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HIV-related Stigma in the Dental Setting: A Qualitative Study

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HIV; stigma; dental care; qualitative methodology; fears; expectations

Background

Persons living with HIV/AIDS (PLWHA) face many challenges that can negatively impact their health, well-being and quality of life^{1,2}. HIV-related stigma, as previously defined³⁻⁵, is known to occur in those who interact with PLWHA due to fear of acquiring HIV as well as the association of HIV with deviant behavior^{3,6}. HIV-related stigma is rooted in issues of homosexuality, gender, race and ethnicity, and class; further, HIV has been associated with other stigmatized behaviors such as sex work and injection drug use^{4,5}. PLWHA who experience stigma report not only lower levels of physical and mental health, but also reduced health-seeking behaviors^{2,7,8}. Therefore, health professionals need to be aware of and able to appropriately address stigma. By managing health care environments to reduce patients' experience of HIV-related stigma, health care providers may help promote greater health, well-being and quality of life for PLWHA.

Oral health is an important component of HIV management. With the advent of highly active antiretroviral therapy (HAART), PLWHA are living longer; therefore, maintaining oral health has become a long-term endeavor. HIV-related stigma may act as a barrier for PLWHA to access and use dental care. This is especially relevant because, even in the

HAART era, HIV-infected individuals are more susceptible to common oral diseases and their complications such as periodontal disease⁹⁻¹¹, xerostomia^{10,12,13}, and premature tooth loss¹⁴. When such oral conditions are left untreated, HIV positive adults are at increased risk for poor oral health outcomes.

HIV-related stigma may negatively impact oral health care utilization in PLWHA^{1,15}. Untreated oral disease and unmet oral health needs are high among PLWHA; previous investigators have found that between 20% and 58% of persons with HIV do not access the necessary dental services that they need¹⁶⁻¹⁸. Underutilization of dental services amongst PLWHA has been associated with lack of insurance, low income, low educational attainment and race/ethnicity¹⁹⁻²¹. Additionally, monetary cost and fear of the dentist have also been identified as barriers to seeking dental care among PLWHA^{10,21}. Recent HAART-era studies have found that HIV-related stigma concerns affect more than a quarter of individuals with HIV and dental needs^{1,22}. Herein, we present the findings of a qualitative study exploring the experiences and expectations of HIV-related stigma among a group of PLWHA receiving dental care primarily in a university setting.

Methods

This was a cross-sectional study of a volunteer sample of HIV+ adults age 18 and older. One-on-one semi-structured face-to-face interviews were administered to sixty-six HIV-positive adults at the Case Western Reserve University School of Dental Medicine between May 2011 and July 2011. The protocol was approved by University Hospitals Case Medical Center (UHCMC) institutional review board (IRB) and written IRB-approved informed consent was obtained on all subjects prior to study participation. Volunteer subjects either responded to IRB-approved rip-tag fliers or were telephoned from a list of persons who had previously expressed interest in past oral health-related research projects¹¹. Subjects were recruited primarily from the UHCMC HIV/AIDS medical clinic in Cleveland, Ohio and from our group's active referral base. Following the receipt of informed consent, interviews were audio-recorded in a private non-clinic room and digital recordings were stored on a password-protected secure server. To protect confidentiality, subjects were assigned a patient id (PID—e.g., S705) which was used in lieu of their actual name during audio recording. Subjects were compensated nominally (\$20) in cash for their time (approximately 60-90 minutes). From the entire interview, four open-ended questions were selected as a focused area of research; to our knowledge, none of these four questions had been used in previous medical or dental studies nor had they been validated. The four questions were transcribed verbatim and analyzed for theme and content following standard qualitative methods²³.

Responses to the following qualitative questions were analyzed:

- 1) Have you ever anticipated being judged, stigmatized or treated with disrespect in a dental setting due to your HIV status? If yes, can you please describe your thoughts?
- 2) Did you change the dentist you saw after your [HIV/AIDS] diagnosis?
- 3) If yes, did you inform [your dentist] that you were HIV-positive?

4) Since your diagnosis, have you ever felt hesitant about visiting a dentist?

Using ethnographic techniques²⁴, major themes and sub-themes were elicited in response to each of the four questions. Each participant may have had more than one response in the thematic analysis and data are presented based on response frequency as opposed to participant number. All data were coded and analyzed by two independent reviewers (NP and JF) and consensus was reached by a third observer (LV) in areas of discrepancy.

