

Stigma Around HIV in Dental Care: Patients' Experiences

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Abstract

Tooth decay and other oral diseases can be highly prevalent among people living with HIV/AIDS (PLWHA). Even though dental professionals are trained to provide equal and non-judgemental services to all, intentional or unintentional biases may exist with regard to PLWHA. We conducted qualitative descriptive research using individual interviews to explore the experiences of PLWHA accessing dental care services in Vancouver, Canada. We interviewed 25 PLWHA, aged 23–67 years; 21 were men and 60% reported fair or poor oral health. Thematic analysis showed evidence of both self-stigma and public stigma with the following themes: fear, self-stigma and dental care; overcoming past offences during encounters with dental care professionals; resilience and reconciliation to achieve quality care for all; and current encounters with dental care providers. Stigma attached to PLWHA is detrimental to oral care. The social awareness of dental professionals must be enhanced, so that they can provide the highest quality care to this vulnerable population.

The World Health Organization Special Programme on AIDS advised the world on 3 phases of the HIV/AIDS epidemic: the HIV epidemic, the AIDS epidemic and the epidemic of stigma–discrimination–denial.¹ In fact, stigma remains a challenge for those living with HIV/AIDS as it has a negative impact on their lives and well-being.^{2,3}

According to Link and Phelan (2006), stigma involves 5 intertwined components: labeling, stereotyping, social exclusion, discrimination and power relations.⁴ Labeling refers to human differences that are often tied to negative stereotyping. Social exclusion may then occur in the form of separation or isolation from the rest of society. Discrimination takes place when someone is discredited by others. The final component of stigma occurs when various power structures (e.g., social, political, economic) are used to confirm and perpetuate discrimination against a person or group.⁴

Public or social (external) stigma entails forming negative beliefs about specific groups and is reinforced by laws, policies and administrative actions.⁵ Self or internal stigma occurs when individuals have negative attitudes about themselves, and may or may not be a result of public stigma.⁶ Stigma is also influenced by whether a person is judged to have a choice in the acquisition of the stigmatizing trait. The self-imposed stigma of being HIV positive may be stronger than that for any other condition (such as diabetes), especially among those raised in a society that has taught them stigmatizing beliefs about HIV in general.⁷

In 2012, there were approximately 71 300 Canadians with diagnosed HIV.⁸ Dental professionals play a significant role in their health outcomes as HIV progression can be associated with the development of specific oral pathologies, even before a formal diagnosis of HIV infection is made.^{9,10} Nonetheless, people living with HIV/AIDS (PLWHA) may be reluctant to get help because they fear judgement, rejection and stigmatization once they disclose their HIV status.¹¹ Although efforts to reduce HIV-related stigma and discrimination have been a common struggle around the world,^{12,13} there is still unwillingness to care for PLWHA based mainly on preconceived assumptions and misconceptions.

Little is known about how PLWHA experience stigma in dental settings in the Canadian context. The objective of our study was to better understand the stigmatizing experiences of PLWHA seeking oral care.

Methods

We conducted qualitative research using individual interviews to examine oral health-related issues in great detail.¹⁴⁻¹⁶ In this study, we used a descriptive approach¹⁷ to offer a comprehensive summary of participants' experiences with stigma. We conducted semi-structured individual interviews after obtaining informed consent from a convenience sample of participants, who were English speaking and over 19 years of age, had a known HIV positive diagnosis and had sought oral care at least once in their lifetime.

Between March and July 2012, we recruited participants by placing posters in 2 community centres in East Vancouver and 2 HIV-focused organizations in downtown Vancouver. We had worked with these organizations during previous studies, and they showed an interest in partnering again. The community centres offer information on HIV-related issues, including prevention, while the HIV organizations offer support, resources and social activities specifically to PLWHA. We used a purposeful sample of participants who were "information-rich"¹⁸ on issues related to their experiences with stigma as per the poster's call: "If you are interested in engaging with other HIV-positive individuals and would like to voice your experience in assessing (or not) dental care, we would like to hear what you have to say. Come on board!"

Potential participants signed on to be part of the study at the information desk in the 4 locations during the 5-month study period. Every 2 weeks, MAB dropped by the locations to collect the email address or telephone number of those interested. A total of 25 people, aged 23–67 years old and living with HIV from 1.5 to 27 years, gave their contact information and were interviewed. Of them, 21 were men, 15 self-identified as Caucasians and 60% self-reported having fair or poor oral health.

