

ARTICLE 2

**Is There Discrimination against
People Living with HIV/AIDS When They Seek Dental Care?**

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Soumis au Journal of Public Health dentistry

This research was supported by the National Health Research Development Program (NHRDP, Canada).

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ABSTRACT

Objectives: Our study examined: (1) the proportion of people with HIV/AIDS who were refused dental care after disclosing their HIV-positivity to the dentist; (2) the reasons given by dentists to explain the refusal; and (3) the characteristics of the respondents and dentists associated with the refusal.

Methods: An anonymous survey was conducted in Québec, Canada, from 1993 to 1995, using a sample of 463 people with HIV/AIDS recruited from different sources.

Results: From the respondents who have disclosed their condition to the dentist, 26% reported having been refused dental care. Of these, 2/3 were not referred to another dentist. To justify their refusal, dentists mainly said that they considered their protocol or equipment for infection control to be inadequate, that they do not treat people with HIV/AIDS or consider themselves competent to treat this population. Drug users were refused in the highest proportion, while female dentists or private practitioners tended to refuse more people with HIV/AIDS.

Conclusions: These results suggest that many people with HIV/AIDS faced discrimination when seeking dental care. Further efforts should be made to promote accessibility of discrimination-free quality oral and dental care to this population.

Key Words: discrimination, people with HIV/AIDS, dentist, refusal to treat, accessibility, dental care.

INTRODUCTION

Despite the low risk of occupational transmission of the human immunodeficiency virus (HIV) during dental treatment, some dentists are reluctant to treat people living with HIV/AIDS while others refuse them care altogether (1, 2, 3, 4, 5). Refusing treatment, however, has far-reaching consequences. The immunodeficiency which accompanies the progression of HIV infection promotes opportunistic oral disease (6, 7, 8, 9). Some types of oral disease are indicative of the progression of HIV disease (10, 11) and many of them cause serious problems, which can range from pain impeding normal eating to infectious or neoplastic disease that can overload an already weak immune system. Any delay in the detection and treatment of lesions associated with these diseases can seriously compromise the health of people living with HIV/AIDS.

Other consequences, equally important but more insidious, also result from the refusal of some dentists to treat people living with HIV/AIDS. Fear of being refused dental treatment may cause some patients not to disclose their health status to the dentist (12). Thus, these patients find themselves deprived of care best adapted to their state of health, whether it be because of a lack of systematic screening for oral lesions associated with HIV, an error in diagnosis, an inappropriate choice of treatment, or a risk of secondary infection related to certain treatments. Moreover, the risk of occupational transmission of HIV can increase since, in practice, despite the established rules of conscientious

professional conduct, universal precautions are applied neither systematically by all dentists nor in the same manner with all patients (3, 13, 14). Out of a false sense of security, these dentists consequently place other patients, their team as well as themselves at risk of contracting HIV.

Since discrimination-free access to care is a basic principle of health services, documenting cases involving refusal becomes important. The perspective of people living with HIV/AIDS has been studied infrequently and only using relatively small samples recruited from dedicated medical or dental facilities (4, 15, 16, 17, 18, 19, 20). Our study takes greater account of this population's perspective by using a large sample to allow more precise estimates, and increasing the number of sampling sources to include subjects who do not visit dedicated health care facilities regularly as well as those who live outside main urban centers.

This study sought three objectives : first, to measure the proportion of people living with HIV/AIDS who were refused dental care after having informed the dentist of their health status; second, to document the reasons given by dentists to explain their refusal; and third, to identify the characteristics of the respondents and dentists associated with the refusal.

METHODS

The present study was conducted in Québec, Canada, from 1993 to 1995. People with HIV/AIDS were recruited from several sources listed in directories of services available to this population. The 15 associations dedicated to people with HIV/AIDS and 10 hospices dedicated to AIDS patients across Québec were contacted. Thirteen associations and all hospices accepted to participate in the study. Since over 80% of the people with AIDS in Québec live in the greater metropolitan area of Montréal (21), four clinics and three hospitals that specialize in screening for and treating HIV infection in Montréal were also contacted. Three clinics and two university hospitals agreed to participate in the study.

