Why individuals with HIV or diabetes do not disclose their medical history to the dentist: a qualitative analysis

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IN BRIEF

- Investigates the reasons why patients don't disclose their medical history to the dentist.
- Discusses the importance of working with other healthcare professionals to promote oral health and improve disclosure.
- Provides advice for dentists on medical history taking.

RESEARCH

VERIFIABLE CPD PAPER

Introduction Evidence shows that some individuals with HIV or diabetes do not report their medical history to the dentist. Disclosure is important because these individuals can be at greater risk of oral disease. **Aims and objectives** The aim of this study is to provide greater understanding of why some individuals do not disclose HIV or diabetes to the dentist. **Methods** In-depth interviews were conducted with 20 participants (10 HIV & 10 diabetes) based around the participant's diagnosis and disclosure history. Data were analysed using framework analysis. **Results** While a lack of disclosure can be found among those with a diagnosis of HIV and diabetes, it appears that the reasons behind disclosure, or lack thereof, are different for each. The reasons are based around: differences in age, understanding of diagnosis, experience of stigma, past disclosure behaviour, trust in dentists and experience of healthcare. Few individuals had discussed the effects of their diagnosis with their dentist or were advised on the importance of seeing a dentist. **Discussion** Individuals with chronic illness should be advised why it is important for the dentist to know their medical history and should be made to feel comfortable to disclose.

INTRODUCTION

Human immuno-deficiency virus (HIV) and diabetes are both chronic illnesses that affect the blood.[1,2] Disclosure of an individual's medical history is of paramount importance to allow for adequate and effective management of the patient's dental needs, which may differ from others due to their medical history. Significant discrepancies have been identified in what is self-disclosed by individuals to some health professionals.[3]

It has been documented that stigma is one of the most common reasons why individuals may not disclose their medical history in full to medical professionals.[4] Different chronic illnesses have varying degrees of stigma associated with them.[5] It is also documented that no other disease puts an individual at risk of stigmatisation as much as HIV.[6,7] Some feel the risks associated with disclosing their status are threatening enough to make them keep this information to themselves when seeking dental care.[6] However, it has been found that up to 22% of individuals with diabetes also do not self-report their medical history.[8] This is interesting as diabetes is thought to be a low stigmatising disease and therefore suggests that stigmatisation cannot be the entire reason involved in an individual's disclosure behaviour.

There is limited knowledge on disclosure specifically to dentists in the UK. There are many papers that suggest possible reasons as to why individuals may not disclose their medical history, but there is limited qualitative research that gives true understanding as to why.

The aim of this study was to explore the attitudes and beliefs of individuals with HIV or diabetes towards disclosure to dentists. The research questions addressed were:

Do people with diabetes or HIV disclose to dentists and why?

How do the experiences of patients with diabetes and HIV compare?

METHOD

This explorative study used qualitative methods to explore why patients with chronic disease may or may not report their medical history to the dentist. In total 20 semi-structured telephone interviews were conducted, with 10 participants attending the diabetes clinic and 10 attending the sexual health clinic at a large teaching hospital. Although small from a quantitative, experimental paradigm, using samples of this size has been shown to be an efficient, practical and yet robust strategy to obtain rich data, explore understanding and identify emerging themes in qualitative, in-depth semi-structured interview designs.[13,14,15,16] Participants were asked to fill out a short questionnaire. At the end of the questionnaire participants were given the opportunity to provide their contact details if they wished to be included further in the study using telephone interviews. Data were collected through semi-structured telephone interviews using an interview schedule to ensure that all areas of interest were covered but allowing for flexibility

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to pursue issues that may arise. Interviews started with asking participants general questions such as gender and occupation. This was followed by a series of disease specific questions covering their disease and diagnosis history. The final part of the interview explored disclosure of medical history to the dentist. All interviews were recorded and transcribed verbatim and the data were analysed following the standard four-stage process (familiarisation, coding frame development, coding, compiling themes).[17] Transcripts were only reviewed at the end of the data collection process and as such, findings were not used to influence participant recruitment.

