

ARTICLE 1

**Do people with HIV/AIDS
disclose their HIV-positivity to dentists?**

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ABSTRACT

This study documents behaviors of people with HIV/AIDS regarding the disclosure of their HIV-seropositivity when seeking dental care. 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. Over 80% of respondents reported having sought dental care since becoming aware of their seropositivity. Of these, 54% reported having always disclosed their HIV-seropositivity to dentists, while 25% reported never having disclosed this information to dentists. However, 83% of all respondents preferred that the dentist be aware of their HIV status. Respondents gave reasons related to the socio-pathological impact of HIV infection to explain their behaviors. The predictors of disclosure of HIV-seropositivity to the dentist were: gender, main source of payment for dental care, prior disclosure of HIV status to family members, prior disclosure of HIV status to co-workers, and trust in the maintenance of confidentiality by the dentist. These results emphasize the need to use universal precautions in the dental office and to promote dentist-patient relations free of discrimination, so that people with HIV/AIDS are not reluctant to disclose their health status and confident that such disclosure will lead to care best adapted to their condition.

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INTRODUCTION

People with HIV/AIDS frequently suffer from opportunistic oral disease (Feigal *et al.*, 1991; Greene *et al.*, 1997; Greenspan & Greenspan, 1993; Schiodt & Pindborg, 1987; Silverman *et al.*, 1986). Some types of oral disease are indicators of the progression of HIV disease (Katz *et al.*, 1993; Shiboski *et al.*, 1994) and many of them cause serious problems, which can range from pain impeding normal eating to infectious or neoplastic diseases that can overload an already weak immune system. Since dentists are the only health care professionals trained to prevent, diagnose and treat oral and dental disease, it is essential for this population to have access to their services.

In order to benefit from care best adapted to their condition, however, people with HIV/AIDS must overcome a particularly delicate barrier, which is disclosing their HIV status. Yet sharing this information is not an easy thing to do, as was shown by several studies in which many but not all participants reported having disclosed their HIV-seropositivity to significant others (Lie & Biswalo, 1996; Mansergh *et al.*, 1995), to their physician or to their dentist (Barnes *et al.*, 1996; Gerbert *et al.*, 1989; Jacobson *et al.*, 1989; King, 1989; McCarthy *et al.*, 1995; Perry *et al.*, 1993; Robinson *et al.*, 1994; Scheutz, 1990; Yedidia *et al.*,

1993). The negative attitudes, discrimination and rejection that people with HIV/AIDS may expect from those they confide in could explain this situation (Limandri, 1989; Mansergh *et al.*, 1995). The all too numerous reports of discrimination or stigmatization against people with HIV/AIDS by various health care professionals (Bennet *et al.*, 1995; Boyer *et al.*, 1994; Gerbert *et al.*, 1991; Hastreiter, 1992; McCarthy *et al.*, 1995; Porter *et al.*, 1995; Sadowsky *et al.*, 1991) would justify the reticence of many to disclose their health status to dentists.

Not disclosing one's HIV status to the dentist, though, can have serious consequences, such as finding oneself deprived of care adapted to one's state of health, whether it be because of a lack of systematic screening for oral lesions associated with HIV infection, 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 (Hastreiter *et al.*, 1992; McCarthy *et al.*, 1996; Soto *et al.*, 1990). Out of a false sense of security or through negligence, these dentists consequently place other patients, their team as well as themselves at risk of contracting HIV. The risk also increases through injury involving instruments contaminated by biological fluids. Dentists, hygienists and dental assistants frequently sustain such injuries (Hastreiter *et al.*, 1992; Siew *et al.*, 1992; Soto *et al.*, 1990). In cases of injury involving HIV-contaminated blood, a prophylactic regimen of antiviral drugs seems to prevent seroconversion effectively, provided

that it is initiated within a very short time postexposure (Centers for Disease Control, 1996). Although there is no means of being absolutely certain that a person is seronegative, the decision to initiate a prophylactic regimen after injury involving a patient's blood or biological fluids is based on knowledge of that patient's HIV status. It is therefore essential that dentists be aware of their patients' health status.

