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Dental care and HIV-infected individuals: are they equally treated?

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Abstract – *Objectives:* To investigate the problems in seeking dental care faced by HIV-positive individuals in Italy. *Methods:* A multicenter observational study was performed by distributing an anonymous self-administered questionnaire to patients of six public healthcare facilities specialized in the treatment of individuals with HIV infection. The questions concerned personal data potentially correlated with discrimination, the patient–dentist relationship before and after HIV diagnosis, and the reasons for seeking dental care in public facilities. We also evaluated the patients' discomfort in the patient–dentist relationship after HIV diagnosis, performing univariate and multivariate analyses. *Results:* Of the 1500 questionnaires distributed; 883 were filled-out completely. A total of 630 persons received dental care after HIV diagnosis: 209 (33.2%) did not tell the dentist that they were seropositive. Of those who did, 56 were refused care. For patients treated by a private dentist, having been treated by the same dentist before diagnosis was a risk factor for great discomfort in the patient–dentist relationship ($P < 0.002$). Being treated in public facilities was associated with having received dental care after HIV diagnosis ($P < 0.001$) and a primary school education ($P < 0.001$). *Conclusions:* There exist episodes of discrimination on the part of some dentists, and a relatively high proportion of HIV-positive persons do not disclose their seropositivity to the dentist. Dentists should be provided with training for promoting both ethically acceptable practices and suitable clinical management of HIV-positive persons.

Key words: discomfort; HIV infection; private and public dental care

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In economically developed countries, the introduction of more effective antiretroviral drugs [namely, highly active antiretroviral therapy (HAART)] has prolonged the life expectancy and increased the quality of life of HIV-infected persons, resulting in an increase in the prevalence of infection. This has led to an increase in the demand for healthcare, including dental care (1–3).

Oral and dental problems are common among HIV-infected individuals (4–7). However, healthcare workers may be concerned with the risk of being infected and thus may fear, or even avoid, close contact with HIV-positive clients. In some cases, dentists are afraid of losing not only members of their staff but even their non-HIV-infected patients (8–11). This has led to discrimination against HIV-positive persons on the part of dentists, although these episodes are isolated and should not be taken as the rule (12–15).

Despite the social relevance of this topic, only a few studies have attempted to define the complex problems that could arise in the relationship between an HIV-positive patient and his/her dentist. The results of these studies, although often difficult to analyze, have shown that up to 40% of HIV-positive persons, especially those belonging to disadvantaged social groups (e.g. women, the

*Members of the BSAHOD Study group are listed in the Appendix.

elderly, persons with a low level of education, and the poor), do not have their dental needs met (16–19). Knowledge of the relationship between dentists and their patients becomes particularly important when considering the above-described changes in the epidemiology of HIV infection, the importance of oral health for HIV-positive persons, and the inappropriate attitudes of some healthcare workers. In light of this situation, we used an anonymous questionnaire to investigate the problems faced by HIV-positive individuals in seeking dental care in Italy.

Methods

Study design

We performed a multicenter observational study using a completely anonymous questionnaire developed by a dentist, an infectious disease specialist, and a psychologist and approved by the Ethics Committee of the study's coordinating center (Università Cattolica, Rome). The questionnaire was sent to six public day hospitals (hospital-based outpatient facilities) specialized in the treatment of individuals with HIV infection. The centers are located in different areas of Italy (i.e. in the cities of Bergamo and Florence in northern Italy; Rome and Chieti in central Italy; and Sassari and Lecce in southern Italy) and were selected based on the following criteria: feasibility (i.e. willingness to participate in the study); geographical representativeness; and the number of HIV-infected persons followed by the center (i.e. >500). Each center was asked to hand out 250 questionnaires and to send the completed questionnaires back to the coordinating center within 6 months. A confidential list of persons who received the questionnaire allowed us to avoid delivering more than one copy to the same individual and thus multiple submissions from the same individual (as the questionnaire itself was completely anonymous, it was not possible to link the returned questionnaire with a single person).

Each questionnaire was accompanied by a cover letter explaining the purpose of the study and containing instructions on how to fill-out the questionnaire, specifying that anonymity would be guaranteed.