Participants also filled out an information sheet containing questions about their educational level, marital status and self-perceived oral and general health (Table 1).

Individual Interviews

Each participant was interviewed once in a designated room at the centre or organization where he or she enrolled in the study. Interviews lasted 34–79 minutes and were audio-recorded for transcription and analysis. A trained research assistant conducted the interviews following a specific guideline and using semi-structured open-ended questions that covered the following topics.

- HIV/AIDS knowledge, values and beliefs: What participants know about HIV transmission, their personal values and beliefs
- Personal experience with stigma: What participants understand by "stigma," how stigma was experienced and how that made them feel
- Oral health education and advocacy needed to reduce stigma: How participants perceive the relation between oral health and the HIV condition, what is needed to decrease stigma in society and professional organizations
- Perceptions of facilitators and barriers to decreasing HIV/AIDS stigma: What resources are available (or not) to decrease stigma, why HIV stigma may still exist

These topics were selected from the existing literature on HIV transmission, stigma and access to health and dental care. They were addressed in the interview guide by such questions as: What do you know about HIV transmission? Have you disclosed your status to your dental team? If yes, why? Did they [dental professionals] make you feel comfortable about disclosing your HIV status? If no, why? Have you ever experienced stigma/discrimination in a dental setting? If yes, how? Given the nature of qualitative research, questions were slightly modified as the interviews progressed. Probing questions were added to tease out more information when needed, and participants were encouraged to disclose any experience related to the topics.

Data Analysis

We adapted the steps suggested by Braun and Clarke¹⁹ to conduct constructivist thematic analysis, while incorporating the structured coding procedures described by Saldaña.²⁰ We used NVivo 9 software (QSR International, Melbourne, Australia) to code the transcripts and keep track of interpretive phases of the analytical process, which helped ensure dependability and confirmability of our interpretations.

The first step consisted of carefully reading each transcribed interview to become familiar with its content while coding the main ideas. Coding was done by selecting sections of the transcript dealing with a particular topic. Two of us (MB and NRM) coded the first interview separately, and then

Table 1 Demographic information from the 25 participants in Vancouver.

Ethnicity	Age (years)	Sex	Marital status	Education	Years since HIV diagnosis	Self-reported oral health	Self-reported general health
White	59	M	Single	High school	27	Poor	Fair
	55	M	Separated	Elementary school	19	Poor	Good
	38	M	Single	High school	9	Fair	Excellent
	50	M	Divorced	High school	13	Poor	No answer
	25	M	Divorced	University	2	Fair	Fair
	55	M	Single	High school	11	Good	Poor
	29	F	Divorced	Elementary school	8	Good	Excellent
	52	F	Single	High school	20	Excellent	Excellent
	23	M	Divorced	University	2	Fair	Excellent
	35	M	Separated	High school	3	Poor	Fair
	39	M	Married	Elementary school	12	Excellent	Good
	37	M	Single	High school	8	Fair	Excellent
	52	M	Divorced	High school	14	Poor	Poor
	25	M	Divorced	University	2	Fair	Good
44	M	Single	High school	14	Good	Poor	
Aboriginal	33	M	Divorced	High school	9	Fair	Good
	39	F	Widow	Elementary school	11	Good	Fair
	67	M	Widow	Elementary school	16	Good	Good
	24	M	Single	Less than elementary school	1.5	Good	Good
Chinese	49	M	Single	Elementary school	12	Fair	Good
	64	M	Single	Grade 10	17	Fair	Fair
Latino	52	F	Single	High school	10	Poor	Good
	36	M	Married	Elementary school	5	Good	Excellent
	41	M	Single	High school	12	Poor	Good
	24	M	Single	University	4	Good	Good

Note: M = male, F = female.

met to check for consistency. Differences in coding were discussed until consensus was reached. NRM coded the remaining transcripts, informing the other authors regularly of the findings. Similar codes were then combined so that we could make assertions pertaining to our objectives.

The final step involved revising and recombining codes in a cross-interview pattern-analysis to identify themes and subthemes.

