes such as ageing or avoiding the dentist when younger.

Only six participants reported oral health problems possibly linked to their diabetes including receding gums, gingivitis, mouth ulcers, a gum abscess and difficulty healing after a tooth extraction. Three of them had been made aware of the possible link to diabetes. For one participant (Steve), the link was made at the dental hospital. One participant (Fred) was told by his dentist that a 'build-up of sugar' could lead to gum disease, another (Neil) had been informed by his diabetes nurse about the link between diabetes and oral health problems. Three other participants were told by a dental professional (dentist or hygienist) that oral health was important for people with diabetes. However, participants recalled little concrete self-care advice related to their oral health; one participant (George) thought that he received the 'usual' messages around regular tooth brushing and stopping smoking.

While all 20 participants reported that they read information about diabetes from newspapers, patient leaflets, 'Balance' magazine (produced by Diabetes UK) and occasional internet use, only two reported having read about the link between diabetes and oral health. Some participants who had not been informed of any specific link between oral health and diabetes by their health professional said that they had themselves made a connection as they were 'more prone to infections' or diabetes 'affected the whole body'. A few recalled that their oral health problems started around the time that they were diagnosed and so felt it could have been related. However, others had long-standing oral health problems that they attributed to other causes such as neglecting their teeth or having to use steroids.

*[Insert Box 2 here]*



Most participants said that they had only become aware of the link between oral health and diabetes when they read information materials for this study; some said that they now aimed to follow up this link by obtaining more information or by discussing oral health and diabetes with their primary care or dental professional more regularly.

### *Interaction with dental health professionals and information exchange*

For most participants, interactions with their dentists about diabetes had been minimal. This was in spite of all participants reporting that they were registered with a dentist and regularly attended for check-ups; many had been with their dentist for a long time. Most had stated that they had diabetes on a general health questionnaire when they first registered at the practice or at subsequent visits, while a few had verbally informed their dentist. However, it was evident that exchanges were often limited to informing the dental practice of their diagnosis and their current medication. They perceived lack of time and lack of specific interest by the dentist as the main barriers to discussing diabetes.

*[Insert Box 3 here]*

### *Roles of dentists*

When asked who should initiate conversations about diabetes in the dental consultation, most participants agreed that it was the patient's role to inform the dentist that they had diabetes; on the other hand, some argued that dentists should then initiate discussions with the patient about their diabetes. Almost all participants wanted their dentist to know about their diabetes because there might be implications for treatments such as anaesthetics, or because this would enable them to give advice regarding oral health and diabetes. When asked about their preferences in relation to dental professionals becoming more involved in aspects of diabetes care such as screening, managing symptoms and interacting with the diabetes team,

participants were fairly positive about the theoretical possibility of dentists offering screening for diabetes if this was co-ordinated with the primary care team. Most participants thought that GPs and dentists should collaborate to aid the flow of information especially if problems arose. However, they were generally agreed that dentists should not make changes to their diabetes management or give advice on non-dental aspects of diabetes. They also had a very clear sense of a boundary between medical and dental services reflecting different areas of competence (see Box 4).

*[Insert Box 4 here]*

#### *Roles of primary care teams*

As the main focus for diabetes care for most of the participants was their general practice surgery, we asked whether they discussed oral health with their GP or practice nurse. Only two participants (Neil and Olive) reported discussing the importance of oral health with their nurse. One participant (Emma) mentioned that she found it ‘kind of odd’ that doctors and nurses would leave oral health to dental professionals but explained it in terms of the historical development of the NHS. However, the main reasons why participants preferred to receive diabetes advice, which could include oral health advice, from their GP surgery were that they experienced GPs and nurses as having greater understanding of their general health needs and more time to spend with patients. Most of the participants also stressed that patients with diabetes should be told about the associations between oral health and diabetes by their general practice staff when they are first diagnosed with diabetes. This included printed information as it had the advantage of remaining accessible once the person with diabetes was ‘ready’ to access it. Some viewed oral health in parallel to other parts of the body such as eyes and feet that needed particular attention and regular checks (see Box 5)

*[Insert Box 5 here]*

## **Discussion**

The key themes which emerged from this study were that participants felt a need for more information and advice about the links between oral health and diabetes, and that while the dentist was seen as central to managing specific oral health needs, the GP team was better placed to provide general advice about oral health and diabetes. However, few had talked to members of either their dental or GP teams about oral health problems. As a result of participating in the study and gaining increased awareness of the importance of oral health in diabetes, some participants reported that they would be more likely to visit the dentist more often and ask their dentist questions about oral health and diabetes. The participants' responses mainly focused on the role of their dentist, and so did not highlight the possible role for other dental professionals such as hygienists in improving oral healthcare for people with diabetes.

