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Manuscript Title Page

Title: Loss to follow-up among adults attending HIV-services in England, Wales and Northern Ireland

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Abbreviations: Antiretroviral Therapy (ART); England, Wales and Northern Ireland (E,W&NI); Survey of Prevalent HIV Infections Diagnosed (SOPHID); National Health Service (NHS)

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Abstract Page

Short Summary: In a national cohort of HIV-diagnosed adults in England, Wales and Northern Ireland, most adults attended HIV-services regularly. However, cumulatively one-in-five were lost to follow-up between 1998 and 2007.

Background: To assess the extent to which HIV-diagnosed adults attending HIV-services in England, Wales and Northern Ireland are lost to follow-up or attend services intermittently.

Methods: A cohort of HIV-diagnosed adults was created by linking records across the 1998 to 2007 national annual Surveys of Prevalent HIV Infections Diagnosed (SOPHID) (n=72,218). Records were also linked to the national HIV and AIDS New Diagnoses Database and to Office for National Statistics death records. Patterns of HIV-service attendance were analysed.

Results: On average, 90% of adults attending HIV-services in any one year attended the following year. Nearly five percent of adults attending services in any one year were lost to follow-up, a further 4% subsequently attended services intermittently, while less than two percent died. Cumulatively, 19% of adults seen for HIV-care between 1998 and 2006 were lost to follow-up by the end of 2007. Factors associated with loss to follow-up included being: female; aged 15 to 34 years; of black-African or “other” ethnicity; not on anti-retroviral therapy; recently diagnosed; infected outside the UK.

Conclusion: Although the majority of HIV-diagnosed adults in England, Wales and Northern Ireland attended HIV-services regularly, cumulatively nearly one-in-five were lost to follow-up between 1998 and 2007. Innovative strategies focusing on those most likely to drop out of regular care should be developed to maintain regular service engagement and to ensure optimal care.

Keywords: diagnosed, HIV, services, loss to follow-up

Introduction

The risk of HIV-related morbidity and mortality among persons living with HIV, as well as the risk of HIV transmission, can be reduced by not only encouraging earlier and more frequent testing for HIV but also through the provision of optimal care and regular clinical review.^{1,2} The British HIV Association guidelines state that diagnosed persons should be encouraged to regularly attend HIV-related health services (referred to here as “HIV-services”) to monitor their CD4 count and HIV viral load as well as providing drug adherence support services for those receiving antiretroviral therapy (ART).^{3,4} The guidelines also recommend a sexual health assessment at first presentation and at six monthly intervals thereafter, and ongoing high-quality counselling and support.⁴

National HIV surveillance data for England, Wales and Northern Ireland (E,W&NI) suggest that people may be leaving the HIV-diagnosed prevalence pool for reasons other than death.^{5,6} Up to the end of 2007, 87,972 adults (aged 15 years or over) had been newly diagnosed with HIV. Of these, 15,833 were reported to have died by the end of 2006. Subtracting the number of reported deaths from the cumulative number of new HIV diagnoses suggests that 72,140 diagnosed adults were living in E,W&NI in 2007. This number greatly exceeds the 52,603 adults reported as attending HIV-services in E,W&NI in 2007. This paper explores annual patterns of attendance at HIV-services among HIV-diagnosed adults seen for care for the period 1998 to 2007. We assess the extent to which HIV-diagnosed persons are lost to follow-up or attend services intermittently across the whole of E,W&NI and determine predictors of loss to follow-up.

Materials and Methods

Data sources

SOPHID: The cross-sectional annual Survey of Prevalent HIV Infections Diagnosed (*SOPHID*) was introduced in 1995 and collects reports of all persons within a calendar year attending National Health Service (NHS) sites offering HIV-services in E,W&NI, including all transfers.⁶⁻⁹ Data from the 1998 to 2007 surveys were included in the analysis (sex, age, use of ART, probable route of infection, ethnicity and whether the person had died).

New-Diagnoses: The HIV and AIDS New Diagnoses and Deaths system (referred to as New-Diagnoses) has operated since 1982, and collects information relating to new HIV diagnoses, first AIDS diagnosis, and deaths among HIV-infected adults across the whole of E,W&NI on an ongoing basis via voluntary laboratory and clinician reports.^{5,10} Information on year of first HIV diagnoses, probable country of infection (assigned by clinicians or during follow-up interviews with patients) and vital status (alive or dead) was abstracted from the New Diagnosis system and linked to the *SOPHID* records. Data are as reported to the end June 2008.

Both the *SOPHID* and New-Diagnoses surveillance systems are held at the Health Protection Agency (HPA),¹¹ and strict attention to confidentiality is maintained at every stage of data collection, analysis and storage. No names are collected or held on either database. Instead, a soundex code (a four character coding of the surname),¹² together with sex and date of birth provide a unique identifier in each system. To reduce under-reporting both systems identify and subsequently contact reporting sites that either have

not reported, or have reported fewer patients than might be expected based on previous reports. Death notifications are reported directly to both systems by clinics and are supplemented by death notifications from the Office of National Statistics.

Record linkage and removal of duplicate records

We created a cohort of persons attending HIV-services by linking records across the 1998 to 2007 annual SOPHID surveys on full and part-linked identifiers (sex, date-of-birth, soundex code, and postcode of residence). Duplicate reports were first identified and removed. A soundex code is not provided for most children and the analyses were therefore restricted to adults aged 15 years and above. Due to improved data collection in later years, some analyses are restricted to the period 2002 to 2007.

Loss to follow-up

We allocated a year of last attendance to any person who was reported to at least one SOPHID survey between 1998 and 2006 for whom no record could be identified in subsequent surveys and for whom no death had been reported. These individuals were defined as being lost to follow-up from that point on.

We calculated the percentage of adults attending services each year who were lost to follow-up from that point on (i.e. they were classified as last attending services during that year). We did this for the overall cohort and for different sub-groups (for example, according to sex, age or ethnicity). We then conducted a univariate analysis to determine the likelihood of being lost to follow-up within each subgroup by comparing, for example, men and women or younger people and older people. In each sub-group

the reference category was the one that was most frequently reported and the comparison of percentages was expressed as a ratio. In addition, we conducted logistic regression to identify factors associated with loss to follow-up cumulatively for the period 2002 to 2006 (restricted to these years due to better variable completion).

Loss to follow-up adjusted for intermittent attendance

We adjusted the percentage of adults who were lost to follow-up each year to take account of people intermittently attending services who may return to care after 2007 (table 1). The adjustment allows for an interval of non-attendance of up to eight years. To make the adjustment, we extrapolated observed patterns of intermittent attendance between 1998 and 2007 to subsequent years. For example, the number of adults lost to follow-up (i.e. last attending services) in 2000 was adjusted for adults estimated to re-attend in 2008 or 2009 (i.e. after a gap of seven or eight years) whereas the number for 2006 was adjusted for adults estimated to attend services again at some point between 2008 and 2015 (i.e. after a gap of one to eight years). The adjusted figures represent best estimates of loss to follow-up.

Finally we calculated cumulative loss of follow-up between 1998 and 2006. For the numerator we added the final estimates of loss to follow-up for each year between 1998 and 2006 (Table 1 bottom row). For the denominator we included all adults attending HIV-services for one year or more between 1998 and 2006 (n=65,040). Pearson χ^2 values and all confidence intervals presented are at the 95% level. STATA 9.0 (Stata Corp., College Station, Texas, USA) was used for analyses.

Results

A cumulative number of 72,218 adults attended HIV-services in at least one year in E,W&NI between 1998 and 2007. These adults comprise the cohort for the analysis. Complete data were available as follows: soundex, date-of-birth and sex 100% (n=72,218); ethnicity 98.2% (70,928); probable route of infection 96.3% (69,537); use of ART 95.7% (69,129); year of diagnosis 85.2% (61,495); probable region of infection 59.6% (43,077).

Overall patterns of attendance

On average between 1998 and 2006, 89.8% of adults attending services in a given year attended services the following year, 2.1% skipped one year of care, 1.2% skipped two or more years, and 1.7% died (decreasing from 2.9% [466] in 1998 to 0.7% [340] in 2006) (table 1). On average 5.7% of adults attending services in a given year were not reported again to SOPHID at any time up to and including 2007, i.e. they were lost to follow-up (before adjusting for intermittent attendance). This percentage ranged from 5.0% in 2001 to 7.4% in 2006.

Loss to follow-up

Table 2 presents the likelihood of being lost to follow-up for the different subgroups for 2002, 2004 and 2006 (data for other years available from authors on request). In all years, men infected through sex between men were less likely to be lost to follow-up compared to adults infected through other routes ($p<0.05$). The following groups were the most likely to be lost to follow-up: people of black-African ethnicity; females;

people aged 15 to 34; those not on ART at last report; people with a recent diagnosis in E,W&NI; and adults infected in Africa (all $p<0.05$) (Table 2).

Combining data for the years 2002 to 2006, multivariate logistic regression identified these same factors to be associated with loss to follow-up as well as being of “other” ethnicity, and being infected in Europe (all $p<0.05$). In terms of probable route of infection, in multivariate logistic regression heterosexual contact was associated with loss to follow-up ($p<0.05$).

Loss to follow-up adjusted for intermittent attendance

After adjusting for adults who may return to care following a period of up to eight years non-attendance, it was found that, on average, 4.9% of adults attending services in any given year between 1998 and 2006 were lost to follow-up (table 1), 4.2% attended intermittently (2.1% + 1.2% + 0.9%) and 1.7% died. The adjusted percentage of adults lost to follow-up fell over time, from 6.3% [\(1,012/16,126\)](#) in 1998 to 3.7% [\(1,776/48,103\)](#) in 2006 ($p<0.01$) (table 1, bottom row).

Overall, we estimated that 12,467 people were lost to follow-up between 1998 and 2006 (table 1, bottom row). This represents one in five adults (19.2%; 12,467/65,040) attending HIV-services for one or more years between 1998 and 2006.

Adjusting national estimates of diagnosed HIV for loss to follow-up and intermittent attendance

Subtracting the number of reported deaths from the cumulative number of new HIV diagnoses suggests that 72,140 diagnosed adults were living in E,W&NI in 2007. This number greatly exceeds the 52,603 adults reported as attending HIV-services in E,W&NI in 2007 based on SOPHID. The disparity between these two estimates ($72,140 - 52,603 = 19,537$) is greatly reduced when loss to follow-up and intermittent attendance are taken into account.

Adjusting for cumulative loss to follow-up between 1998 and 2006 (19.2%), reduces the new-diagnoses-minus-deaths figure from 72,140 to 58,300. The SOPHID figure increases from 52,603 to 54,550 when we take into account adults who did not attend services in 2007 but may do so subsequently (the 2006 intermittent attendance estimate of 3.7% in Table 1 was applied). The disparity between the two estimates then becomes 3,750 ($58,300 - 54,550$) compared with 19,357 before adjustment.

Discussion

Our findings indicate that the vast majority of adults with diagnosed HIV living in E,W&NI are regularly seen for HIV-care after diagnosis. Overall, nine out of ten adults attending HIV-services in any one year attended for care the following year—, four percent subsequently attended services intermittently, while less than two percent died. Although there has been a significant decline over the study period in the percentage of adults lost to follow-up (from 6.3% in 1998 to 3.7% in 2006), on average, Nnearly five percent of adults attending services in any one year were lost to follow-up,~~a further four percent subsequently attended services intermittently, while less than two percent died.~~ Cumulatively, however, one-in-five (or an estimated 12,500) adults attending HIV-related services in E,W&NI between 1998 to 2006 were lost to follow-up by the end of 2007.

How can we explain loss to follow-up among people diagnosed with HIV in E,W&NI? One possible explanation is that some adults diagnosed with HIV in E,W&NI subsequently emigrate. New HIV diagnoses among adults of black-African ethnicity, many of whom have recently arrived in the UK, have increased since 1999.^{1,5,13-15} It is possible that the association between loss to follow-up and black-African ethnicity, acquiring HIV-infection abroad, and having a recent diagnosis can be explained by migrants to the UK leaving shortly after receiving an HIV diagnosis. Their emigration may be voluntary or involuntary, temporary or permanent. Although these associations provide some evidence of emigration contributing to loss to follow-up, we are unable to

judge the extent to which an HIV diagnosis, or HIV-related morbidity, would influence this.

Another possible explanation for loss to follow-up is diagnosed adults withdrawing from HIV-related treatment and care. Discrimination and HIV-related stigma, within and outside the health care system, are major barriers to healthcare service usage. Discrimination has been reported among persons of black-African ethnicity living with HIV in the UK,^{16,17} a group for whom an elevated risk of loss to follow-up was found. It is possible that some people withdraw from HIV treatment and care once they are diagnosed, only to present again some years later when they are symptomatic. This is consistent with the association between loss to follow up and not being on ART at last report and having a recent HIV diagnosis.

It is unlikely that loss to follow-up is due to diagnosed adults attending non-NHS (i.e. private) services. In the UK, it is recommended that people diagnosed with HIV regularly attend specialist NHS outpatient clinics which are free at the point of access and which are encouraged to offer clinically effective HIV care that matches local population needs.^{3,4} A study of HIV-diagnosed persons attending two London NHS clinics found that only 15 out of 225 respondents had private health insurance.¹⁸ It is therefore unlikely that loss to follow-up is a result of adults attending private HIV-services once they stop going to an NHS clinic.

There are some limitations to our analyses. It is possible that our estimates of loss to follow-up and intermittent attendance are inflated due to problems with data linkage

across surveys. For example, unfamiliar African surnames may result in soundex codes being reported differently over time,¹⁹ making record linkage difficult. This could result in loss to follow-up estimates among black-Africans being inflated. To reduce this potential bias, we increased the likelihood of matching records by using an algorithm that included variations in soundex and date of birth.

It is also possible that our estimates may be inflated due to the under reporting of adults over time to SOPHID. However, we believe this is unlikely. The SOPHID survey collects data from all NHS sites throughout the UK which offer open and free access to HIV-related care and treatment. In addition to the active follow-up of all non-reporting and under-reporting sites by the HPA, annual survey outputs are linked to the local commissioning of HIV-services. For underreporting to SOPHID to contribute to loss to follow-up, it would require adults attending HIV-related services to be omitted from clinic reports in all years subsequent to the year of last report. Since this could result in the underfunding of services in subsequent years it is unlikely that this is common.

It is also unlikely that underreported deaths among HIV-diagnosed persons in E,W&NI have a major impact as overall numbers are relatively small.⁵ Also, the likelihood of underreporting is reduced by the supplementation of HIV and non-HIV related death reports from clinics with information from the Office of National Statistics.²⁰

Our estimates of loss to follow-up and intermittent attendance help to explain the disparity between our two estimates of diagnosed HIV prevalence, one based on reports to SOPHID, the other based on new HIV diagnoses minus deaths. After taking loss to follow-up and intermittent attendance into account, the disparity was greatly reduced.

Our cumulative estimate of adults lost to follow-up during our study period is the same as that reported from a London clinic-based study where one in five patients registered between 1997 and 2005 were lost to follow-up by the end of 2006.²¹

The HPA has recently developed measures to evaluate the quality of care received by people accessing HIV-services, including timely access to care following an HIV diagnosis.²² In 2008, 80% of people newly diagnosed with HIV were seen for care within one month of their diagnosis with almost 95% seen within three months.²² The HPA will also provide annual estimates of loss of follow-up among HIV diagnosed adults as an additional indicator of quality of care.

In conclusion, the vast majority of adults with diagnosed HIV living in E,W&NI are regularly seen for HIV-care after diagnosis, in line with guidelines recommending regular patient contact with HIV-services.⁴ Nevertheless, we identified a significant proportion of HIV-infected adults either permanently lost to follow-up or intermittently attending services. Innovative strategies should be developed to maintain regular service engagement among those groups found to be at increased risk of dropping out of regular care.

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