Results

Quantitative Results

Of the sixty six (66) HIV+ adult subjects that were interviewed, sixty (60) were included in the qualitative analyses. Six (6) audio tapes were saved on an alternate recorder that malfunctioned and/or experienced battery failure; subjects with missing audio recordings were excluded from the analyses. Most subjects were black (82%), and majority were male (78%) with an education beyond a high school degree or GED (see Table 1). Mean age was 49 years old and mean year of HIV seroconversion was 1996, with a mean time since HIV seroconversion of 15.7($\pm$ 7.2) years. Most subjects had seen a dentist in the past year and 32% of subjects had previously been involved in our prior dental research studies^{11,25,26} and an ongoing longitudinal study, “Immune and Inflammatory Consequences of Intensive Periodontal Disease Treatment in HIV+ Adults,” (R21 DE21376-01).

Table 1 shows the demographics of the study population:

Qualitative Results

Table 2 lists the number of subjects who responded “Yes” to each of the 4 stigma-related questions asked in the interviews

Further analysis of the interview responses to each of the four questions revealed multiple thematic areas. These are described in Table 3, below:

Question #1) Anticipation of being judged, stigmatized or treated with disrespect in a dental setting due to HIV status—In thematic response category 1.1, fifty percent (50%) of responses were focused on concerns about receiving humane, respectful and appropriate treatment. Within this thematic category, subthemes included: A) anticipated overuse of personal protective measures (e.g. double gloving) by the dentist and/or dental staff, B) thoughts that the dentist would be apprehensive to treat them, and C) concerns about confidentiality being maintained in the dental office. These subthemes are illustrated by the following selected responses by participants (i.e., S705, S604 and S607):

S716: [1.1; subtheme A] “The fear was that she [staff or dentist] would overreact by maybe potentially re-gowning, or putting on a double mask or double gloves.”

S705: [1.1; subtheme A] “They were just gonna treat you just as fine, and you know the gauze is in your mouth, and then the next thing you see people are coming back with like all types of gloves and masks and things all over

S604: [1.1; subtheme B] "...I might be the first person that they actually have to deal with who is HIV positive, I don't know. And so they might feel scared or nervous...you know like, 'do I remember everything?!' ..."

S607: [1.1; subtheme C] "...they may not talk to me privately...you have to go stand at that [reception] window and everybody can hear you...And then you know people are afraid, they don't want to be in that dentist's office if they know you've been working on somebody with HIV..."

In thematic response 1.2, twenty-seven percent (27%) of responses were focused on concerns about being judged or looked down upon by their dentist. One patient thought he would be stereotyped as homosexual due to his HIV status, as illustrated below:

S706: [1.2] "I let them know I'm HIV, the first question is, 'are you gay?' And I don't have anything against gay people, or anybody else's sexual preference...that ain't the way I contracted HIV, but society stereotypes people with HIV and AIDS as being gay."

An unexpected finding from this analysis was that in thematic category 1.3, thirteen percent (13%) of responses discussed patients' own fear of transmitting HIV to their dentist, as noted below:

S805: [1.3] "I just, I want [the dental staff] to be safe...I'd hate to have somebody catch it, from [pause] a mistake."

Personal fears that were unrelated to the dentist were identified in thematic category 1.4, as illustrated below:

S504: [1.4] "It was just the guilt, and shame and remorse, out of knowing better, and um, seroconverting for me. So it really had nothing to do with my dentist, it was my own [stuff]."

S710: [1.4] "I'm always self-conscious about—you know, I have a body odor or something, or a mouth odor."

S712: [1.4] "I know my teeth are bad, but I don't want anybody else seeing how bad they are [laughter]. Is that normal?"

Question #2) Changing the dentist after HIV diagnosis—In response to Question #2, thematic categories included: 2.1) pragmatic reasons unrelated to HIV status, 2.2) insurance-guided change (see definition below) and 2.3) concerns about receiving professional/appropriate treatment. In thematic category 2.1, fifty-one percent (51%) of responses cited pragmatic reasons for changing dentists that included moving or relocating, patients' not having a regular dentist prior to their diagnosis, dentists being too old or having recently died, or that the patient was looking for better pain management.

Thematic response category 2.2 identified that 38% of responses indicated having switched dentists after their HIV-diagnosis in order to access federally-funded insurance (termed herein as *insurance-guided change*) such as Ryan White or Medicaid/Medicare. Specifically, this category included reports of changing providers in order to obtain care

from a dentist who would accept Ryan White insurance as well as being referred to such a dentist by an infectious disease physician. In response to Question #2, 11% of subjects directly stated that they changed their dentist due to HIV-related reasons—central to this category was that subject's reported changing dentists due to concerns about receiving professional and/or appropriate treatment, as illustrated below:

S501: [2.2] “I found out about having HIV, then I hear a lot of dental doctors, dentists, whatever, don't like really too much to deal with HIV patients because they're more complicated to deal with, is what I was told”

Question #3) Informing new dentist about HIV status—In response to Question #3, only one participant reported that he did not inform his new dental provider that he was HIV positive; his response is presented below: [S503 and S604]

S503: [3] “Cuz, I, I felt like um [pause] I kind of felt like I would've been discriminated against. And the way they set up in there, um they're cautious about dealing with dental patients anyway, um as far as gloves and stuff like that, um and I don't feel as though I'm a risk, for what I'm going there anyway, to, to, um, to be honest with you I just didn't feel...I'm tired of telling people this man. I know you have to inform people, but, and then, you don't ever need to know. You gonna take me or you're not gonna take me. Um everywhere I go, it's just I've been discriminated against a lot because of my HIV. Even my family.”