The study was conducted according to a protocol approved by the ethics committee of the Université de Montréal. In order to maintain the confidentiality of the individuals solicited, an anonymous survey using a self-administered questionnaire was used to gather data. The above-mentioned organizations were responsible for the distribution of the questionnaire, either by mail or by hand. Self-addressed, pre-stamped envelopes were included with the questionnaire, as was a cover letter explaining the importance of the study and confirming its anonymity. Because the sources of the sample were not mutually exclusive, the cover letter requested that the questionnaire be returned blank if the respondent had already sent in a completed one. One week after distributing the questionnaire, the associations and hospices sent out a letter to encourage

participation in the survey by reminding all those solicited of its importance. From the 800 questionnaires that were distributed, around thirty were returned to the addressor owing to bereavement or to a change of address without forwarding instructions, and around twenty were returned unopened by respondents who had received more than one. In all, 463 questionnaires were returned completed, giving a response rate of 62%. The proportions of non-respondents did not differ according to sampling sources namely associations, hospices, clinics and hospitals.

The final questionnaire contained 78 items, mostly closed-end questions, and took about 15 minutes to complete. The pertinence, clarity and acceptability of the questions had been tested beforehand by people with HIV/AIDS and experts working in the field. The rate of refusal was measured among respondents who had consulted a dentist since learning of their seropositivity and had disclosed their health status to the dentist. The dentists' reasons for refusing treatment were measured with an open-ended question. Besides basic sociodemographic (gender, age, main source of payment for dental care, and level of education), information on respondents' HIV infection was also obtained, including most probable route of HIV infection, presence of HIV-related symptoms, and number of years since discovering they were HIV-positive. Finally, the respondents reported the basic sociodemographic characteristics (gender, age, preferred language, location of practice, type of practice, type of dental office) of the last dentist who had refused to treat them and the last one who had accepted to do so.

The answers obtained from open-ended questions were categorized according to their similarity, and representative verbatim were listed. Data analysis consisted of basic descriptive statistics, chi-square tests for studying the association between the refusal and the characteristics of respondents and dentists, as well as of logistic regression analysis of refusal using the same sets of variables.

RESULTS

Table 1 presents the characteristics of the study population. Ninety percent of respondents were male with a mean age of 37 years. Most of them believed they had acquired HIV through homosexual practices while less than 10% believed they had acquired HIV by sharing contaminated syringes. The remaining ten percent of the sample was made up of female respondents who for the most part reported heterosexual practices as the probable source of their infection. Generally younger (34 years vs 37 years) and less educated than men, women seemed to be at a less advanced stage of the infection since they reported AIDS symptoms less often and had been diagnosed HIV-positive more recently.

Table 1: Characteristics of study population according to respondents' gender. Québec 1993-95, N=461.

| CHARACTERISTICS | Gender | | chi ² | p value |
|--|----------------------|-----------------------|------------------|---------|
| | Male (n=414) % | Female (n=47) % | | |
| Sociodemographic characteristics | | | | |
| <i>Age</i> | | | | |
| • < 30 (years) | 15 | 34 | | |
| • 30 to 34 (years) | 27 | 21 | | |
| • 35 to 39 (years) | 24 | 26 | | |
| • >= 40 (years) | 34 | 19 | 11.8* | .01 |
| <i>Level of education</i> | | | | |
| • High school or less | 36 | 51 | | |
| • College | 27 | 28 | | |
| • University | 37 | 21 | 5.5 | .06 |
| <i>Main source of payment for dental care</i> | | | | |
| • Dental insurance plan | 26 | 30 | | |
| • Dental plan for welfare recipients | 24 | 17 | | |
| • No insurance plan but able to pay | 40 | 49 | | |
| • No insurance plan and unable to pay | 10 | 4 | 3.1 | .37 |
| HIV-related variables | | | | |
| <i>Most probable route of HIV infection</i> | | | | |
| • Homosexual practices | 86 | 0 | | |
| • Intravenous drug use | 9 | 29 | | |
| • Heterosexual practices | 3 | 62 | | |
| • Blood products | 2 | 9 | 230.7* | .00 |
| <i>Presence of HIV-related symptoms</i> | | | | |
| • Yes | 50 | 40 | | |
| • No | 50 | 60 | 1.5 | .23 |
| <i>Had sought dental care since discovering they were HIV-positive</i> | | | | |
| • Yes | 85 | 77 | | |
| • No | 15 | 23 | 2.4 | .12 |
| <i>Number of years since discovering they were HIV-positive</i> | | | | |
| • < 2 years | 11 | 15 | | |
| • 2 to 5 years | 48 | 68 | | |
| • > 5 years | 41 | 17 | 9.3 | .01* |