Non-disclosure of HIV infection to the dentist is, therefore, a major issue in public health. While the disclosure of HIV infection to the dentist has been the object of a number of studies (Barnes *et al.*, 1996; Gerbert *et al.*, 1989; Jacobson *et al.*, 1989; King, 1989; Perry *et al.*, 1993; Scheutz, 1990), only two have actually focused on non-disclosure (McCarthy *et al.*, 1995; Robinson *et al.*, 1994). Studying disclosure alone, in fact, does not exclude the possibility of overlooking instances of non-disclosure, as some respondents may not disclose their HIV status under certain circumstances but may decide to do so in others. Not studying non-disclosure as such stands in the way of evaluating its impact. Generalizing results is another problem that these studies have to deal with. All of these studies, except for one (Perry *et al.*, 1993), recruited their subjects from dedicated medical or dental facilities (Barnes *et al.*, 1996; Gerbert *et al.*, 1989; Jacobson *et al.*, 1989; King, 1989; McCarthy *et al.*, 1995; Robinson *et al.*, 1994; Scheutz, 1990). It can be assumed that subjects recruited from these units would disclose their seropositivity more readily since they are already seeking specialized medical treatment and that, therefore, subjects having developed health problems are

overrepresented. In addition, the relatively small sample sizes of these studies yield estimates with large variability.

We sought to remedy these problems by documenting both disclosure and non-disclosure of HIV-seropositivity to the dentist. We increased also the number of sampling sources to include subjects who did not develop health problems or who did not seek medical treatment in dedicated facilities. Finally, we recruited a large sample of people living with HIV/AIDS to allow more precise estimates. The aim of the present study was to document disclosure and non-disclosure of HIV status to the dentist using a large sample of people with HIV/AIDS. In order to gain a better understanding of both behaviors, two other points were also studied: what could justify the respondents' actions and how the respondents' characteristics could influence their decision to disclose or not to disclose their HIV status to the dentist.

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 for people with HIV/AIDS and 10 hospices for AIDS patients across Québec were contacted. Two associations declined to participate in the study. Since over 80% of the people with AIDS in Québec live in the greater metropolitan area of Montréal (Direction de la santé publique, 1997), four clinics and three hospitals specialized in screening for and treating HIV infection in Montréal were also contacted. Three clinics and two university hospitals agreed to participate in the study.

Data were gathered through an anonymous survey using a self-administered questionnaire. Associations, hospices, clinics and hospitals were responsible for its distribution, 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 questions focused, among other things, on respondents' disclosure and non-disclosure of their HIV status to the dentist, the preferences and attitudes of respondents regarding particular aspects of dental care, characteristics related to respondents' HIV infection, and their sociodemographic characteristics. The pertinence, clarity and acceptability of the questions had been tested beforehand by people with HIV/AIDS and experts working in the field. The final questionnaire contained 78 items, mostly closed-end questions, and took about 15 minutes to complete. The answers obtained from open-ended questions were categorized according to their similarity. Besides basic descriptive statistics, data analysis consisted of chi-square tests and polychotomous logistic regression analysis. This type of regression analysis computes estimates of parameters of logistic models for multinominal data using a reference category (Dixon 1990). It was used because disclosure of HIV status to dentists occurred in three variations: always, sometimes or never.

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 mainly reported heterosexual practices as the probable source of their infection or, to a lesser degree, the sharing of contaminated syringes. Generally younger (34 years vs 37 years) and having a lower level of education than the male respondents, they 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 by 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>Education level</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		
• Heterosexual practices	3	62		
• Intravenous drug use	9	29		
• Others	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 year(s) since discovering they were HIV-positive</i>				
• ≤ 1 year	11	15		
• 2 to 5 years	48	68		
• ≥ 6 years	41	17	9.3	.01*

Over 80% of respondents reported having consulted a dentist since being diagnosed HIV-positive. Of this group, slightly more than half reported having always disclosed their HIV status to the dentist, while one in four reported never having done so (Table 2).

Table 2: Respondents' disclosure of their HIV-positivity to the dentist and reasons underlying their choice, Québec 1993-95.