Questionnaire structure

The questionnaire was divided into three main sections. The first section was used to collect general personal data that seem to be correlated with discrimination against HIV-positive persons seeking treatment. These data were divided into three categories: predisposing, enabling, and need (PEN), as described by Dobalian (17). Predisposing factors are age, gender, marital status, and nationality; enabling factors are place of residence, educational level, profession, and income; and need factors are the severity of the infection (based on CD4+ cell count) and treatment with HAART.

The second section was used to investigate the relationship between the patient and the dentist and to determine if and how the relationship changed after the patient was diagnosed with HIV infection. This section included questions on whether the individual had been provided with dental care on a regular basis prior to diagnosis, whether this care had been provided by a private dentist or by a public facility, and whether the individual had been to a dentist since diagnosis. This section also included multiple choice questions on whether the individual had informed the dentist of his/her infection status (and if not, why) and whether he/she had been refused treatment (and if so, why); for these two questions, it was possible to provide only one mutually exclusive reason for not having informed the dentist and for why treatment was refused. For patients who had changed dentists after the diagnosis, there was a question on how they sought care after having decided to make this change.

To evaluate the level of discomfort experienced by an HIV-positive individual in his/her relationship with the dentist, we analyzed the questionnaires of persons who sought dental care after diagnosis and quantified the difficulty in obtaining care by assigning a score to the following questions: (1) 'Did you tell the dentist that you were infected with HIV?': 'Yes': 0 points; 'No': 1 point. (2) 'How many dentists did you see before finding one willing to treat you?': 'Less than two': 0 points; 'two or more': 1 point. (3) 'How did you manage to get treated?'; 'No particular strategies': 0 points; 'A specific strategy': 1 point. (4) 'Did your dentist refuse to treat you?'; 'No': 0 points; 'Yes ': 2 points (given the gravity of this point, an affirmative answer to this question was assigned a score of 2). A total score of three or more was considered as indicative of a high level of discomfort. To identify possible risk factors for discomfort, we evaluated the association between personal data (PEN) and a high score.

The third part of the questionnaire was used to determine whether the individual had sought

dental care in a public facility and how he/she was treated in this facility.

Statistical analysis

Quantitative variables were tested for normal distribution and compared by means of Student's two-tailed unpaired *t*-test. Differences between group proportions were assessed using chi-square test and Fisher's exact test. Univariate analysis was performed to identify potential risk factors for 'discomfort in the relationship between patient and dentist' and for the decision to seek dental care in a public facility. To determine the statistical significance of the odds ratios (OR), 95% test-based confidence intervals (95% CI) were used. Stepwise logistic regression models were used to adjust for the effect of confounding variables. Two-tailed tests of significance at the $P \leq 0.05$ level were used to determine statistical significance. Statistical analysis was performed using the software program Intercooled Stata 7.0 (Stata Corporation, TX, USA).

Results

Of the 1500 questionnaires sent to the day hospitals, 913 were completed and returned within the designated 6-month period (302 of the 500 questionnaires distributed in northern Italy; 308 of the 500 from central Italy; and 303 of the 500 from southern Italy). The average response rate was 913 of 1500 (60.9%). Thirty questionnaires were excluded because they contained practically no useful information; thus a total of 883 questionnaires were analyzed. The PEN data, which describe the demographic and social characteristics of the study population, are reported in Table 1.

Most of the study participants are treated by private dentists, as are most people in Italy; most had at least a primary school education and an annual income of under €10 000, and most were undergoing HAART.