### *Limitations of the study*

These findings should be seen in the context of a small sample size (20) of participants within one English sub-region that may not reflect the population overall. Most participants were coping well with diabetes, reported good oral health and were satisfied with the care they received from their GP practice, and their responses may be different from those in poor oral health. In the context of qualitative research outlining lack of time as a central difficulty in achieving truly patient centred diabetes care,<sup>15</sup> exacerbated by the use of computerised checklists,<sup>16</sup> it was surprising that several participants thought their primary health care team had more time to discuss oral health than dental teams. The majority was also satisfied with their dental care, with a few participants unhappy with the time dentists allotted to each patient. As this was a small, exploratory study, we did not reach complete saturation but succeeded in identifying and describing a range of responses within each of the themes.

However, as this is the first qualitative study in the UK on oral health that explores the perspectives of a community-based sample of patients with diabetes, it is a beginning for building an evidence base in this area. The main issues raised here are similar to themes emerging from a qualitative study conducted concurrently in the United States<sup>17</sup> although there were differences in the experience of care (less continuity and more difficulties paying for health and dental care in the American group).

#### *Roles for general practice and dental teams*

While the majority of respondents felt it was the dentist's role to ask the patient about their diabetes, many felt that this was a two-way process and it was up to the respondents themselves to also tell their dentist about their diabetes. The information given by their dentist or hygienist was reported as 'general' oral health advice rather than tailored specifically to a person with diabetes, and self-care advice was also fairly minimal. The exchange of information between participants and health professionals appeared to be influenced mostly by: 1) lack of awareness of the part of the participant that some oral health problems were linked with diabetes; 2) perception that their dentist did not have the time to discuss their diabetes in depth; and 3) the view that if there was a problem the health professional would raise it and would do 'what was best'.

*[Insert Table 2 about here]*

#### *Involvement of dental teams in diabetes care*

Previous research suggests that it may be possible for dental teams to be more involved in general health promotion, especially if this can be done by non-dentists such as dental nurses and hygienists.<sup>18</sup> However, participants in this study raised concerns about whether dental

teams would have time to carry out screening, communication regarding the results and whether there would be a fee charged to patients in contrast to such activities carried out in general practice. Participants were keen that the results of any screening were referred back to their general practitioner. They were less enthusiastic about their dentist being involved in giving more general diabetes advice and possibly changing medication. The majority felt this should remain the role of their GP or nurse, who knew them best. Participants also agreed that information about oral health and diabetes should be given by primary care professionals at diagnosis, and leaflets given then should also contain information on the importance of oral health.

#### *Implications for clinical practice*

Oral health promotion leaflets for people with diabetes have been developed in other countries (e.g. Ireland<sup>19</sup> and Canada<sup>20</sup>); however, there is a lack of evidence on their use in practice or their effectiveness in improving oral health. As with diabetes education overall,<sup>21</sup> oral health education should focus on self-management, emphasize behavioural strategies, and provide individually relevant information. General oral health messages may therefore need to be ‘tailored’ more specifically to persons with diabetes, with consideration of age or culture specific information needs. As for most participants their regular point of contact for ongoing advice and support is their ‘diabetes nurse’ in general practice,<sup>15,22</sup> a brief item on oral health should be included in routine diabetes reviews. To aid this, there may be a place for developing patient leaflets or toolkits for use in these consultations. Our study highlights a need for development of written information regarding diabetes and its possible effects on oral health which needs to be readily available to persons with diabetes, especially at diagnosis. If patients’ awareness is raised they may well build this knowledge into their self-care/management of their diabetes.