Findings

Our study revealed the influence that both self-stigma and public stigma have on PLWHAs who seek dental care. Four themes emerged: fear and self-stigma in disclosing one's HIV status; overcoming past offences during encounters with dental care professionals; resilience and reconciliation to achieve quality care for all; and current encounters with dental care providers.

Fear, Self-Stigma and Disclosing One's HIV Status

Participants described their struggles with anxiety and fear associated with dental professionals' reactions and responses to their HIV status. For example, anxiety was induced by questions that went through a participant's mind.

[It's] hard enough to go in there, and having to say that you're HIV positive. You think "Is this office prepared for that?" and all the questions that goes with it? That makes me apprehensive. [P21, male with HIV for the past 17 years]

Another participant emphasized the importance of learning how to contain the fear and distress of being HIV positive while trying to focus on finding dental professionals who would make them feel comfortable despite knowing their HIV status.

[J]ust learning to not to be afraid of it [HIV]... just being comfortable with who you are and who

you're going to see. I'm a peoples person and I can read people fairly good. [P3, male with HIV for the past 9 years]

Indeed, the fear of disclosing one's HIV status was closely related to self-stigma for some: "HIV is like a curse and it is on your face. You try to hide, you try to avoid talking about it, you try to avoid bringing it up" (P17, female with HIV for the past 11 years).

Participants also indicated concern about confidentiality. For example, one participant reported

fear of sharing personal health matters with someone else, even a health care provider.

[I] think a lot of the fear is the fear of stigma and of people finding out... having that information not in your hands anymore and out of control, you know, because it's a private health matter that you're sharing with a professional who is going to be in your life, and who will know who you are. [P19, male with HIV for the past 3 years]

On the other hand, when participants felt confident and secure, they experienced less stress when disclosing an HIV-positive status.

I feel confident with my dentist. I can pretty well say anything, making sure you can divulge information properly and securely in your life, 'cause you know, something like I said my own family doesn't know I have it. [P9, male with HIV for the past 9 years]

Our findings indicated that self-stigma motivates participants to look for dentists who are knowledgeable and caring toward PLWHA and with previous experience in treating HIV patients. Participants believed the active seeking of an experienced dentist influenced their overall wellness. For others, self-stigma was also deeply engrained as participants still questioned HIV transmission routes despite the universal precautions regularly used in dentistry.

[D]entists have to know how to sterilize all of their stuff to make sure there's no particles and things... because they are drilling inside your mouth and if HIV gets in there, BANG, you can contaminate others, isn't that right? [P17, male with HIV for the past 18 years]

Overcoming Past Misdemeanours during Encounters with Dental Care Professionals

"Misdemeanour" encompasses any discriminatory, labeling, stereotyping and other unprofessional behaviour observed or felt by the participants. For example, participants felt that the patient–dentist relationship changed once HIV status was revealed.

You could see it on him... that there was just not that spirit there anymore, it was like there was no feeling, not responding the way he was before I disclosed my HIV status. [P9, male with HIV for the past 2 years]

The possible change in the dental care experience as perceived by participants was also related to the fact that some dentists automatically labeled patients as "infectious." PLWHA reported being told "sorry, we don't have anybody to deal with that [HIV/AIDS]" (P1, male with HIV for the past 27 years), while others were turned away because the clinic was reportedly full and could not take them on as a patient.

[T]he first [dental clinic] was all good... but as soon as the HIV issue came up, they were all full and there was no time. I had to find another dentist. The second dental

clinic I went to was the same. They both basically said they were full and didn't have the time but that didn't come up until I was open about HIV. I have experienced direct discrimination. [P22, female with HIV for the past 10 years]

Other discriminatory experiences included watching dentists double-glove and use extra protection "as if we were highly infectious or contaminated, or else" (P19, male with HIV for the past 1.5 years). Participants found this behaviour discriminatory and insulting and believed that it negatively affected their self-esteem because it was seen as a reflection of society's perceptions of PLWHA.

One participant also indicated that their HIV status caused dental professionals to assume that they were drug users, further contributing to discriminatory behaviour.

[D]rug use is a big one that comes with being HIV positive too because we are stigmatized already and you get further stigmatized about drug use... but drug users don't have to be HIV positive and not all HIV positive [people] are drug users. [P6, male with HIV for the past 11 years]

Participants also noticed other stigmatizing and discriminatory behaviour by dental professionals, both subtle and overt, including avoiding eye contact, dismissing a request or comment, not shaking the patient's hand, using scented aerosol spray after the patient left and referring the patient to another professional without fully explaining the reason. These behaviours were described as vividly experienced by participants; we did not attempt to confirm how they knew about such behaviours. Some participants also stated that dental office staff acted strangely and fearful while providing services to them.