Of the 883 questionnaires considered in the analysis, 868 contained information on dental visits made prior to diagnosis: 751 persons had been to a

Table 1. Demographic and clinical characteristics of 883 HIV-positive persons interviewed about access to dental care

	No. of questionnaires with answer	Number and/or percentage
Mean age in years (±SD)	883	39.5 ± 7.6
Gender		
Male	883	584 (66.1%)
Female		299 (33.9%)
Marital status		
Married/live-in partner	860	451 (52.4%)
Single		409 (47.6%)
Country of origin		
Outside of the European Union	883	18 (2%)
European Union		8 (0.9%)
Italy		857 (97%)
Area of residence		
North (Bergamo, Firenze)	857	25.5%
Center (Roma, Chieti)		43.5%
South (Lecce, Sassari)		31%
Educational level		
Primary school	853	83 (9.7%)
Middle school		405 (47.5%)
High school		292 (34.3%)
University degree		73 (8.5%)
Employment status		
Employed	816	62%
Unemployed		21%
Self-employed		17%
Annual income		
Lower than €10 000	785	50%
€10 000–20 000		39.6%
Higher than €20 000		10.4%
Undergoing HAART	849	92%
Most recent CD4 count	754	82% with CD4 count higher than 200 CD4/ml

dentist at least once prior to diagnosis; of these persons, 281 (37.4%) had received dental care on a regular basis in a private facility, 167 (22.3%) in a public facility, and the remaining in both types of facilities.

Analysis of the accessibility and the quality of dental care

Of the 880 individuals who answered the question on dental visits made after diagnosis, 630 (71.6%) had seen a dentist after diagnosis. Of these persons, 209 (33.2%) had not disclosed their seropositivity: 120 (57.4%) were concerned that other people might be told; 51 (24.4%) feared being treated differently; and 38 (18.2%) feared being refused treatment.

Of the 421 participants who disclosed their seropositivity to the dentist, 56 (13.3%) were refused treatment. According to these patients, the reasons given by the dentists were: lack of proper equipment (22 dentists – 39.3% of cases); concern over possible 'dental complications' because of HIV-related immunosuppression (12 dentists – 21.4% of cases); and unwillingness to treat HIV-infected persons (six dentists – 10.7% of cases); in the remaining cases (16 dentists – 28.6% of cases), the dentist referred the patient, without any explanation, to either a public facility (13 dentists – 22.1% of cases) or another private dentist (three dentists – 5.9% of cases).

Of the 630 persons who received dental care after diagnosis, 217 had changed dentists. Most of them found another dentist willing to treat HIV-positive persons ($n = 90$, 41.4%; Table 2). Of note is the finding that at least 129 of the 217 participants (59.4%) who changed dentists disclosed their seropositivity to every new dentist until finding one who was willing to treat HIV-positive persons.

Table 2. Strategies for seeking dental care for the 217 persons who changed dentists after HIV diagnosis

Strategy	Number (%)
Immediately found a private dentist willing to treat HIV-positive persons	90 (41.4)
Sought care at a public facility	45 (20.7)
Had to change several times before finding a private dentist willing to treat HIV-positive persons	39 (18.0)
Changed dentists without disclosing their seropositivity to the new dentist	28 (12.8)
Used other strategies to obtain dental care	15 (7.1)

Level of discomfort in the relationship with dentists

The 630 persons who had been to a dentist after diagnosis were divided into two groups: (i) the 69 (10.9%) persons who experienced great discomfort in their relationship with the dentist(s) (score of 3 or more); and (ii) the 561 (89.1%) persons who did not experience great discomfort.

The univariate analysis of factors potentially associated with the experience of great discomfort indicated a statistically significant association for the variable: 'having been treated by the same private dentist before and after diagnosis' (OR = 2.58, 95% CI = 1.55–4.27; $P < 0.001$; Table 3). Those who had been treated in public facilities either before or after diagnosis were less likely to have experienced great discomfort (OR = 0.60, 95% CI = 0.38–0.96; $P = 0.03$), as were those who had been undergoing HAART for at least 3 months (OR = 0.48, 95% CI = 0.24–0.93, $P = 0.03$; Table 3).

According to the multivariate analysis, the only variable statistically associated with the dependent variable 'great discomfort in the relationship between patient and dentist' was 'having been treated by the same private dentist before and after diagnosis' (OR = 2.68, 95% CI = 1.43–5.00, $P = 0.002$; Table 3).

Relationships with dentists in public facilities

Overall, 384 persons had received dental care in a public facility either before or after diagnosis. Of these, 153 had decided to change from a private dentist to a public facility after having been diagnosed with HIV infection. Of the 384 persons being treated in public facilities, 150 (39.1%) were being treated in facilities that provide specialized dental care for HIV-positive persons.

Of the 345 persons who answered the question on whether or not they had told the dentist in the public facility that they were HIV-positive, 292 (84.6%) responded 'yes'. Of the 313 persons who answered the question on whether or not they had experienced difficulties in finding a dentist willing to treat them in a public facility, 62 (20%) experienced some difficulty and 71 (29.3%) were sent to public facilities that provide specialized dental care for HIV-positive persons. Only 87 persons answered the question on whether or not they had been put on a waiting list in a public facility; the average wait was 37 days (approximately 25 working days). Of the 334 persons who answered the question on discrimination in public facilities,

Table 3. Factors associated with having experienced great discomfort in the relationship between patient and dentist: univariate and multivariate analysis

	Odds ratio	Confidence interval	*P*-value
Univariate analysis			
Having been treated by the same private dentist before and after HIV diagnosis	2.58	1.55–4.27	<0.001
Having been treated in a public facility either before or after HIV diagnosis	0.6	0.38–0.96	0.03
Undergoing HAART for at least 3 months	0.48	0.24–0.93	0.03
Multivariate analysis			
Having been treated by the same private dentist before and after HIV diagnosis	2.68	1.43–5.00	0.002

Table 4. Factors associated with having sought dental care in a public facility: univariate and multivariate analyses

	Odds ratio	Confidence interval	*P*-value
Univariate analysis			
Having received dental care after HIV diagnosis	1.94	1.55–2.43	0.004
Primary school education	1.31	1.12–1.53	<0.001
Annual income of <€10 000	1.3	1.1–1.54	<0.001
Annual income of more than €20 000	0.71	0.51–0.99	0.02
Self-employed (e.g. lawyers, physicians, accountants)	0.7	0.54–0.92	0.003
Living in southern Italy	0.68	0.48–0.98	0.02
Multivariate analysis			
Having sought dental care after HIV diagnosis	3.13	2.13–4.60	<0.001
Primary school education	1.51	1.08–2.11	<0.001

257 (77%) responded that they were not aware of any discrimination.

According to the univariate analysis (Table 4), having sought dental care in a public facility was associated with the following variables: 'primary school education' (OR = 1.31, 95% CI = 1.12–1.53, $P < 0.001$); 'annual income of €<10 000 (OR = 1.3, 95% CI = 1.10–1.54, $P < 0.001$); and 'having sought dental care after diagnosis' (OR = 1.94, 95% CI = 1.55–2.43; $P = 0.004$). An inverse association was found for: 'living in southern Italy' (OR = 0.68, 95% CI = 0.48–0.98, $P = 0.02$), 'annual income of more than €20 000 (OR = 0.71, 95% CI = 0.51–0.99, $P = 0.02$), and 'being self employed' (e.g. lawyers, physicians, accountants) (OR = 0.70, 95% CI = 0.54–0.92, $P = 0.003$).

According to the multivariate analysis, having sought dental care in a public facility was associated with 'having sought dental care after diagnosis' (OR = 3.13, 95% CI = 2.13–4.60, $P < 0.001$) and 'primary school education' (OR = 1.51, 95% CI = 1.08–2.11, $P < 0.001$; Table 4).

Discussion

Many studies have reported that HIV-positive persons require particularly meticulous dental care, not only because they are more prone to diseases of the oral cavity, which can be aggressive, but also because poor oral health can interfere with both eating and the administration of therapy, in addition to the quality of life in general (17). Despite its importance, and despite reports of discrimination against HIV-positive persons, only a few studies have been conducted on the access to dental care and the patient–dentist relationship, and the results of these studies, most of which have been conducted in the United States or Canada, highlight just how complex and delicate this relationship can be.

In Italy, the initial HIV epidemic mainly involved intravenous drug users, whereas in the past decade there has been an increasing proportion of cases because of sexual contact. Compared with other industrialized countries (e.g. the United States and Canada), healthcare professionals' awareness of the epidemic, and their reactions to it, occurred with a delay of 1–2 years (1–3). Moreover, in Italy there is no statute stating that it is illegal for a dentist or healthcare professional to deny care solely on the basis of a HIV status, unless it is emergency care.