RESULTS

Participants were approached by members of the clinical team in the reception area while attending the clinics. Out of 40 people (20 HIV and 20 diabetes) who filled out the short questionnaire, 20 people (10 HIV and 10 diabetes) agreed to participate further in telephone interviews. In total six themes emerged from the data: demographics (age); history of diagnosis; history of disclosure; stigma (enacted and felt); trust in dentists; and knowledge and presence of oral side effects. These themes are discussed as a narrative with quotes used from the interviews to reinforce the ideas.

Demographics – age

Participants in this study diagnosed at a younger age appeared less likely to disclose. One 21-year-old woman, newly diagnosed with type 1 diabetes, was not aware that the dentist needed to know her diagnosis; *'I'm not sure, does he need to know'*. In contrast, a man recently diagnosed with diabetes at the age of 43 years stated that he discloses his medical history to the dentist as a precaution: *'in case anything happens'*.

The same pattern was found within the HIV sample. A 38-year-old student with a recent diagnosis of HIV did not disclose his medical history to the dentist but in contrast a 61-year-old diagnosed with HIV within the last seven years discloses his medical history to the dentist and always has done.

It is unclear why there is a link between age and disclosure. One possibility could be related to the level of information or understanding an individual has about their diagnosis. For example, a woman diagnosed with diabetes at a young age said: *'I didn't take it seriously when I was young; it's only now because I have started to get some of the side effects.'*

This may also be linked to how serious an individual feels that their diagnosis is. One individual who has a dual diagnosis of HIV and diabetes suggests that people prioritise conditions regarding disclosure: *'I guess some people don't because they think it's only diabetes, especially if they have more important things to tell like HIV.'*

Therefore, individuals with other diagnosed medical conditions may prioritise disclosure according to the perceived importance of the competing diagnoses. There is also a suggestion that some participants see diabetes as a part of the ageing process and not strictly as a chronic illness. For example, one 62-year-woman who has never had side effects with her diagnosis stated: *'I'm not really ill, just getting old.'*

History of diagnosis

One factor which seemed highly significant in disclosure was the socio-historical context of the diagnosis. For example, one individual diagnosed with HIV in the 1980s does disclose but suggests that he is much more likely to disclose now because there was a significant stigma around HIV in the 1980s which is less apparent today. *'The difference between now and then is it is not much of a taboo subject any more.'*

The same relationship between socio-historical context and disclosure can also be found in those diagnosed with diabetes. One woman who was diagnosed with diabetes as a young child does disclose to the dentist and again highlights positive changes in the public reaction to diabetes. *'There was a lot more stigma years ago when I was first diagnosed but not now. I am much more comfortable with my diagnosis now than when younger.'*

At a more personal level, individual reactions and perceptions were also significant. Some patients are very shocked by their diagnosis and struggle to accept it. Refusing or being unable to accept a diagnosis can make participants less likely to disclose. One woman aged 21, diagnosed with diabetes who does not disclose explained: *'it's still sinking in – I was really shocked I don't want to take insulin for the rest of my life and my diet has to change massively'*.

Perhaps unsurprisingly, the same response was encountered from those diagnosed with HIV. One 53-year-old male acknowledged that he was very unhappy with the diagnosis: *'[I had] a very bad reaction, I was not expecting my diagnosis. It was devastating; I was very shocked that it happened.'*

The results from these interviews suggest a link between general levels of disclosure of HIV and disclosure to the dentist. Perhaps unsurprisingly, those who disclose to friends and family are more likely to also disclose to their dentist. One female participant, who had chosen to disclose her diagnosis of HIV to the dentist, explained that she was not worried about disclosure, even where family members used the same dentist, as they also knew about her diagnosis. *'No, because my family all know.'* This could suggest that support or behaviour of family members towards an individual's diagnosis may sway an individual from disclosing in other environments.