Stigmatizing experiences also occurred with regard to the \$1000 for dental care that PLWHA may be entitled to receive every 2 years as a Canadian disability insurance benefit. Participants emphatically stated that some dentists did not accept such insurance while others said, "It is not enough; it does not take you too far when you have lots to be done" (P13, male with HIV for the past 14 years). Others, however, were somewhat content with having some dental coverage, which may have been an incentive for them to be more engaged in oral self-care.

Resilience and Reconciliation to Achieve Quality Care for All

Resilience has been a long-term companion for those affected by HIV. The ability to be resilient seems to be protective against self-stigma. Participants also made use of available resources to better frame their individual response to HIV.

I like to come here [to the organization where the interview was taking place] as I feel safe. They offer material and information that have helped me to understand better what I was going through, the need to

adhere to the medication. They even [provide] spiritual support. [P24, male with HIV for the past 12 years]

Others seemed to have relied on family and close friends to find inner strength, as expressed by P2 (a male with HIV for the past 19 years): "If it wasn't for my family, I wouldn't be here today. They supported me all the way and still do, even when I doubt myself and was feeling ashamed for being [HIV] positive."

Despite all the challenges and barriers, PLWHA seem to continue to seek care, strive for optimal oral health and try to overcome adversities related to their HIV diagnosis. Even though most participants (60%) reported having fair or poor oral health, some added that "it could have been much worse, much worse, like my parents who do not have HIV and have no teeth left" (P16, male with HIV for the past 9 years).

According to some participants, reconciliation would entail coming to terms with oneself in the face the infection: "It was not long after I accepted that I got infected that I could look myself in the mirror and re-start taking care of my health... my teeth were horrible after years of neglect" (P18, male with HIV for the past 16 years).

For others, reconciliation would require both society at large and dental professionals to become more knowledgeable about HIV and create a stigmatizing-free environment. For example, some suggested a Q&A session for dental professionals about HIV and oral health. Without being specific, other participants suggested that greater knowledge and education could act as powerful tools to improve understanding of the disease progression.

[K]nowledge, knowledge and education... you should be well informed of who you are and your own history of dental care, that's all you need for HIV, for your health, for anything, doesn't matter what. I guess I do need more of that education. [P4, male with HIV for the past 13 years]

Participants believed that providers' increased knowledge and clinical experience would lower self-stigma and act as a bridge to improve the relationship between the patient and the dentist.

Current Encounters with Dental Care Providers

According to our participants, bad experiences with dental professionals had happened in the past; they were now under the care of "friendly and open-minded, very knowledgeable and non-judgemental dentist(s)" (P7, female with HIV for the past 8 years). In fact, despite past discriminatory experiences, participants indicated that their current dental encounters were quite positive, and referred to advances in communication and at-your-finger-tips information.

When the [HIV] was discovered back in 1980s, there [was] general fear caused by misinformation or the unknown. Today, almost anywhere you go, you have

all sorts of pamphlets, brochures, and newsletters that can enlighten those seeking for knowledge. [P11, male with HIV for the past 12 years]

Other participants gave examples of how they experienced dental care recently. For one (P3, male with HIV for the past 11 years), it was important that his current dentist was well informed about HIV and able to perform procedures without being fearful or judgemental: "[T]he dentist was well informed. He understood the ways to get HIV, not from my saliva. He was quite talkative and concerned with my health. I felt at ease."

Likewise, other participants reported experiencing less stigma and discrimination when they encountered dental care professionals with higher levels of HIV knowledge and a non-judgemental demeanor. Nonetheless, they did mention that such good experiences may be a result of the fact that they live in a metropolitan area, while "up north or in the suburbs, I heard that some dentists are still refusing or finding lame excuses to not provide care to an HIV positive client" (P15, male with HIV for the past 14 years).