Table 2: Reported reasons given by dentists for refusing dental care to people living with HIV/AIDS. Québec 1993-95, N=68.

| Reasons for refusal | N* | Verbatim examples** |
|---|-----------|---|
| Inadequacy of the protocol or equipment for infection control | 24 | <p><i>He wasn't equipped to sterilize his tools.</i></p> <p><i>The sterilizers weren't strong enough.</i></p> <p><i>He would have to disinfect the room.</i></p> <p><i>A special room was needed.</i></p> <p><i>The dentist was afraid for me! Risk of superinfecting the gums.</i></p> |
| Does not treat people living with HIV/AIDS | 14 | <p><i>Because I am seropositive.</i></p> <p><i>I don't touch that kind of thing, you have to go to another dentist who treats things like AIDS cases.</i></p> <p><i>You're a hospital case.</i></p> |
| Not qualified to treat people living with HIV/AIDS | 10 | <p><i>He wasn't qualified to treat that kind of people.</i></p> <p><i>He didn't want to carry out the extraction because this could cause a lot of blood.</i></p> <p><i>That he wasn't prepared for the kind of procedure that I needed (gum infection, extraction, etc.).</i></p> <p><i>Not capable of doing my fillings.</i></p> <p>Unable to provide a good follow-up.</p> |
| Detrimental to dentist, employees and clients | 5 | <p><i>My presence (with my virus) alone was already a very big danger for all of his clients.</i></p> <p><i>This could damage his clientele.</i></p> <p>Afraid for his staff and his clients.</p> |
| Too busy | 4 | <p><i>They can't take any new clients.</i></p> <p><i>He refused to do my filling because there was too much to do.</i></p> <p>He was too busy.</p> |
| No treatment needed | 4 | <p><i>I didn't need any treatment.</i></p> <p>He told me that I didn't have any cavities when I had two teeth that were hurting me.</p> |

| | |
|----------------|--|
| Others reasons | <hr/> 9 The dentist wanted to get more information before making a decision. Because I had an oral fungus infection. The dentist gave me an invalid reason. |
| No reasons | <hr/> 8 No reason, but he was afraid He just said to get out his office and that he didn't want to see me anymore His secretary cancelled my appointment and didn't call me back |