DISCLOSURE AND REASONS	%
Disclosure	
<i>Frequency of disclosure of their HIV-positivity to the dentist (n=370)</i>	
Always	54
Sometimes	21
Never	25
Reasons	
<i>Main reasons for disclosing their HIV-positivity to the dentist^{1†} (n=275)</i>	
• I consider it my moral duty	34
• To prevent HIV transmission	33
• Because the dentist asked me	22
• To prevent being infected during dental care and/or to receive care appropriate to my condition	15
<i>Main reasons for not disclosing their HIV-positivity to the dentist^{1‡} (n~158)</i>	
• The systematic use of universal precautions to prevent contamination during dental care	75
• Fear of being refused dental care	49
• Fear of being judged negatively	36
• Fear of breach of confidentiality	32
• Because the dentist didn't ask me	30

¹Percentages do not equal 100% because more than one reason may be given.

[†]From an open-ended question.

[‡]From a closed-end question. The *n* vary because of missing data for some reasons.

Reasons reported for disclosure were primarily motivated by moral considerations (to be truthful, to give the dentist the choice of treating them or not, to have a relation based on trust, etc.) or out of concern for the prevention of HIV transmission to the dentist, the dental assistants or other patients of the office. Other reasons included the dentist having asked, either directly or by means of a medical questionnaire, if they were HIV-positive, the fear that a risk of secondary infection was associated with certain types of treatments, or the wish to receive care best adapted to their health condition. Although male and female respondents all gave the same reasons, half of female respondents reported having disclosed their seropositivity to prevent HIV transmission, while 31% of male respondents reported having done so for the same reason ($p=0.03$).

Among the reasons considered important for not disclosing one's HIV status to the dentist, a large majority of respondents referred to the fact that dentists are bound in any case to take the same precautions with all their patients. Fear of being refused dental treatment or of being judged negatively strongly motivated many not to disclose this information, as did the fear of breach of confidentiality or the simple fact that the dentist had not asked for this information. Since the number of female respondents in this sub-sample was too small ($n=9$), no reliable statistics could be calculated in order to compare their responses to those of the male respondents.

Over 80% of all respondents reported preferring that the dentist be aware of their HIV status (Table 3). The reasons underlying this preference were similar

to those justifying disclosure or non-disclosure. No significant difference was found in the responses related to this preference between men and women or between respondents having visited a dentist or not since their HIV diagnosis.

Table 3: Preferences of study population regarding dentist's awareness of respondents' HIV-positivity, Québec 1993-95.

PREFERENCES AND REASONS	%
<i>Prefer that the dentist be aware of their HIV-positivity (n=450)</i>	83
<i>Main reasons for preferring that the dentist be aware of their HIV-positivity^{1†} (n=328)</i>	
• To prevent HIV transmission	42
• To be truthful to my caregiver	42
• To prevent being infected during dental care and/or to receive care appropriate to my condition	35
<i>Main reasons for preferring that the dentist not be aware of their HIV-positivity^{1†} (n=67)</i>	
• The systematic use of universal precautions to prevent contamination during dental care	43
• Fear of discrimination	34
• Lack of trust in the confidentiality of dental records	28

¹Percentages do not equal 100% because more than one reason may be given.

[†]From an open-ended question.

The results presented in Table 4 indicate in what way the respondents' sociodemographic profile and their HIV-related characteristics influenced their tendency to disclose their HIV-seropositivity to the dentist or not. The respondents' characteristics that were associated with a higher degree of HIV disclosure to the dentist included: a lower level of education, welfare status, prior disclosure of HIV status to family members and/or co-workers, preference

regarding the dentist's awareness of their HIV status, and trust in the maintenance of confidentiality by the dentist. It is interesting to note that female respondents seemed to be more willing to disclose their serostatus than their male counterparts, though the low number of female respondents in the sample does not make this observation significant. The same observation can be made of intravenous drug users who had the highest proportion of disclosure compared to those who contracted the HIV infection through sexual contacts. But again, this result is not significant. The final results of polychotomous logistic regression analysis include the following variables: gender, main source of payment for dental care, prior disclosure of HIV status to family members, prior disclosure of HIV status to co-workers, and trust in the maintenance of confidentiality by the dentists.