Question #4) Hesitancy to visit the dentist—From the 26 individuals who felt hesitant to visit the dentist, three thematic response categories were identified: 4.1) concerns about one's confidentiality being maintained and receiving professional/appropriate care, 4.2) general fear of the dentist, and 4.3) pragmatic concerns and care-provider drawbacks/limitations.

In thematic category 4.1, thirty-five percent (35%) of responses noted concern about one's confidentiality being maintained and receiving caring, appropriate treatment, examples of which are illustrated below:

S705: [4.1] “I've had like a couple of bad experiences with dentists. I've had like, I've had to like go out of my way to be afraid of my confidentiality because I've had to tell people in like open areas or spaces”

An equal number of responses (35%) in thematic category 4.2 of Question #4 were in regard to a general fear of dentists and dental procedures, as noted below. Importantly, none of the responses in 4.2 were from the same patient who endorsed 4.1.

S708: [4.2] “I just don't like the dentist...and then you look at all that stuff on that tray...it's like, you aint using that on me [laughter]”

The remaining 29% of responses were categorized as pragmatic barriers and care provider drawbacks/limitations. Themes endorsing subjects' hesitancy to visit the dentist included: lack of transportation, financial concerns (i.e., expense), dislike of long waits, dislike of hectic waiting rooms, language barriers with the (foreign-born) treating dentist and dislike of having to attend multiple visits. One subject said:

S808: [4.3] “Lack of transportation or transportation difficulties. Uh, and it's always a multiple visit. You just don't go in—and get it done in one visit. It's sometimes two or three or maybe even four visits for the same thing...that's when you wait until your heads gonna explode—and then you go in.”

Discussion

The results of this study demonstrate the wide range of fears and concerns that impact PLWHA prior to or during dental care. Overall, our data brings to attention both the HIV and non-HIV related concerns of PLWHA during dental visits. Almost half of the sixty participants reported anticipation of being judged, stigmatized, or treated with disrespect during a dental visit; it is important to note that themes included overuse of personal protective measures, concerns of giving HIV to the dentist, and concerns of whether or not the dentist would feel comfortable treating them. Many of these issues could be addressed by the dental care team. Other identified themes, such as personal fears unrelated to the dentist, may add more complexity to the patient-provider interaction and indicate the importance of dental providers being sensitive and empathetic.

The overwhelming majority of patients interviewed reported changing their dental provider after their diagnosis; however, the majority stated that they did so for logistical reasons that patient's (in the context of this question) did not directly link to HIV infection or stigma. A limitation of these data is that, in other areas of the interview, we found evidence of subjects not being aware that they had switched dental providers in order to access dental services funded by Ryan White. Regardless, many patients explained that they changed providers in order to utilize Ryan White insurance. This finding suggests the economic importance and broad reach of Ryan White insurance. While previous studies have found that stigma and fear of discrimination can lead to failure to disclose HIV status^{15,27} only one participant in our cohort reported intentional failure to disclose their HIV status. In our cohort, however, utilization of providers who accept Ryan White insurance (i.e., large hospital or university-associated clinic with Ryan White funding, Part A) was high, and when using this insurance, the patient was, in essence, forced to disclose their status (as only those with HIV infection can use Ryan White insurance). In such a have promoted an environment in which it is easier to disclose confidential medical information.

Of the twenty-six participants (43.3%) who reported hesitancy to visit the dentist, the majority of responses were related to dental anxiety and receiving appropriate care. It is important to note that, of these responses, over one-third (35%) were a general fear of the dentist or fear of pain. Likewise, an equal percent of responses (35%)—and, importantly, these responses were from different subjects—expressed concerns about confidentiality being maintained and receiving professional/appropriate treatment. Thus, given that dental fear is reportedly common in this population^{10,21}, our data suggests that HIV-related stigma and other concerns may be equally prevalent and important in regards to underutilization of dental care.