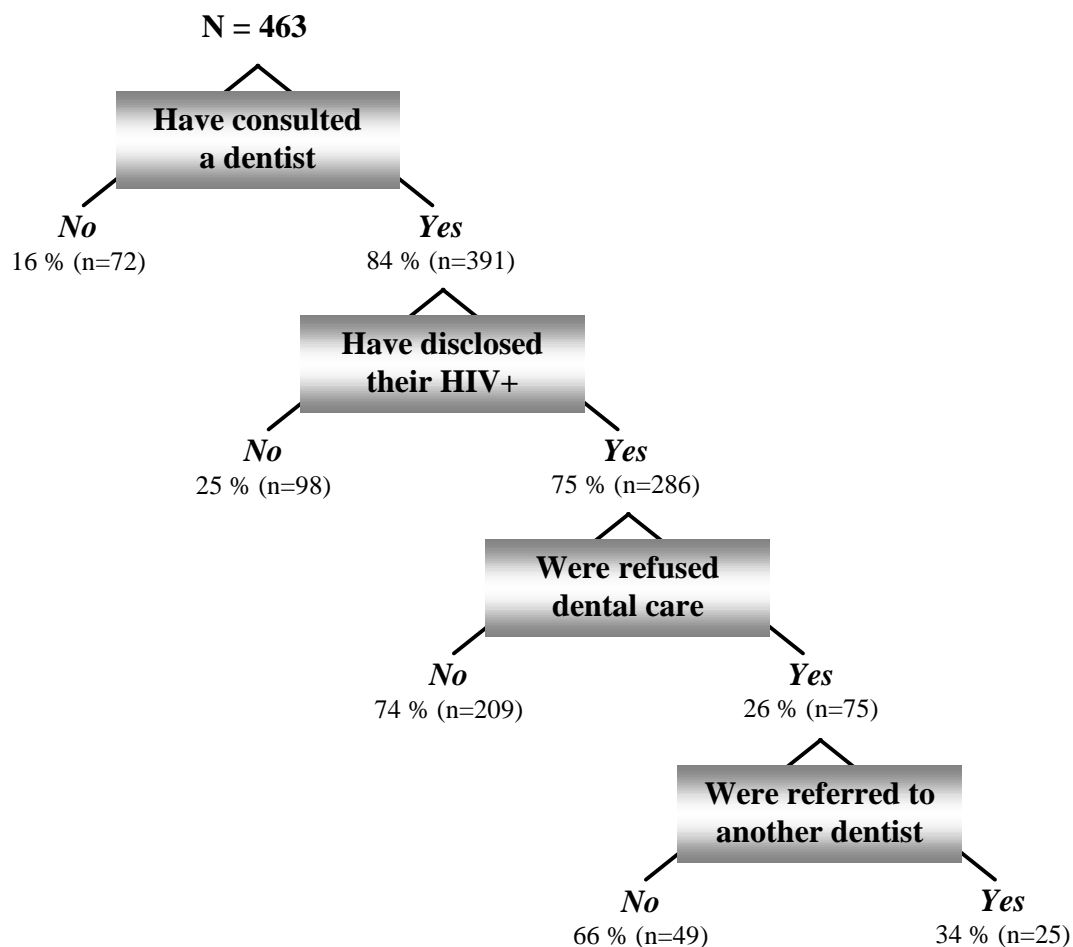
* *More than one reason can have been given.*

***Translated from french.*

Experience of refusal

Since being diagnosed HIV-positive, 391 of the 463 respondents reported having consulted a dentist. As shown in Figure 1, not all of them reported having disclosed their HIV status to the dentist. From the 286 respondents who reported having done so at least once, 26 % indicated having been refused at least once by a dentist. Of the latter, 28 % reported having been refused more than once. Finally, one third of all respondents who had been refused treatment were referred to a colleague by their dentist. The remaining two thirds were left on their own to find a dentist willing to treat them.

Figure 1 : Pathway of experiences of people living with HIV/AIDS when seeking dental care. Québec 1993-95, N=463.



Reasons for refusal

In an open-ended question, the respondents who had been refused treatment by a dentist were invited to share the reasons the dentist had given them to justify the refusal. Table 2 presents these reasons as they were reported by 68

of the 75 respondents involved. For the most part, the dentists justified the refusal by saying that they considered their protocol or equipment for infection control to be inadequate, that they did not treat people living with HIV/AIDS, or that they did not consider themselves qualified to treat these patients. At the same time, some dentists alleged that they feared treating people living with HIV/AIDS would be detrimental to them, their employees and their clients, that they were too busy, or that they felt that the respondent's condition did not require any treatment. Four respondents did not report the reasons given to them by the dentist but described them as invalid, and three of them felt that the dentist was afraid. One respondent reported that the dentist wanted to get more information before making a decision, and another respondent reported being refused because of an oral fungus infection. Finally, eight respondents stated that no reason had been given to them.

Predictors of refusal

Table 3 presents the relationship between respondents' characteristics and refusal by dentists to treat them. Respondents' gender, age, level of education and main source of payment for dental care were not associated with refusal of dental care. The way in which respondents had contracted HIV was however linked to the refusal. Indeed, 48 % of respondents who have contracted HIV through intravenous drug use reported having been refused dental care compared to 25 %, 21 % and 14 % of those having contracted HIV through homosexual practices,

heterosexual practices or blood products respectively. Interestingly, respondents of the IVDU category were the most underprivileged and the least educated.

