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Estimating the size of the HIV epidemic among injecting drug users in Amsterdam

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Abstract. Aim of this study was to assess the cumulative incidence of HIV-infection, AIDS and pre-AIDS death in the population of injecting drug users (IDU) in Amsterdam. By assuming equivalence, between a cohort of IDU and the IDU population, of the ratios of incidences of AIDS and pre-AIDS death to the number of HIV positive persons giving rise to these incidences, the numbers of HIV positive persons and pre-AIDS deaths in the population could be calculated, given that other parameters were known. Cohort study data on HIV prevalence and incidences of HIV infection, AIDS, and pre-AIDS death, were combined with national AIDS surveillance data. As of 1 October 1994, the estimated cumulative number of HIV positive IDU in Amsterdam was approximately 1280, far higher than a recent back-calculation estimate. Of the 1280, 204

HIV positive IDU had been diagnosed with AIDS, while about 270 had died pre-AIDS. The HIV prevalence of IDU residing in Amsterdam that were still alive and free of AIDS was hence estimated at around 800. Since the incidence of pre-AIDS death and AIDS exceeded the number of seroconversions during the past four years, the HIV epidemic among IDU in Amsterdam appears to be dwindling. A lower bound of the number of HIV positive IDU being alive, AIDS-free and living elsewhere in the Netherlands was roughly estimated at 600. Because of untimely deaths, only a limited number of HIV positive IDU can be expected to be diagnosed with AIDS in the future. Since these estimates are based upon some rather bold assumptions, they should be interpreted with caution and require further validation by independent sources.

Key words: AIDS incidence, Estimation, HIV-1, HIV prevalence, Injecting drug users, Mortality

Introduction

Injecting drug users (IDU), those with homosexual contacts included, are the second major risk group for AIDS in the Netherlands (population 15.4 million). By 30 September 1994 a cumulative total of 3247 AIDS cases had been reported to the national AIDS surveillance centre (Medical Inspectorate of Health, Rijswijk), of whom 343 (11%) were IDU [1]. More than half of all notified AIDS cases among IDU was resident of Amsterdam (population 725,000), making the capital the epicentre of the national AIDS epidemic among IDU [2]. Although IDU comprise only a relatively small segment of all AIDS cases reported in the country, their contribution to the annual reported numbers of AIDS cases continues to rise [3] and there is evidence that many HIV positive IDU die before being diagnosed with AIDS [4, 5], indicating that the relative contribution of IDU to the national HIV epidemic is larger than might be expected from the distribution of emerging AIDS cases.

For several reasons it is important to gain a good understanding of the size of the HIV-epidemic

among IDU. Firstly, estimates of the total number of AIDS patients and HIV positive IDU give insight into future health care needs and may help in health care planning. Secondly, these estimates give insight, either directly or through incorporation in mathematical models [6], into the role HIV positive IDU play in furthering the epidemic among other IDU and among the 'general' heterosexual population and may thereby guide prevention strategies.

This paper presents estimates derived from application of an adapted version of a simple method described by Taylor et al. [7]. The estimates include overall cumulative incidence of HIV-infection, AIDS and pre-AIDS death for IDU residing in Amsterdam and are based on data from a cohort study among IDU in Amsterdam and from the Amsterdam and national AIDS surveillance systems.

Methods

We define cumulative incidence of HIV infection among IDU as the cumulative number of IDU

residing in Amsterdam who have been infected with HIV, including infected IDU who died.

Central to the estimation method applied here is the assumption that within a given time period the ratio of the cumulative numbers of persons who are HIV positive and who are diagnosed with AIDS (HIV/AIDS ratio) in the Amsterdam cohort study among IDU is equivalent to the ratio of these numbers for the Amsterdam population of IDU. Within the limits of that time period, by multiplying the total number of reported AIDS cases among Amsterdam IDU with the HIV/AIDS ratio found in the cohort, an estimate of the cumulative HIV incidence among IDU in the population would result. Likewise, the pre-AIDS death/AIDS ratio from the cohort was used to estimate pre-AIDS mortality in the HIV positive IDU population.