Table 4: Characteristics of respondents regarding disclosure of their HIV-positivity to the dentist, Québec 1993-95, N=370.

RESPONDENTS' CHARACTERISTICS	DISCLOSED			chi ²	p value
	Always (n=200) %	Sometimes (n=79) %	Never (n=91) %		
Sociodemographic characteristics					
<i>Gender</i>					
• Male	52	22	26	4.7	.10
• Female	70	18	12		
<i>Age</i>					
• < 30 (years)	47	36	17	11.8	.07
• 30 to 34 (years)	52	18	30		
• 35 to 39 (years)	60	18	22		
• ≥ 40 (years)	54	19	27		
<i>Education level</i>					
• High school or less	61	24	15	10.3*	.04
• College	51	18	31		
• University	50	21	29		
<i>Main source of payment for dental care</i>					
• Dental insurance plan	48	24	28	20.9*	.00
• Dental plan for welfare recipients	67	19	14		
• No insurance plan but able to pay	44	19	37		
• No insurance plan and unable to pay	45	29	26		
HIV-related variables					
<i>Most probable route of HIV infection</i>					
• Homosexual practices	52	21	27	5.7	.46
• Heterosexual practices	58	21	21		
• Intravenous drug use	69	20	11		
• Others	63	25	12		
<i>Presence of HIV-related symptoms</i>					
• Yes	55	24	21	2.6	.28
• No	53	19	28		

RESPONDENTS' CHARACTERISTICS	DISCLOSED			chi ²	p value
	Always (n=200) %	Sometimes (n=79) %	Never (n=91) %		
Groups informed of respondents' HIV-positivity					
<i>Family</i>					
• Yes	59	22	19	17.7*	.00
• No	39	20	41		
<i>Friends</i>					
• Yes	54	22	24	.26	.88
• No	52	19	29		
<i>Co-workers</i>					
• Yes	60	22	18	14.4*	.00
• No	42	20	38		
Attitudes					
<i>Preference regarding dental care setting</i>					
• Regular	51	21	28	3.7	.16
• Specialized	60	21	19		
<i>Preference regarding dentist's awareness of respondent's HIV-positivity</i>					
• Yes	63	23	14	109.3*	.00
• No	10	15	75		
<i>Lack of trust in maintenance of confidentiality by dentists</i>					
• Yes	35	25	40	65.8*	.00
• No	75	17	8		

Table 5: Results of logistic polychotomous regression: Disclosure of their HIV-positivity to the dentist, by respondents' characteristics. Québec 1993-95, N=326.

RESPONDENTS' CHARACTERISTICS	b	p value	OR	95 % CI
Socio-demographic characteristics				
<i>Gender</i>		.14		
• Male			1.0	Reference
• Female	0.66		1.9	0.8-4.8
<i>Main source of payment for dental care</i>		.002		
• No insurance plan but able to pay			1.0	Reference
• Dental insurance plan	0.13		1.1	0.6-2.1
• Dental plan for welfare recipients	1.14		3.1	1.6-5.9*
• No insurance plan and unable to pay	0.37		1.4	0.5-4.1
Groups informed of respondents' HIV-positivity				
<i>Family</i>		0.009		
• No			1.0	Reference
• Yes	0.74		2.1	1.2-3.6*
<i>Co-workers</i>		0.23		
• No			1.0	Reference
• Yes	0.34		1.4	0.8-2.5
Attitudes				
<i>Trust in maintenance of confidentiality by dentists</i>		0.000		
• No			1.0	Reference
• Yes	1.8		6.2	3.8-10.0*

DISCUSSION

Much care was taken to develop measures that reflect the experience of people living with HIV/AIDS regarding disclosure of their HIV-seropositivity to the dentist and to obtain a high response rate. As for the quality of estimates, social desirability was diminished by using anonymous survey. To insure the best possible representativity of the respondents, we used many sampling sources. The distribution of respondents according to gender and route of their HIV infection was comparable to that of the AIDS cases declared for the corresponding period (Direction de la santé publique, 1997).