The results of our multicenter study indicate that discrimination against HIV-positive persons on the part of dentists seems to exist in Italy. Of note is the finding that 33% of the persons who received

dental care after having been diagnosed with HIV infection did not tell the dentist that they were infected. This percentage, which is about twice as high as that reported in other countries, is cause for concern, and as reported in Canada, such reticent behavior could result in HIV-positive persons' being provided with therapy that is not suitable (18, 19).

The most common reason for keeping this information from the dentist was not fear of discrimination but instead concern over other people discovering that the individual was infected, which emphasizes the importance of guaranteeing complete privacy in the patient–dentist relationship (19). However, in interpreting this result, the fact that it was only possible to provide one answer to this question must be taken into account. It must also be considered that most people in Italy seek care from a private dentist, with whom they may be on friendly terms, which could create emotional stress for the patient who is deciding whether or not to disclose the fact that he/she is HIV-positive. This could explain why having been treated by a private dentist (i.e. someone who the patient already knows) before diagnosis was predictive of discomfort. Furthermore, as in Italy the same dentist generally treats the entire family, HIV-positive patients may fear that the dentist could inadvertently disclose their status to family members.

A 13.3% of the persons who had disclosed their seropositivity were explicitly refused dental care, and 69 persons suffered 'great discomfort' in their relationship with dentists. These findings confirm those of the study conducted in the United States by Greene et al. (15), who found that a low proportion of HIV-positive persons met difficulty obtaining dental care. Of interest is the finding that, according to our multivariate analysis, having experienced great discomfort in the relationship between patient and dentist was correlated with having been treated by a private dentist before the diagnosis of HIV infection, which confirms that discrimination indeed exists, stressing the need to promote medical ethics and to increase knowledge by training dentists in the proper care of HIV-positive persons.

With regard to the reasons for refusing treatment, about 40% of the dentists were reported as having said that they did not have the necessary equipment. Although this could be interpreted as an excuse to convince HIV-positive persons to seek care elsewhere, it may indicate the need to further educate dentists.

Another interesting finding was that, at the univariate analysis, undergoing HAART was inversely associated with discomfort in the patient–dentist relationship. This could be due to the better general conditions of patients undergoing HAART, who usually do not show clinical signs of severe HIV-related disease.

With regard to the persons treated in public facilities, it should be pointed out that the majority of them had disclosed their seropositivity to the dentist, were regularly treated, and did not feel that they would be discriminated against. Moreover, only 20% of the persons treated in public facilities experienced some difficulty in receiving dental care. An evident disadvantage of public facilities is the long waiting list, which results in an average wait of more than 1 month before receiving care. This problem is of particular concern for socially disadvantaged groups (e.g. those belonging to a lower economic class, lower education), who likely cannot afford a private dentist and must thus wait for a long time before receiving dental care, as indicated by the finding of an association between being treated in a public facility and primary school education. These considerations stress the need to improve public facilities or to create specific services for providing dental care to HIV-positive persons belonging to socially disadvantaged groups.

With regard to the methodology of our study, self-administered questionnaires have proven to be a very suitable means of collecting certain types of data, given that they are completely anonymous and, unlike interviews, do not entail a face-to-face confrontation, which could eventually lead to false answers being provided (17). With regard to the measurement of the level of discomfort, although the tool was not validated, the scores were chosen by the investigators to reflect the level of discomfort on the basis of objective parameters (e.g. 'direct refusal of treatment' was considered to be strong evidence of discrimination and was thus assigned a score of '2'). Furthermore, as mentioned, a possible limit of the methodology was that the answers to some of the questions (e.g. the reasons for not having disclosed infection status to the dentist and for having been refused dental care) were mutually exclusive.

On a final note, although some dentists engage in the ethically unacceptable practice of refusing to treat HIV-positive persons, this cannot guarantee that these dentists, or their patients, will avoid exposure to the virus, in that HIV-positive

individuals do not always disclose their seropositivity or they may be unaware of being infected. These considerations stress the necessity of adopting universal safety precautions under all circumstances.

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Appendix

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