The Amsterdam cohort study among drug users started December 1985 and has been extensively described elsewhere [8, 9]. Basically, it is an open cohort with continuous intake of new participants, although starting 1 September 1990 the cohort has been closed for new entrants during one year. Recruitment took place at seven methadone outposts and a sexually transmitted diseases clinic for drug-using prostitutes. Both HIV positive and HIV negative, injecting and non-injecting drug users could participate, independent of sexual preference. Drug users with AIDS were excluded from entering the cohort. Each participant was asked to return every four months for repeat visits. For those who did not return for repeat visits, vital status was assessed annually by consulting population registers and other sources. In cases where death occurred without preceding, concurrent, or successive (retrospective) AIDS diagnosis, death was coded as pre-AIDS. The present study is limited to drug users who reported ever to have injected drugs and who were recruited before September 1990.

The HIV/AIDS ratio within the cohort was calculated for the period 1 September 1990 to 1 October 1994 (study period). We assumed that new infections during the study period were in the same proportion to the number already infected at the start of the study period in the cohort as in the population. For the numerator of the HIV/AIDS ratio in the cohort the sum was taken of the number of HIV positive participants who were alive and AIDS-free at 1 September 1990, and the number of participants who were HIV negative at that data but who seroconverted within the study period. Since follow-up for HIV negative IDU was incomplete, the number of seroconversions within the cohort was adjusted to the number that could be expected when follow-up would have been complete. This adjustment was based on a Kaplan-Meier estimate of cumulative incidence at the end of the study period. Since the likelihood of developing AIDS during the first few years after HIV-infection is small [10, 11], we further

assumed that no AIDS cases were to be expected from these construed seroconversions before 1 October 1994.

The denominator of the HIV/AIDS ratio within the cohort and within the population was assessed by using data collected by the Amsterdam AIDS surveillance at the Municipal Health Service, supplemented By Medical Inspectorate of Health data from the rest of the country. This AIDS surveillance system registers and actively traces AIDS cases diagnosed in Amsterdam, thereby limiting underreporting to an approximate 5–10% [12]. The Amsterdam AIDS surveillance and the national AIDS surveillance exchange information so as to increase data quality. National AIDS-case reporting commenced in 1982, although the first diagnosis of AIDS in an IDU was not made until 1985. Until January 1994, the 1987 CDC definition of AIDS applied [3], while subsequently the European definition was utilized [14]. Cohort participants who had been reported with AIDS were identified through record linkage, based on initials, gender and date of birth. Cohort staff does not report AIDS cases among cohort participants to the surveillance system but may enhance reporting of these cases by others. Cohort participants who developed AIDS but who had not (yet) been reported to the surveillance system were not counted as AIDS cases for the present study. To restrict the influence of reporting delay, case reports to the surveillance system were taken into consideration until 3 months after the end of the study period. No additional adjustments were made for underreporting and reporting delay since these apply to some extent to cohort participants as well as to the IDU population and can be considered relatively minor.

Because cohort data are lacking for the remaining part of the Netherlands the same methodology could not be applied there. However, by assuming that the ratio of AIDS cases that either were or were not Amsterdam residents reflects the underlying ratio of prevalent numbers of HIV positive IDU, we estimated the number of HIV positive IDU that live in the Netherlands but not in Amsterdam. For this purpose we used data from the national AIDS surveillance.

