

EDITORIAL

Knowledge, attitudes and health outcomes in HIV-infected travellers to the USA

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Background
The USA bans entry to non-citizens unless they obtain a waiver visa.

Aim
To establish how many people with HIV infection travelled to the USA, whether they were aware of the travel restriction, whether they travelled with a waiver visa and HIV inclusive medical insurance and how they managed with their antiretroviral medication (ARV).

Design
Collation of data from cross-sectional studies conducted independently at three different medical centres, Manchester, Brighton and London, using a structured self-completion questionnaire.

Results
The overall response rate was 66.6% (1113 respondents). 349 (31%) had travelled to the USA since testing HIV positive, of whom only 14.3% travelled with a waiver visa. 64% and 62% of the respondents at Manchester and Brighton were aware of the need of a waiver visa. 68.5% (212) were on ARV medication at the time of travel and, of these, 11.3% stopped their medication. Of those taking ARV medication, only 25% took a doctors' letter, 11.7% posted their medication in advance. Of those discontinuing treatment (n = 27), 55.5% sought medical advice before stopping, 11 were on NNRTI-based regimen and one developed NNRTI-based mutation. Only 27% took up HIV inclusive medical insurance. Many patients reported negative practical and emotional experiences resulting from travel restrictions.

Conclusion
The majority of HIV patients travel to the USA without the waiver visa, with nearly half doing so with insufficient planning and advice. A significant minority (11.3%) stop their medication in an unplanned manner, risking the development of drug resistence.

Key words: HIV-infected, travel to the USA

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Introduction

Since the introduction of highly active antiretroviral treatment (HAART) in 1996, there have been substantial reductions in deaths and hospital admission rates in the developed nations. Increasing numbers of HIV-infected people are back in work and are travelling for holiday, family or business reasons. Some countries impose regulations that restrict the travel of those known to be HIV-positive. Such regulations are not based on scientific or medical grounds and cannot be considered an efficient way to restrict the further spread of the HIV epidemic [1,2].

Currently, the USA is one of 15 countries to effectively ban HIV-positive travellers from entry (http://www.aidsnet.ch and www.travel.state.gov/visa). The USA legislation against HIV-positive tourists was introduced in 1987 during the HIV/AIDS pandemic by Senator Jesse Helms [3]. It requires anybody who is HIV-infected to apply for a visa to enter the USA by personal interview at a US embassy, and it may take 3 months or longer to obtain the

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visa. The person's passport is endorsed to show that they may not enter without the visa, which must be renegotiated for each entry. This can cause further HIV disclosure issues on entering other countries where immigration officers may want to know why the passport holder is barred from the USA.

The Visa Waiver Program allows citizens of 27 countries, including the UK, to enter the USA without a visa for up to 90 days. Yet travellers to the USA who are HIV-positive are not eligible to travel visa-free under the Visa Waiver Program and need to apply for a visa and a waiver of ineligibility, which is granted under a few special circumstances [4].

The USA is a popular holiday destination among British HIV-positive patients. Case studies of HIV-positive travellers to the USA described by the Terence Higgins Trust have suggested that many patients travel without a visa and do not disclose their status on the visa form. Some individuals discontinue their antiretroviral drugs prior to travel, for fear of being searched at the airport, questioned and denied entry [5].

The common aim of the three studies conducted separately at three different centres at different time-points was to identify how many people living with HIV travelled to the USA, whether they were aware of the travel restrictions and the need for the waiver visa and whether they took out medical insurance, and to establish how they managed their antiretroviral medication.

Table 1 Demographics

Variable	Manchester	Brighton	London
Study period	01/06/04–31/08/04	17/02/03–28/03/03	28/06/04–13/08/04
Total no. of respondents	408	346	359
Male gender (%)			
Respondents	82	96.5	89.7
Clinic population	77	90	85
Median age (years)	40	41	40
Age range (years)	22–70	23–73	18–65

Methods

Data from the three separate studies undertaken in Manchester, Brighton and London were collated and analysed.

Principal investigators at the three respective centres individually designed their questionnaire and sought ethical approval from their respective local ethics committees. At each centre, the questionnaire was piloted before the actual conduct of the study. At all the three centres, exclusion criteria for participation included HIV-infected patients who were below the age of 18 years.