## **Declaration**

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Conflict of interest: None

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### Box 1: Summary of the questionnaire study

<b>Objectives</b>	To investigate oral health awareness, oral hygiene and attitudes towards general dental practitioners' involvement in diabetes care and screening in adults with diabetes
<b>Design</b>	Self-completion questionnaire
<b>Participants</b>	Adults with diabetes attending clinics in general medical practices
<b>Sample</b>	All 76 general practices in a West Midlands Primary Care Trust which includes rural, urban and inner city areas were approached; 14 practices agreed to participate and distributed 615 questionnaires; 229 of these (37%) were returned; 108 consented to being contacted for a telephone interview
<b>Conclusion</b>	Adults with diabetes are receiving limited advice about the oral health complications associated with diabetes, have poor awareness of oral health risks and their oral self care may not be satisfactory in preventing oral disease

### Box 2: Understandings of the link between diabetes and oral health

The conversations you have with health professionals is that sort of feeling of 'you're more likely to get problems as a diabetic' ... Infections generally ... It was the hygienist who was saying about gums and sort of infections more likely to be occurring ... you sort of read between the lines (Emma, aged 41).

Obviously there was some connections because [diabetes] presumably affects your blood and your body generally, which must affect your teeth or your fingernails or anything else but I didn't realise that there was any considered risk, if you like (Helen, aged 82).

I think we accept a certain amount of bleeding from our gums just because we take it as a sign of ageing ... If we're informed it's a possible side effect of diabetes then I think we're more likely to go rushing to the dentist and say 'what is going on?' (Neil, aged 52)

When I was younger I was terrified of the dentist, so I tended not to go. Then when I did go I ended up getting pyorrhoea [advanced periodontitis] in all my gums. That was before I was diagnosed as diabetic ... basically my youth shot my mouth, if you know what I mean? (George, aged 52)

### Box 3: Barriers to discussing diabetes with dentists

Don't discuss diabetes with the dentist as I didn't know it was of any specific interest to him (Tim, aged 61).

They [dentists] just don't have the time (Olive, aged 72).

I've never brought it up and as far as I can remember she's never treated it as a specific issue (Bob, aged 49).

I don't know whether they're too busy or whether they've... I mean it's whatever—£17 or £16 for minutes in the dentist's chair really... I would say five minutes tops (Irene, aged 73).

### Box 4: Opinions on dentists' involvement in diabetes care

I think they've got to decide where doctors finish and (dentists) start. (Dan, aged 64)

The dentist ... would only know about the particular dental aspect (Neil, aged 52).

Dentists have different training (Victor, aged 58).

That's the domain of a doctor to give advice on my diabetes. Dentists can give advice on my teeth. I mean you don't go to a plumber to have your electrics done do you? (George, aged 52).

[Diabetes] is something really that your doctor should address, because your doctor has a better picture of your all-round health (Neil, aged 52).

### **Box 5: Opinions on GPs and nurses giving oral health advice**

I mean there's all sorts of reading matter that you're given when you are told that you've got diabetes ... your feet and your eyesight and things like that. It would be a good idea if they put dentistry in there as well (Anthony, aged 65).

The eyes and the teeth are sectioned off slightly, but obviously that's in terms of the NHS and historical legislation, but I think it's helpful for professionals like diabetic nurses to know as much about your general health as possible, including teeth and eyes (Emma, aged 42).

[Nurse] sees me every six months and she does go through things with me. If [the HbA1c] is high she does ask me what I've done; have I been eating properly, have I been exercising, and goes through what could be happening and gives me a thorough sit-down (Fred, aged 40).

**Table 1: Participant characteristics**

Age (years)	4 participants [40-49]; 3 participants [50-59]; 9 participants [60-69]; 2 participants [70-79]; 2 participants [80+]; mean age 60.8, range 40-82
Gender (female, male)	8 participants [F]; 12 participants [M]
Years since diabetes diagnosis	6 participants [2-4]; 5 participants [5-9]; 6 participants [10+]; mean 8.1, range 2-25
Practice Location	11 participants [urban]; 7 participants [small town]; 2 participants [rural]

**Table 2: Preferred roles in oral health promotion for people with diabetes**

Patients	<ul style="list-style-type: none"><li>• Inform dentist about their diabetes and any changes e.g. in medication</li><li>• Aim to adhere to recommendations</li></ul>
Dental Professionals	<ul style="list-style-type: none"><li>• Give oral health information tailored to people with diabetes</li><li>• Communicate with primary care professionals</li><li>• Possibly screen for diabetes and refer results to GP</li></ul>
Primary Care Professionals	<ul style="list-style-type: none"><li>• Give information on oral health at diagnosis</li><li>• Provide written leaflets</li><li>• Routinely discuss oral health at diabetes reviews</li></ul>