The development of HIV infection into AIDS, as measured by the presence of symptoms of HIV infection, was not related to the refusal. Finally, respondents diagnosed with the disease in the last two years were refused in the same proportion as those who were diagnosed longer ago.

Table 3: Respondents' characteristics associated with refusal of dental care, Québec 1993-95, N=284.

| RESPONDENTS' CHARACTERISTICS | n | Have been refused dental care | | chi ² | p value |
|---|-----|----------------------------------|--------------------|------------------|------------|
| | | No (n=209) % | Yes (n=75) % | | |
| Sociodemographic characteristics | | | | | |
| <i>Gender</i> | | | | | |
| • Male | 252 | 75 | 25 | 1.4 | .23 |
| • Female | 31 | 65 | 35 | | |
| <i>Age</i> | | | | | |
| • < 30 (years) | 53 | 72 | 28 | 2.7 | .44 |
| • 30 to 34 (years) | 73 | 74 | 26 | | |
| • 35 to 39 (years) | 67 | 67 | 33 | | |
| • >= 40 (years) | 89 | 79 | 21 | | |
| <i>Level of education</i> | | | | | |
| • High school or less | 107 | 67 | 33 | 4.1 | .13 |
| • College | 72 | 81 | 19 | | |
| • University | 104 | 75 | 25 | | |
| <i>Main source of payment for dental care</i> | | | | | |
| • Dental insurance plan | 74 | 73 | 27 | 2.4 | .50 |
| • Dental plan for welfare recipients | 129 | 71 | 29 | | |
| • No insurance plan but able to pay | 55 | 82 | 18 | | |
| • No insurance plan and unable to pay | 24 | 71 | 29 | | |

| RESPONDENTS' CHARACTERISTICS | n | Have been refused dental care | | chi ² | p value |
|---|-----|----------------------------------|--------------------|------------------|------------|
| | | No (n=209) % | Yes (n=75) % | | |
| HIV-related variables | | | | | |
| <i>Most probable route of HIV infection</i> | | | | | |
| • Homosexual practices | 215 | 75 | 25 | 8.9 | .03* |
| • Intravenous drug use | 31 | 52 | 48 | | |
| • Heterosexual practices | 24 | 79 | 21 | | |
| • Blood products | 7 | 86 | 14 | | |
| <i>Presence of HIV-related symptoms</i> | | | | | |
| • Yes | 150 | 74 | 26 | 0.0 | .87 |
| • No | 138 | 73 | 27 | | |
| <i>Number of years since discovering they were HIV-positive</i> | | | | | |
| • < 2 years | 27 | 74 | 26 | 0.0 | .99 |
| • 2 to 5 years | 130 | 74 | 26 | | |
| • > 5 years | 126 | 73 | 27 | | |

Similar results were obtained when logistic regression analysis was performed on the same set of variables. Of all the variables studied, only how the respondents thought they had contracted HIV proved to be a good predictor of dental care refusal. The chances of being refused when disclosing the probable source of one's infection were greater for those reporting the sharing of contaminated syringes (IVDU) than for those reporting heterosexual contact (OR=3.6, CI 95%:1.1-12.0).

As for dentists characteristics associated with refusal of dental care, our results show that female dentists and those in private dental practice had proportionally a greater tendency to refuse care (table 4). Logistic regression analysis confirms that the probability of having refused care to a person living with HIV/AIDS was greater if the dentist was female (OR= 2.2, CI 95%: 1.1-4.3), or had a private dental office compared to dentists practicing in a hospital setting (OR= 3.4, CI 95%: 1.3-8.8).