Strengths of this study include that the analysis was based on verbatim transcripts of patient responses during face-to-face interviews. Additionally, our sample size was large for

qualitative research and we had a wide age range of participants. On average, subjects had been HIV seropositive for 16 years; thus, this cohort provides an important historical context. Oral health providers should note that many HIV+ adults have been dealing with HIV prior to the more optimistic HAART era in which HIV has become a more manageable, albeit serious, chronic illness. Experiences in dental settings and prevailing societal attitudes prior to HAART may continue to influence some HIV+ subject's reactions and perceptions.

Limitations of this study include that the analysis relied on self-reported data; there was no objective quantification of our data. The four questions we examined had not been previously validated, but our study provides some evidence for their initial validation. Some participants only reported perceived stigma after being further probed by the interviewer; an unequal degree of probing between interviews may have affected some participant responses and may have introduced bias. The loss of 6 audiotapes in our study occurred randomly; it is unlikely that this introduced bias into the results. HIV-related stigma is multifactorial^{2, 4, 5}; it is possible that, within our cohort, race (82% black) and insurance type (95% federal funding—a possible marker of socioeconomic status) may have enhanced perceived stigma. As well, this cohort contained many subjects (78%) who had utilized dental services within the past year; thus responses from PLWHA who underutilize dental services (e.g., last dental visit >2 years ago) may be under-represented. As well, 32% had previously been in our dental research studies; such experiences may have encouraged greater use of available dental services²⁶.

In order to improve dental care for HIV positive individuals, dental providers should be made aware of the potential for perceived stigma among PLWHA. Seacat et al, 2009 found that increased knowledge of HIV among dental students is associated with decreased negative attitudes towards HIV positive patients²⁸. Coupled with other studies^{29,30}, our data suggests that dental school curricula should provide experiences to promote cultural sensitivity, enhance awareness of HIV-related stigma, and cultivate effective, empathetic and humane communication skills.

Future qualitative studies should examine different geographic areas in the United States and include a more representative sample of HIV+ adults (i.e., those engaged and unengaged in ongoing dental care). Future studies may also benefit by examining this topic on a more granular level—since more nuanced examples of stigma occurring on an individual³¹ or systems level may be replacing more overt examples of stigma.

Conclusion

Identifying factors that promote tolerance and/or mitigate stigma may help educators, providers and organizations foster an environment and culture that treats PLWHA with respect and human dignity. In turn, longitudinal studies can determine whether effectively reducing stigma in the dental setting encourages greater dental care utilization and improved oral health for PLWHA.

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Table 1

Study Participant Characteristics (N=60)

	%	N	Mean ($\pm$ St. Dev)
Age		60	48.5 ($\pm$ 8.6)
Gender			
Male	78	47	
Female	22	13	
Ethnicity			
Black	82	49	
White, non-Hispanic	18	11	
Insurance			
Federally-funded *	95	57	
Private	5	3	
Education			
<High school	5	3	
HS diploma/GED	30	18	
Some college	43.3	26	
College graduate	18.3	11	
Graduate school	3.3	2	
Last dental visit			
<1 yr	78.3	47	
1-5yrs	15	9	
>5 yrs	6.7	4	
Previously in Dental Research	32	19	
Years since HIV seroconversion		60	15.7 ($\pm$ 7.2)

Key:

* Funded under Medicaid, Medicare and Ryan White.

Table 2

Number of Subjects Answering “Yes” to 4 HIV-Related Stigma Questions (N=60)

Question	N	Percent (%) of total subjects
1) Anticipation of being judged, stigmatized or treated with disrespect in a dental setting due to HIV+ status	27	45
2) Changing dentist after HIV+ diagnosis	44	73
3) Informing new dentist about their HIV+ status	43 [*]	98 [*]
4) Hesitancy to visit the dentist	26	43

Key:

* Among the 44 subjects who reported changing their dentist.

Table 3

Thematic Response Categories to 4 HIV-Related Stigma Questions

Question	Thematic Response Categories	N	% Subjects	% Responses
1) Anticipation of being judged, stigmatized or treated with disrespect in a dental setting due to HIV status		27	45	
	1.1) Concerns about receiving humane, respectful and appropriate treatment from the dentist			50
	1.2) Concerns about being judged or stereotyped by the dentist			27
	1.3) Concerns about giving HIV to the dentist			13
	1.4) Personal fears that were unrelated to the dentist's actions			10
2) Changing dentist after HIV diagnosis		44	73	
	2.1) Pragmatic reasons unrelated to HIV status			51
	2.2) Insurance-guided change			38
	2.3) Concerns about receiving professional/appropriate treatment.			11
3) Informing new dentist about HIV status (of total N=44)		43	98	
4) Hesitancy to visit the dentist		26	43	
	4.1) Concerns about confidentiality and receiving professional/appropriate treatment			35
	4.2) General fear of the dentist/pain			35
	4.3) Pragmatic concerns and care-provider drawbacks/limitations)			29

Note: Response percentages were rounded to the nearest whole number.