Results

At the start of the study period (1 September 1990) 210 HIV positive and 446 HIV negative IDU were included in the cohort and were alive and free of AIDS. During the study period 23 out of the 446 initially HIV negative participants seroconverted. Adjusting for incomplete follow-up raises the number of seroconversions to 40, thereby increasing the adjusted cumulative number of HIV positive IDU in the cohort per 1 October 1994 to 250 (Table 1). During the study period, 30 cohort participants were

Table 1. Recorded and estimated numbers of HIV positive injecting drug users in a cohort and in the population in Amsterdam, up till October 1994

	Cohort	Population
<i>During study period (1 September 1990–1 October 1994)</i>		
HIV positive alive and free of AIDS at study entry	210	882
Seroconversions (adjusted for cohort)	<u>+ 40</u>	<u>+ 168</u>
Total HIV positive	250	1050
AIDS diagnoses	30	126
Pre-AIDS deaths (adjusted for cohort)	29	122
<i>Preceding 1 September 1990</i>		
AIDS diagnoses		78
Pre-AIDS deaths		≈150
<i>By 1 October 1994</i>		
AIDS diagnoses		204
Pre-AIDS deaths		≈272
HIV positive, alive and free of AIDS (prevalence)		802
Total cumulative HIV incidence		≈1278

Recorded numbers are displayed in normal font; estimated numbers are displayed in bold. The ratio of the number of AIDS diagnoses in the cohort and the population during the study period (30:126) was applied to recorded cohort figures to estimate the numbers of HIV positives alive and free of AIDS at study entry, seroconversions, total HIV positives, and pre-AIDS deaths in the population.

diagnosed and reported with AIDS, while during the same period the total number of diagnosed and reported cases of AIDS among all IDU in Amsterdam was 126. The number of HIV positive IDU, alive and free of AIDS at 1 September 1990, plus the number of seroconversions during the study period may thus be estimated as 1050 in the Amsterdam population ($250 * [126/30]$). During the study period, 28 HIV positive IDU in the study died without AIDS having been diagnosed. For the adjusted number of HIV positive IDU we might expect 1 additional death, bringing the adjusted death count at 29. Using the death/AIDS ratio to estimate pre-AIDS deaths in the HIV positive IDU population we find 122 deaths ($29 * [126/30]$) during the study period, or about 30 per year.

To estimate the cumulative HIV incidence in the population from the very start of the epidemic until 1 October 1994, the figure of 1050 should be raised by the numbers of AIDS case diagnoses and pre-AIDS deaths among HIV positive IDU that occurred before 1 September 1990. While the number of reported AIDS cases up to this date is known (78), the number of pre-AIDS deaths can only be roughly approximated. Based on (1) the estimated starting point of the HIV epidemic among IDU in Amsterdam in 1981, (2) the subsequent development of the epidemic leading to a stabilization of the HIV prevalence level by 1985 [15, 16], (3) the first AIDS case in an IDU which was not diagnosed until 1985, (4) the observation that the shorter the infection duration, the more likely pre-AIDS death is to occur (relatively, as opposed to AIDS diagnosis) [5], and (5) our estimate reported above that since 1990 about 30 pre-AIDS IDU deaths occurred annually, estimating the

number of pre-AIDS deaths preceding 1 September 1990 at roughly 150 would seem reasonable. As of 1 October 1994 the cumulative HIV incidence thus comes down to an approximate 1278 IDU ($1050 + 78 + 150$). Of these, an estimated 802 IDU were still alive and free of AIDS, while 204 had been diagnosed with AIDS and about 272 HIV positive IDU died pre-AIDS.

Table 1 furthermore shows that within the cohort, AIDS diagnoses and pre-AIDS deaths are only partially compensated by new seroconversions (59 versus 40). This suggests that the prevalent number of AIDS-free HIV positive IDU in the population shrank by 80 ($126 + 122 - 168$) during the study period, a 9% decline.

National AIDS surveillance data show that during the study period among IDU residing in the Netherlands AIDS was diagnosed and reported outside Amsterdam in 94 cases, compared to 126 cases from within the city. As of 1 October 1994, the number of HIV positive IDU being alive and free of AIDS and residing in the Netherlands but outside Amsterdam can thus be roughly estimated at 598 ($94/126 * 802$).