Table 4: Dentists' characteristics associated with refusal of dental care. Québec 1993-95, N=343.

| DENTISTS' CHARACTERISTICS | n | Had refused dental care | | chi ² | p value |
|--|-----|-------------------------|--------------------|------------------|---------|
| | | No (n=269) % | Yes (n=74) % | | |
| <i>Gender</i> | | | | | |
| • Male | 292 | 80 | 20 | 4.4* | .04 |
| • Female | 48 | 67 | 33 | | |
| <i>Age</i> | | | | | |
| • < 35 (years) | 125 | 82 | 18 | 0.8 | .37 |
| • ≥ 35 (years) | 209 | 78 | 22 | | |
| <i>Main language</i> | | | | | |
| • French | 285 | 78 | 22 | .44 | .80 |
| • English | 45 | 82 | 18 | | |
| <i>Location of practice</i> | | | | | |
| • Main urban centers (Montreal, Quebec City, Sherbrooke) | 287 | 79 | 21 | 0.2 | .64 |
| • Outside main urban centers | 54 | 76 | 24 | | |
| <i>Type of practice</i> | | | | | |
| • Group | 141 | 78 | 22 | 0.1 | .73 |
| • Solo | 199 | 79 | 21 | | |
| <i>Type of dental office</i> | | | | | |
| • Private | 280 | 76 | 24 | 6.6* | .04 |
| • Hospital | 56 | 91 | 9 | | |
| • University | 6 | 83 | 17 | | |

DISCUSSION

The present study shows that, among the respondents who had disclosed their seropositivity to the dentist, one in four was refused dental care. This observation is comparable to the rates of refusal ranging from 15% to 28% reported by others (4, 18, 19, 20). Given this high rate of refusal, one could be lead to believe that a great number of patients who were refused were referred to another dentist. Our data show that this is not the case; two thirds of the patients who were refused were not referred and had to find another dentist on their own. Our study also shows that the situation seems not to have improved over the last years, since the rates of refusal and referral are similar for the respondents who were diagnosed in the last two years and for those diagnosed longer ago. These results reveal the persistent problem of accessibility to dental care that people living with HIV/AIDS are faced with.

Reasons given by dentists for justifying refusal corroborate those reported in previous studies (4, 19). They include: distinctive sterilization and disinfection measures that need to be taken with people with HIV; dentists not considering themselves qualified for treating HIV infected patients; and dentists fear of infecting themselves, their staff or their clients. These reasons are in contradiction with scientific evidence and professional ethics in dental care. As such, they appear as pretexts for refusing to treat HIV infected people.

While the fear of AIDS could underlie the dentists' refusal, our results show that fear alone cannot account for it completely. Our results show that respondents who had contracted HIV through intravenous drug use were refused more often than respondents who had contracted HIV through sexual contact or blood products. Since it is not likely that the respondents would disclose to the dentist how they had contracted HIV, one wonders whether the high rate of refusal could be linked to a projected image suggesting marginal social behavior, an image that made the dentists and their clients ill at ease. The hypothesis that the dentist's response changes according to an individual's social image and that access to care varies according to the individual's social status warrant further study.

Respondents were refused care more often by female dentists than by male dentists. One should interpret this result with caution. Considering that the feminization of the profession is a recent development, on average, female dentists are younger than their male colleagues. One would assume that female dentists would be more willing to treat people living with HIV/AIDS as they were trained since the beginning of the HIV/AIDS epidemic in comparison with a large proportion of their older male colleagues trained earlier. However, Kunzel and Sadowsky reported that in New York City, a lower percentage of female dentists than their male colleagues indicated willingness to treat HIV-positive patients (22). Explanations proposed by the authors for this gender contrast were mainly related to women's family responsibilities and roles. Moreover, in our survey

some respondents indicated in their comments that they chose their dentist among the male homosexual dentists well-known in the community for their willingness to treat people with HIV/AIDS. So if many respondents chose to consult them first, the over-representation of these dentists could explain why respondents were refused care less often by men.

As far as the difference between dentists in a private practice and those practicing in a hospital or university is concerned, the higher refusal rate by private practitioner could be explained by the greater isolation of dentists working in private practice, their more limited access to information about HIV infection, and the perceived danger to the profitability of their practice.

Since the number of people living with HIV/AIDS continue to grow, the results of the study bring to light several challenges for a profession concerned about the people oral health. Clearly, the main challenge is in improving access to quality oral care for groups that are particularly susceptible to oral problems as is the case for HIV infected people. Further efforts should be made to promote a dentist-patient relationship without discrimination, where people living with HIV/AIDS are not reluctant to disclose their health status and are confident that they will receive care best adapted to their condition.

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