The results of this study show that although a great majority of people with HIV/AIDS would prefer the dentist to be aware of their health status, only half of the respondents reported that they systematically disclosed their HIV-positivity to the dentist. In addition, one fourth of respondents reported never having disclosed their HIV status when receiving dental treatment. The results of this study support those obtained by Robinson (Robinson *et al.*, 1994) and show that non-disclosure of HIV-positivity to the dentist is a widespread occurrence that is not to be dismissed.

In order to better understand what prompts people with HIV/AIDS to disclose their condition to the dentist or not, the present survey also studied the reasons given by respondents for their choice. Reasons given by disclosers were numerous. There was mention of moral considerations, such as being respectful to

and honest with the dentist, leaving the choice to the dentist to treat them or not, or having confidence in the relation with the dentist. Similarly, they were concerned about the transmission of the disease to others or wished to prevent secondary infections and receive care adapted to their state of health.

Among the main reasons reported by non-disclosers, several indicated that it was not necessary to do so since the dentist is obligated to take the same precautions with all his patients whether they be HIV-seropositive or not. The other prime reasons for these respondents were fear of discrimination or breach of confidentiality.

The reasons given by disclosers and non-disclosers are legitimate. It can be noted that both groups based their decision on a set of factors related to the particular socio-pathological character of their HIV infection. In fact, if people with HIV/AIDS trust the dentist to apply universal precautions properly, they may not perceive any advantage in informing the dentist of their serostatus, even more so if they do not see any benefit in it to their health and if they want to protect themselves from discrimination or the risk of breach of confidentiality. These points are at the heart of the matter. At the present time, no other disease puts the individual at such a risk of being stigmatized and rejected as HIV infection. The potential risk of being rejected by close ones and by health care professionals including dentists, facing homophobia reactions, losing one's employment and having difficulty finding housing, besides living in fear of a future made uncertain by illness, are all problems which people with HIV/AIDS are likely to face.

Overcoming them is no easy matter and some feel that the risks associated with disclosing their status are threatening enough to keep this information to themselves when seeking dental care.

Factors like the risk of being stigmatized and rejected are not easy to change and lead us to think that non-disclosure is far from disappearing. If we add to the number of people who do not disclose their seropositivity all those who do not yet know that they are HIV-positive, then it is conceivable that a large number of seropositive individuals are treated by dentists who are unaware of their condition. From this point of view, the data gathered from this study strongly supports the use of universal precautions by all dentists with all patients, and as such, they should constitute an integral part of the standard practice of professional and responsible dental medicine.

Another consequence of non-disclosure is that it prevents access to preventive and curative dental care that is most appropriate to the state of health of people with HIV/AIDS. The factors described above, however, can put us on the road to finding solutions that encourage disclosure. On the one hand, the benefits provided by dental care in maintaining the quality of life of people with HIV/AIDS do not seem to be well known to this population. On the other hand, this population appears to be preoccupied by the confidentiality of the information given to dentists. However, doctor-patient confidentiality applies to dentists to the same degree that it does to physicians. Dentists could solve these two problems by giving out clear, pertinent and coherent information on the importance for people

with HIV/AIDS to maintain oral health and by letting their patients know that dentists are bound by doctor-patient confidentiality. Finally, considering the fact that respondents appeared to be very sensitive to dentists' attitudes and that many fear discrimination, dentists who want to encourage disclosure could wear an AIDS ribbon on their smock. This simple and universal sign allows people affected by the disease to recognize that the dentist takes part in the fight against HIV/AIDS and empathizes with them. This would also help other patients who would recognize this symbol to feel free to discuss points that concern them, such as the effectiveness of universal precautions, the routes of HIV transmission and the risks associated with certain sexual and social practices.

Considering the steadily growing number of people with HIV/AIDS, it is of the utmost importance that dentists adopt an open and professional attitude towards this population to make access to quality dental care easier for them. In this way, dentists could take advantage of their expertise and become partners in maintaining the quality of life of their HIV-positive patients.

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