However, some participants were happy to disclose to dentists and other healthcare professionals while taking steps to avoid discovery by family and friends. One woman chose to disclose to her dentist but ensured that she used a different dentist from her family so that they would not inadvertently discover her diagnosis. *'Because I would be worried they would find out.'*

A final group of participants chose to disclose neither generally nor within a healthcare context. *'I think some people find it difficult to disclose and that's how I lived my life for a very long time. It's only been the past year that I've told anyone, let alone sort of medical professions.'*

All the participants with diabetes interviewed disclosed their history to their friends and family and there did not appear to be a link between general disclosure and healthcare specific disclosure in those with diabetes.

Felt stigma

One young 38-year-old male, newly diagnosed with HIV and diabetes, does not disclose his HIV status to the dentist, but does disclose his diagnosis of diabetes. This

was in fear of being treated differently by the dentist due to his HIV diagnosis. *'There isn't much stigma associated with [diabetes] dentists may treat me differently.'*

Due to changes in public opinion, levels of 'felt' stigma appears to be improving in HIV. *'The difference between now and then is it is not as much of a taboo subject anymore.'*

Public opinion also seems to changing with regard to type 2 diabetes, with negativity increasing because of its association with obesity. For example, one young female recently diagnosed with diabetes, was concerned about her grandmother having diabetes because she is fat. *'My Nan got it because she is fat! I'm not fat yet though.'*

Enacted stigma

'Enacted' stigma at the dentist, for those diagnosed with HIV, seems to be a very big factor in adapting an individual's disclosure behaviour, with many examples of past negative experiences causing individuals not to disclose, but also past positive experience that have actively encouraged disclosure. The general consensus, however, is that attitudes and opinions of dentists seem to be improving.

One participant describes his past experience at the dentist, when he and his entire family were not allowed to attend any of his local dentists because they found out they had HIV. *'The first dentist I ever had, found out that I was HIV positive during some surgery and boycotted me and my family in the area that we lived. It was a horrible experience and I didn't go to the dentist for about fourteen years after that.'* He goes on to talk about opinions changing and progressing within the dental profession, and finding a dentist that did accept them. *'Then as opinions changed and progressed within the medical community, we found another dentist.'* He followed on to say that this new dentist's opinion was very different and the experience was much less stigmatising.

Stigmatisation like this can have a profound effect of an individual's life. For example, this participant also states that this one experience with the dentist made him less likely to disclose in other social and professional circumstances: *'with my history of what happened with my dentist when I was younger has made me very secretive about everything in my life not just my illness.'*

There are, however, individuals that have had a very positive experience with the dentist. One participant does disclose her diagnosis of HIV to the dentist and states never having a problem with her dentists due to her HIV diagnosis. *'My dentist was absolutely fine with it, he was very friendly and didn't bat an eyelid.'*

There was little evidence in the data that shows enacted stigma in an individual diagnosed with diabetes.

Trust in dentists

The data shows that that trust in dentists may affect an individual's disclosure behaviour, mainly relating to HIV. The lack of trust on the part of those diagnosed with HIV could be attributed to the fear of breach in confidentiality. Interestingly, it was apparent that individuals felt more confident to disclose in a hospital, due to greater confidence in confidentiality. This lack of trust showed a serious impact on an individual's disclosure behaviour.

'I had some dental treatment done at the hospital recently and I did tell them, but that's because I felt more comfortable with it being a hospital. They have more repercussions if they break my confidentiality. With the high street dentist they have the doors open with people walking past and young nurses and receptionists. I just don't trust them.'