Discussion

To achieve our objective of better understand the stigmatizing experiences of PLWHA seeking oral care, qualitative research was an appropriate method for exploring such sensitive issues. Although the scientific literature is filled with information about the biomedical aspects of HIV,^{21,22} much less emphasis has been placed on the experiences of PLWHA.²³ Participants in our study reported feeling directly or indirectly labeled, stereotyped, excluded, isolated and discriminated against when they sought care from dental health professionals, which supports the findings of Link and Phelan.⁴ As most participants in our study had experienced negative responses from dental health professionals in the past, their oral health may have deteriorated. In fact, 60% still reported having fair or poor oral health even though some are currently seeing a dental professional.

Our findings are consistent with the fact that public stigma toward HIV directly influences self-stigma. A study among PLWHA in South Africa found that more than 30% of participants felt dirty, ashamed or guilty about their HIV infection,²⁴ feelings shared by some of our participants, particularly in terms of guilt over having the disease. Moreover, our participants felt immense anxiety related to the public's perceptions of HIV; they have acquired a condition that was ostracized long before they were diagnosed.⁷ For health care providers, rejection seems to be the easiest way to achieve social distance from stigmatized populations.

To avoid discrimination, participants sought dental clinics where they knew the providers had previous experience treating PLWHA and were more knowledgeable,

open-minded and friendly. Our findings are consistent with those of Ingram and Hutchinson (1999),²⁵ who reported that patients' experience of being "labeled" by health care providers made them feel they had lost their identity. This phenomenon of depersonalization and derealization has also been documented with respect to people stigmatized for being overweight.²⁶

Participants told us that they perceived a change in their relationship with their dentist after they disclosed their HIV status. Dentists who have a more socio-humanistic approach may overcome issues that interfere with the normal routine of treatment.¹⁶ However, oral health care may still be denied to PLWHA. For example, the Alberta Dental Association and College²⁷ reported that 1 in 5 PLWHA is refused treatment by a dental professional and almost 40% of PLWHA spend more than a month finding another dentist. Similar situations were experienced by the participants in our study. Dental clinics that reject PLWHA, do not accept their government-sponsored dental insurance or lack professionals trained and competent to provide care to PLWHA are not complying with their duty to accommodate individual needs.²⁸

Participants pointed out that, in the past, their dentists wore extra protection when treating them. This practice is unwarranted, as universal precautions used in the current practice of dentistry are sufficient to make the risk of HIV transmission virtually inexistent from either dental professional to patient, patient to dental professional or even patient to patient.²⁷

Participants believed that stigma and discrimination were greater in the past, and they suggested that education, clinical experience and ready-to-use information might have helped reduce stigma. Because HIV content is included in the curriculum at most faculties of dentistry, new graduates tend to be more aware of HIV issues.²⁹ They may also be more aware of the historical context of the disease that may make some patients anxious about disclosing their HIV status and patients' past adverse encounters with dental professionals.

Education does not necessarily change behaviour, and young dentists have been observed to refuse to treat PLWHA.¹² Nonetheless, recent graduates should be more open-minded and less fearful. To instill this attitude, undergraduate dental curricula should not only cover HIV routes of transmission, treatment and implications for dental care, but also promote stigma-reducing activities, such as inviting PLWHA to share their stories with students.³⁰

Our study had several limitations. Although informative, the accounts presented here came from a diverse yet purposeful sample of participants; thus, they may not reflect those of all PLWHA. Aside from the small number of participants and the male predominance, we also did not explore the influence of ethnicity, educational levels, marital status or age on the views and experiences of

the participants. Moreover, the interview situation may have been intimidating to some participants, who may have been embarrassed or uncomfortable about sharing their stories. The types of questions posed during the interview may not have allowed them to share in-depth information. We also acknowledge that, because we did not observe any of the participants' experiences in dental settings, the reported stigmatizing incidents might have been a result of misinterpretation of the clinical situation.

Conclusions

The stigma attached to PLWHA can prevent optimal oral care and be detrimental to their overall health and well-being. Our study highlighted the need to prepare current and future dentists so that they thoroughly understand the needs of PLWHA. It also highlights the importance of keeping in perspective the historical impact the disease has had in terms of patients' comfort in disclosing HIV status and the harmful effects of previous adverse experiences with dental care professionals; PLWHA may feel stigmatized, labeled, stereotyped and discriminated against. Findings from our study may be used for educational purposes to enhance the social awareness of dental professionals about the complexities of navigating HIV disease.

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