Discussion

Within the limitations of our assumptions, we estimated the prevalent number of HIV positive IDU who were alive and free of AIDS and residing in Amsterdam as of 1 October 1994 at approximately 800. The mortality rate within this group is high and only part of these HIV positive IDU therefore will ever be diagnosed with AIDS [5]. While until

1 October 1994, a total of 204 IDU had been diagnosed with AIDS, as many as 270 HIV positive IDU may have died pre-AIDS. Even if we assume 10% underreporting of AIDS, these numbers might be 224 and 250 respectively, and pre-AIDS death would still be the more common event.

Back-calculation is an alternative and more commonly used method for estimating cumulative HIV incidence [17], with largely different strengths and weaknesses. It is based on reported numbers of AIDS and an assumed AIDS incubation function and routinely ignores pre-AIDS deaths. Our estimates of cumulative incidence and AIDS-free prevalence of HIV infection among IDU in Amsterdam (1278 and 802 respectively) are much higher than recent back-calculation estimates (IDU with homosexual contacts excluded): as of 1 January 1995, back-calculation estimates were 792 and 612, respectively (S. H. Heisterkamp, personal communication, 1995). This indicates that back-calculation may indeed seriously underestimate the total size of the HIV epidemic among IDU by neither including past pre-AIDS deaths, nor prevalently infected IDU who will die pre-AIDS in the future [5, 18]. Because IDU who die pre-AIDS may still demand extra care for HIV-related disorders [19] and are likely to contribute to further transmission of HIV before death, they are important from the perspective of health care planning and for the study of transmission dynamics. Hence, they should be included in HIV incidence and prevalence estimates that are to be used for such purposes.

Generalizing findings from the cohort study to the population suggests that the HIV epidemic among IDU in Amsterdam has been slowly dwindling in the early nineties, after previous evidence had shown that the epidemic stabilized in the second half of the eighties [16]. Since the majority of AIDS-free HIV positive IDU who are currently alive are probably already infected for more than 7 years [15], we may expect a decline in annual AIDS diagnoses and HIV-associated morbidity in the near future.

The number of HIV positive IDU residing outside of Amsterdam was estimated at about 600. For several reasons this is likely to be a lower bound estimate: it is probable that the HIV epidemic among IDU in the rest of the country started off later than in Amsterdam, causing the HIV/AIDS ratio outside Amsterdam to be higher than within Amsterdam. Likewise, due to less intense tracing of AIDS diagnoses in the rest of the country, reporting delays are longer outside Amsterdam [20], and underreporting of AIDS cases may be more extensive.

The incidence and prevalence estimates that we presented here should be considered crude and must be interpreted with caution: many factors may bias our estimates. Physicians working at the cohort study are not involved with treatment and do not report AIDS cases themselves, but through fraternal con-

sultation they may enhance correct and prompt diagnosis and reporting of actual AIDS cases and consequently may decrease the likelihood of pre-AIDS death. For cohort participants there may therefore be less underreporting and a shorter reporting delay of AIDS cases and possibly fewer pre-AIDS deaths than in the IDU population. On the other hand, timely application of early therapy may also become more likely for cohort participants, causing diagnosis of AIDS to be postponed. Our assumption that after adjustment new infections within the cohort would be in the same proportion to the number of IDU who are already infected as in the population is debatable: due to their participation in the study, IDU may well behave more safely [21, 22] and be less likely to seroconvert, although there are also indications that particularly IDU with a history of high risk behaviour were likely to participate in the cohort study [23], with possibly a higher likelihood to seroconvert and to die pre-AIDS. Furthermore, the dynamical properties of the IDU population in Amsterdam are not fully taken into account in our estimates. Participants who left Amsterdam for other parts of the country during follow-up were not excluded from our prevalence estimate for the city. Moreover, one out of every three IDU diagnosed with AIDS in Amsterdam has a foreign nationality, both within the cohort and within the city as a whole, and it is known that many foreign HIV positive IDU eventually return to their home country, either before or after developing AIDS. However, just how the migration balance has been developing over time is unclear, since little is known on new HIV positive IDU taking up residence in Amsterdam. Bearing in mind all these limitations, by taking into account pre-AIDS mortality (contrary to conventional back-calculation procedures), these estimates may be put to good use as long as better validated estimates are lacking.