However, not all participants feared confidentiality was an issue with their dentist, and this was mainly in those who had disclosed to significant others already. Indeed, one 45-year-old male had every confidence that his high street dentist would keep his diagnosis confidential, but interestingly did not disclose to the dentist, as he felt that with universal precautions it was not necessary. *'I just trust that the dentist will keep it confidential.'*

Some participants with HIV discussed either fearing being mistreated by the dentist or actually experiencing mistreatment. This was given as a main factor behind not disclosing their HIV status to dentists. *'I haven't been back as I wasn't happy with the response that I received* [after disclosing]. *I am trying to find a new dentist that will take me on. I'm not sure if I would tell them now because of the last dentist.'*

There was no evidence of lack of trust in relation to treatment or confidentiality in the diabetes sample. Although one woman suggested that she did not understand why her dentists needed to know her diagnosis and thought they were just being nosey, suggesting a possible lack of trust in the dentist's professional judgement.

Knowledge and presence of oral side effects in HIV and diabetes

Only two participants with diabetes disclosed to their dentist because they knew of oral side effects of diabetes and the ramifications it can have on their dental treatment: *'the gum disease really'; 'in case I have any cuts in my mouth [and] they will want to do treatment with local anaesthetic instead of a general.'*

Both these participants had also discussed the oral side effects of diabetes with their dentist, and one participant had also had a course of treatment to resolve some gum disease.

Only one participant with HIV gave potential oral disease as the importance of disclosing to the dentist. *'Health reasons like bleeding gums.'*

Despite understanding this, the participant still does not disclose to the dentist because of his fear of stigma and the possibility of a breach of confidentiality.

Most individuals interviewed with both diabetes and HIV, were not aware of the potential oral risks. Most individuals had never discussed this with a dentist. None of the participants were advised by doctors at diagnosis that it was important to see a dentist and why.

DISCUSSION

Disclosure of HIV or diabetes to the dentist is essential to enable effective and tailored treatment of dental disease, but more importantly prevention of oral disease for those more at risk.

It has been indicated in the literature that stigma is a major cause for individuals not disclosing their medical history to the dentist.[9] There are many examples in this study of stigma that go some way to explain why some individuals with HIV or diabetes may not disclose their medical history. There are obvious differences between diabetes and HIV and it would seem, perhaps unsurprisingly, that there is a greater level of stigma with HIV.

It would appear that public opinion is improving with regard to those diagnosed with HIV. Public opinion also seems to be changing with regard to diabetes, with negativity increasing because of its association with obesity in type 2. This may have ramifications for the future with regard to on an individual's disclosing behaviour in both HIV and diabetes. Most individuals with HIV felt that dentists' opinions of them were improving. No individual interviewed with diabetes felt that the dentist had a negative opinion of them and there was no evidence of enacted or felt stigma in diabetes in the dental setting.

Table 1 A summary of advice and some recommended resources when communicating medical histories with the dental patient

A guide to communicating medical histories with the patient
Always discuss the patient's medical history in detail even if they have filled out a form
Removing 'are you fit and healthy' from your medical history form may be appropriate
Discuss the patient's medical history in a private room with the door closed
Always reassure confidentiality
Always have a positive attitude and respect towards individuals diagnosed with a long-term condition
Always discuss the oral ramifications and the greater risks of oral disease associated with some chronic diseases
Communication resources
Dougall and Fiske 2008, *BDJ* series. Special care dentistry. Part 2: communication[18]
Rozier *et al.* 2011, Dentist-patient communication techniques used in the United States[19]
Kalet *et al.* 2004 Teaching communication in clinical clerkships: models from the Macy Initiative in health communications[20]

The data suggests that although many individuals fear stigma, other factors play a huge role in disclosure. Previous quantitative studies have shown that age may be a significant factor in medical history disclosure.[10] This analysis revealed that participants diagnosed at a younger age were less likely to disclose in both HIV and diabetes. However, the relationship between age and disclosure is dynamic and more analysis is required to explore this further.

Some studies have alluded to the fact that an individual's understanding of their diagnosis, may have an effect on their disclosure behaviour.[11] This study also showed non disclosure was also linked to how serious an individual felt their diagnosis was. This came out as a particular issue for those diagnosed with diabetes, who saw it as unproblematic, so they did not understand why a dentist would need to know. Diabetes is also generally diagnosed much later on in life and there was a suggestion that some participants see diabetes as a part of the ageing process and not strictly as a chronic illness, possibly making them less likely to disclose.

There is already literature to suggest that many individuals with chronic disease do not feel unwell and therefore do not associate their diagnosis with ill health.[12] This may result in non disclosure of medical history to the dentist, especially if combined with a lack of understanding as to why the dentist needs to know. Some individuals with other diagnosed medical conditions may prioritise disclosure according to the perceived importance of the competing diagnoses. One individual also suggests that because the first question on the medical history at the dentist is – are you currently fit and healthy? She didn't see the relevance in filling the rest of the form out.

Individual reactions and perceptions were significant in disclosure. Some patients were very shocked by their diagnosis and struggled to accept it. Refusing or being unable to accept a diagnosis can make participants less likely to disclose both HIV and diabetes. It would seem likely that acceptance of a diagnosis would make a participant more likely to disclose, but some HIV participants who reported accepting their diagnosis, still did not disclose to their dentist.

In addition to the psychosocial response of being diagnosed with a long-term condition, a diagnosis of HIV or diabetes can mean massive changes in lifestyle. Struggling to come to terms with the lifestyle shifts may make individuals less likely to disclose to their dentist.

This study showed that perhaps unsurprisingly those who disclose to friends and family are more likely to also disclose to their dentist. The relationship does not always work the other way around, however, and some participants were happy to disclose to dentists and other healthcare professionals, while taking steps to avoid discovery by family and friends. A final group of participants chose to disclose neither generally nor within a healthcare context. There were also obvious differences found between HIV and diabetes. All the participants with diabetes interviewed disclosed their history to their friends and family. There did not appear to be a link between general disclosure and healthcare specific disclosure in those with diabetes.

This study shows that the vast majority of HIV participants used risk of transmission as their motivating factor for disclosing to the dentist. However, they were also aware of the universal cross infection precautions that dentists use for all patients, and didn't actually feel concerned regarding transmission to others. Some did not feel it necessary to disclose because of universal precautions but still felt the dentist had the right to know.

The data would suggest that very few of the participants with HIV and diabetes understand the ramifications of their diagnosis on their dental treatment. They also had not discussed the matter with their dentist or medical professionals on diagnosis. It does, however, seem that once individuals with diabetes are made aware of the oral side effects of their diagnosis, they are more likely to disclose to the dentist. The case is different for individuals with HIV and the data suggests that despite some participants with HIV understanding why a dentist should be aware of their diagnosis, they may not necessarily be more likely to disclose their status due to overriding factors.

The results suggest that some individuals with HIV lack confidence in dentists keeping confidentiality and this was seen mainly in those who had not disclosed to significant others. Some participants with HIV discussed either fearing or actually being mistreated by the dentist as the main factor behind not disclosing their HIV status. Individuals with diabetes do not appear to have any trust issues surrounding disclosure to their dentist. Behaviour of dentists towards their patients and a lack of trust that some patients have, can be a highly emotive reason as to why individuals may not disclose their medical history.

CONCLUSION

This study highlights the multi-factorial paradigm behind self-disclosure of medical histories. While a lack of disclosure can be found among those with a diagnosis of HIV or diabetes, it appears that the reasons behind non disclosure are different for each. This study like others, confirms the role of stigma in disclosure behaviour. However, it also highlights that disclosure behaviour can be affected by age, history of diagnosis, history of disclosure, professionalism of dentists, and knowledge and presence of oral effects.

This study has clear implications for dental professionals, in the way in which medical histories are taken and discussed with patients, to improve medical history disclosure. For example, asking if the patient is fit and healthy at the start of a medical history may not be appropriate. There is a need for more information to be made available for individuals with chronic conditions and the impact their diagnosis can have on their dental health and treatment. Working with other medical professionals is key to educating these individuals as to the importance of dental attendance and disclosure when they are first diagnosed. The study also highlights the need for the dental team as a profession to address how they behave and communicate with their patients, taking individual factors into consideration. Patients should feel comfortable to disclose with key consideration given to the environment where disclosure occurs, and reassurance given in confidentiality. See Table 1 for a summary of advice and some recommended resources to assist the dental team with communicating regarding medical histories.

1. Cook L B, Elemans M, Rowan A G, Asquith B. HTLV-1: Persistence and pathogenesis. *Virology* 2013; **435:** 131–140.
2. Knowler W C, Barrett-Connor E, Fowler S E *et al.* Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin. *N Engl J Med* 2002; **346:** 393–403.
3. Scully C, Boyle P. Reliability of a self-administered questionnaire for screening for medical problems in dentistry. *Community Dent Oral Epidemiol* 1983; **11:** 105–108.
4. Marks G, Bundek N I, Richardson J L, Ruiz M S, Maldonado N, Mason H R. Self-disclosure of HIV infection: preliminary results from a sample of Hispanic men. *Health Psychol* 1992; **11:** 300–306.
5. Scambler G. Health-related stigma. *Sociol Health Illness* 2009; **31:** 441–455.
6. Charbonneau A, Maheux B, Béland F. Do people with HIV/AIDS disclose their HIV-positivity to dentists? *AIDS Care* 1999; **11:** 61–70.
7. Mitchell M M, Knowlton A. Stigma, disclosure, and depressive symptoms among informal caregivers of people living with HIV/AIDS. *AIDS Patient Care STDS* 2009; **23:** 611–617.
8. Martin L M, Leff M, Calonge N, Garrett C, Nelson D E. Validation of self-reported chronic conditions and health services in a managed care population. *Am J Prev Med* 2000; **18:** 215–218.
9. Moore G A, Hawley D A, Bradley P. Hepatitis C: studying stigma. *Gastroenterol Nurs* 2008; **31:** 346–352.
10. Wu S C, Li C Y, Ke D S. The agreement between self-reporting and clinical diagnosis for selected medical conditions among the elderly in Taiwan. *Public Health* 2000; **114:** 137–142.
11. Fenlon M R, McCartan B E. Validity of a patient self-completed health questionnaire in a primary care dental practice. *Community Dent Oral Epidemiol* 1992; **20:** 130–132.
12. Robinson P G. Implications of HIV Disease for Oral Health Services. *Adv Dent Res* 2006; **19:** 73–79.
13. Crouch M, McKenzie H. Social realities of loss and suffering following mastectomy. *Health* 2000; **4:** 196.
14. Crouch M, McKenzie H. The logic of small samples in interview-based qualitative research. *Soc Sci Info* 2006: **45:** 483.
15. Kai-Cheong Chan, N, Gillick A C. Fatness as a disability: questions of personal and group identity. *Disability Soc* 2009; **24:** 231–243.
16. Bourke, S, Burgman I. Coping with bullying in Australian schools: how children with disabilities experience support from friends, parents and teachers. *Disability Soc* 2010; **25:** 359–371.
17. Green J. The use of focus groups in research into health. In Saks M, Allsop J (eds). *Researching health: qualitative, quantitative and mixed methods.* p. 112. London: Sage, 2007.
18. Dougall, A, Fiske J. Special Care Dentistry: Part 2: Communication. *Br Dent J* 2008; **205:** 11–21.
19. Rozier, G R, Horowitz, A M, Podschun G. Dentist patient communication techniques used in the United States: The results of a survey. *J Am Dent Assoc* 2011; **142:** 518–530.
20. Kalet A, Pugnaire M P, Cole-Kelly K *et al.* Teaching communication in clinical clerkships: models from the Macy Initiative in health communications. *Acad Med* 2004; **79:** 511–520.