Structured anonymous self-completion questionnaires were distributed to all eligible HIV-positive patients attending the out-patient clinics between 1 June and 31 August 2004 at Manchester, between 28 June and 13 August 2004 at the Mortimer Market Centre, London and between 17 February and 28 March 2003 at the Brighton clinic.

Study periods varying between 6 and 12 weeks were chosen at the three different centres because most HIV-infected patients tend to have follow-up out-patient appointments between 6 to 12 weeks, and thus these study periods allowed maximum participation of the patients.

Data from the Manchester study were analysed with Excel; in London, data were entered into access databases and analysed with the SPSS package (v9, SPSS Inc., Chicago, IL, USA), and in Brighton, data were entered into and analysed with SPSS version 11 (SPSS Inc., Woking,

Table 2 Study findings at the three different centres

	n/total (%)		
Variable	Manchester	Brighton	London
HIV-positive people travelling to the USA since diagnosis	99/408 (24.3)	135/346 (39)	115/359 (32)
Those who travelled without a waiver visa	94/99 (95)	133/135 (98.5)	72/115 (62.6)
Those who took up HIV-inclusive medical insurance	21/99 (21)	44/135 (33)	31/115 (27)
Those on HAART at the time of travel	75/99 (75.8)	83/135 (61)	81/115 (70)
Those discontinuing their HAART during their travel/holiday period	7/75 (9.4)	10/83 (12)	10/81 (12.3)
Of those continuing HAART, those taking a doctor's letter	22/68 (32.4)	8/73 (11)	23/71 (32.4)
Of those continuing HAART, those who post their medication in advance	7/68 (10)	12/73 (16.4)	9/71 (12.7)
Of those discontinuing HAART, those who took doctor's advice	4/7 (57)	5/10 (50)	6/10 (60)
Of those discontinuing HAART, those on NNRTI-based HAART combination	2/5* (40)	5/10 (50)	4/7† (57)
Of those discontinuing HAART, those developing resistance	0	1‡	ND

HAART, highly active antiretroviral therapy; ND, not done; NNRTI, nonnucleoside reverse transcriptase inhibitor.
*Two patients could not name their HAART regimen.
†Three patients could not name their regimen.
‡This patient developed the NNRTI-resistant mutation Y188L.

UK). Data from the three centres were collated by the principal author. Voluntary written consent was obtained at the Manchester and Brighton centres to study the case notes of those who stopped antiretroviral drugs.

Results

Sample characteristics

The demographics of the samples are presented in Table 1. The response rate was 73% (408 respondents out of 560) in Manchester, 54% (346 respondents out of 642) in Brighton and 73% (359 out of 489) in London.

The majority of respondents at the three centres were male: 82% in Manchester, 96.5% in Brighton and 89.7% in London. The median age of the participants was 40 years and age ranged between 18 and 73 years.

Of the total of 1113 respondents from the three centres, 349 (31%) had travelled to the USA since diagnosis of HIV infection.

Visa and HIV-inclusive medical insurance status

The findings obtained at the three centres are summarized in Table 2. Of the 349 patients who had travelled to the USA, 299 (85.7%) travelled without a waiver visa. Of the respondents in Manchester and Brighton, 64% and 62%, respectively, were aware of the need for a waiver visa. Overall, 27% took up HIV-inclusive medical insurance.

Treatment interruption

At the time of travelling to the USA, 239 patients (68.5%) were taking antiretroviral (ARV) treatment. Twenty-seven people (11.3%) stopped their ARV treatment at the time of travel. Of the 212 continuing their ARV treatment, only 53 (25%) took a letter from their clinic doctor with them. Twenty-eight people (11.7%) on ARV treatment posted their medication to the USA in advance, of which 25 received it on time.

Thirty-nine people from Manchester and London had their hand baggage searched on arrival in the USA; this issue was not investigated at the Brighton centre. None of these patients was refused entry to the USA. Of the 27 discontinuing treatment, only 15 (55.5%) sought medical advice before stopping ARV treatment. Eleven were on a nonnucleoside reverse transcriptase inhibitor (NNRTI)-based regimen. Five individuals could not name their regimen. Among those who had consented to a case-notes review (nine out of ten in Brighton and four out of seven in Manchester), one individual developed an NNRTI-based mutation.

Investigators at the Manchester centre ($n = 99$) also examined how medication was carried onto the plane (hand or hold luggage) and the dosing interval. Seventy-nine per cent of patients carried their medication in their hand luggage and 47% took their medication on time. For the remainder, there was a delay of 1–6 h in 32% of cases, 7–12 h in 15% and 19–24 h in 1%, and 4% could not remember the time delay.

In addition, the study performed at the Manchester centre included space for free text on the questionnaire for patients to add their comments/feelings with respect to their travelling experience to the USA if they wished to do so. Of the 99 who had travelled to the USA, 44 had put down their comments, which were as follows: 23 commented on worry and stress, eight felt they were discriminated against, seven said that they would not travel again to the USA and six mentioned concerns about being discovered.

The Brighton and London studies detailed why HIV-infected patients stopped treatment before travel. In Brighton it was found that 10 individuals who had discontinued treatment did so because they were afraid of being searched by the immigration authorities. In London, 10 out of 81 patients stopped therapy. Their reasons were that they were 'entering a country with an official travel ban for HIV-positive subjects' (all 10 of the patients), that they had a 'fear of being found out' (four of the 10 patients) and that they wished a 'holiday from drug side-effects' (three of the 10 patients). More than one answer was allowed.

Discussion

There has been very little information available on the knowledge, attitudes and health outcomes of HIV-positive patients travelling to the USA. This study is the first of its kind in Britain. Overall, the three medical centres cater to the health care of 4280 adult HIV-positive people (total HIV-infected cohorts as per annual records were 1212 and 2070 HIV-positive patients for the year 2004 at Manchester and London, respectively, and 998 for the year 2003 at Brighton).

In the centres evaluated, 31% of HIV-positive individuals visited the USA.

While a high proportion of individuals (62–64%) said that they were aware of the need for a waiver visa, the majority (85%) travelled to the USA illegally. A significant proportion (11%) of HIV-positive people discontinued their treatment in an unplanned way. Of these, half (11 of 22 patients) were able to name their regimen and were on an NNRTI-based regimen. NNRTI-containing regimens need to be stopped sequentially in order to avoid functional NNRTI monotherapy and a risk of developing NNRTI-resistant

virus [6]. It is a concern that 44% of people altered therapy without medical advice. Only a quarter took up HIV medical insurance.

In our study, no HIV-infected participant was denied entry to the USA. In the literature it is well documented that travellers carrying ARV medications have been deported on a number of occasions [7]. Discrimination against and harassment of travellers have been reported [8]. Although not assessed objectively, comments made by respondents in free text reveal that many individuals suffered significant distress. This fear of discovery was a common reason for stopping treatment in the Brighton and London studies. The majority of patients who carried their treatment with them commented that they had disguised their ARV medication using alternative containers such as vitamin bottles. Thirty-nine travellers' hand luggage had been searched in the Manchester and London cohort; none was deported. It is not clear how they carried their ARV medication or whether it was disguised. A recent article highlights many of the issues with respect to the travel ban on HIV-positive people [9]. The discrimination faced by travellers is contrary to international health regulations which do not specify special measures for HIV infection. These regulations call for implementation with full respect for the dignity, human rights and fundamental freedoms of persons [10]. Precious resources are being wasted to set up barriers which experts have found utterly ineffective [3].

Our study has several limitations. Although data from multiple centres were collated in the study, the questionnaires were not identical, although all were primarily conducting a study on similar issues of travel to the USA (knowledge of a visa waiver, travelling with a visa waiver, taking up HIV-inclusive medical insurance, stopping ARV treatment and any ill effects with stopping treatment). Clinical details of patients who stopped treatment were based on retrospective data from case notes at the two centres. Despite these qualifications, we believe that the results of the study are important.

Conclusions

This study shows that the USA is a popular tourist destination amongst HIV-positive individuals. The majority of these travellers enter the USA illegally by not using the correct visa for entry. A significant minority stopped their medication in an unplanned manner, risking the development of drug resistance.

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