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References

1. European Centre for the Epidemiological Monitoring of AIDS. AIDS surveillance in Europe. Saint-Maurice, France: European Centre for the Epidemiological Monitoring of AIDS, 1993. Quarterly Report No. 39.
2. Anonymous. AIDS patiënten gemeld in Amsterdam

- [AIDS patients, reported in Amsterdam]. Amsterdam: GG & GD, 1994. Quarterly report No. 22.
3. Anonymous. AIDS in Nederland, derde kwartaal 1994 [AIDS in the Netherlands, 3rd quarter 1994]. Rijswijk: Staatstoezicht op de Volksgezondheid, 1994.
 4. Perucci CA, Davoli M, Rapiti E, Abeni DD, Forastiere F. Mortality of intravenous drug users in Rome: a cohort study. *Am J Public Health* 1991; 81: 1307–1310.
 5. Van Haastrecht HJA, van den Hoek JAR, Coutinho RA. High mortality among HIV-infected injecting drug users without AIDS-diagnosis: Implications for HIV-infection epidemic modellers? *AIDS* 1994; 8: 363–366.
 6. Anderson RM. The role of mathematical models in the study of HIV transmission and the epidemiology of AIDS. *J Acquir Immune Defic Syndr* 1988; 1: 241–256.
 7. Taylor JMG, Muñoz A, Kingsley LA, Chmiel JS, Saah AJ. Two quick estimates of the HIV prevalence in homosexual men in Los Angeles, New York and San Francisco. The Multicenter AIDS Cohort Study. *AIDS* 1990; 4: 921–922.
 8. Van den Hoek JAR, Coutinho RA, van Haastrecht HJA, van Zadelhoff AW, Goudsmit J. Prevalence and risk factors of HIV infections among drug users and drug-using prostitutes in Amsterdam. *AIDS* 1988; 2: 55–60.
 9. Van den Hoek JAR. Epidemiology of HIV infection among drug users in Amsterdam [dissertation]. University of Amsterdam, 1990.
 10. The Italian Seroconversion Study. Disease progression and early predictors of AIDS in HIV-seroconverted injecting drug users. *AIDS* 1992; 6: 421–426.
 11. Alcabes P, Muñoz A, Vlahov D, Friedland G. Maturity of human immunodeficiency virus infection and incubation period of acquired immunodeficiency syndrome in injecting drug users. *Ann Epidemiol* 1994; 4: 17–26.
 12. Bindels PJE, Jong JTL, Poos MJJC, Leentvaar-Kuijpers A, Jager JC, Coutinho RA. Het epidemiologische beloop van AIDS in Amsterdam, 1982–1988. *Ned Tijdschr Geneesk* 1990; 134: 390–394.
 13. Centers for Disease Control. Revision of the CDC surveillance case definition for acquired immunodeficiency syndrome. *MMWR* 1987; 36: 1S–15S.
 14. Ancelle RA. European AIDS definition. *Lancet* 1992; 339: 671.
 15. Van Haastrecht HJA, van den Hoek JAR, Mientjes GHC, Coutinho RA. Did the introduction of HIV among homosexuals precede the introduction of HIV among injecting drug users in the Netherlands? *AIDS* 1992; 6: 131–132.
 16. Van Haastrecht HJA, van den Hoek JAR, Bardoux C, Leentvaar-Kuijpers A, Coutinho RA. The course of the HIV epidemic among intravenous drug users in Amsterdam, The Netherlands. *Am J Public Health* 1991; 81: 59–62.
 17. