SHORT REPORT

Non-disclosure of HIV status in UK sexual health clinics—a pilot study to identify non-disclosure within a national unlinked anonymous seroprevalence survey

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ABSTRACT

Objectives To identify if HIV-infected individuals attending genitourinary clinics in the UK are not disclosing their HIV status, and to examine the potential utility of drug detection as a method to indicate non-disclosure.

Methods HIV-positive samples from the unlinked anonymous seroprevalence survey from one London centre in 2009 had viral load (VL) assays performed to identify samples with VL below the level of detection (50 copies/ml, VLBD) or <1000 copies/ml. After data matching, known HIV positives were excluded and the remaining samples analysed for the presence of a panel of antiretroviral drugs.

Results Of 130 HIV-positive samples with sufficient clinical information and not undergoing an HIV test, 18 were classified as remaining undiagnosed after the clinic visit. Thirteen (72%, 95% CI: 47% to 90%) had a VLBD ($n=11$) or VL <1000 copies/ml ($n=2$). Eight had sufficient volume to undergo ARV testing, and all were positive for the presence of drug; all with therapeutic levels of clinically appropriate combinations.

Conclusions Non-disclosure of HIV status occurs among individuals attending sexual health services in the UK. This study demonstrates the feasibility and utility of using both VL and ARV assays in serum samples. Furthermore, the close correlation of detection of ARV with VLBD suggests drug detection would be a useful tool to monitor non-disclosure prospectively, thus enabling the use of stored serum samples in future studies. The extent to which these findings can be extrapolated to other settings, and the potential impact of non-disclosure on undiagnosed estimates warrants urgent prospective study.

INTRODUCTION

Currently, of all people living with HIV in the UK, it is estimated that 24%, approximately 22 200 individuals, are unaware of their infection.¹ This figure is derived from statistical modelling of multiple surveillance- and survey-based data sources. One of the surveillance programmes is the unlinked anonymous seroprevalence survey: GUMAnon Survey,² conducted at 16 UK genitourinary (GU) clinics. The methodology is described elsewhere;² in brief, unlinked residue from routine syphilis blood specimens are tested for HIV antibodies; broad-risk categories and whether the

individual is categorised as previously diagnosed, diagnosed at the clinic visit or left the clinic unaware of their HIV status are available. Using 2009 data, it was estimated that 27% of previously undiagnosed individuals left the clinic unaware of their positive HIV status. Anecdotally, expert opinion has been that some patients aware of their positive HIV status attend GU services but do not disclose their status. A report by Whitlock and colleagues,³ describes a small (1.9%) proportion of patients self-reporting this behaviour. This phenomenon could result in an overestimation of the proportion of individuals who are unaware of their status. We therefore undertook the following study to objectively determine if this behaviour occurs, and to examine the potential utility of drug detection to indicate non-disclosure.

Several assumptions were made underpinning the methodology and interpretation of the data. Given that London HIV treatment rates among individuals accessing HIV care are over 80%, and the effectiveness of antiretroviral (ARV) therapy in clinical practice exceeds 90%,¹ if non-disclosure behaviour was prevalent, there would be a significant number of non-disclosers (ND) on ARV therapy, and a significant number of these individuals (ND on ARV) would have undetectable or very low viral loads (VL). Furthermore, of all diagnosed HIV patients, only a very small proportion (0.15%) are elite controllers with undetectable VLs when not on treatment.⁴

METHODS

All HIV-positive samples identified through GUMAnon from one London centre in 2009 were included. VL assays identified samples with VL below the level of detection (50 copies/ml, VLBD) or <1000 copies/ml and, after matching with clinical information to exclude samples from those previously diagnosed, these samples were analysed for the presence of a panel of ARV drug.

HIV antibody test

Pooled specimens were screened for HIV antibodies using enzyme immunoassay (Abbott Diagnostics, Maidenhead). Reactive pools were retested singularly, and reactive specimens subsequently tested with an in-house IgG class specific capture assay.⁵ Discrepant results were tested by an in-house IgG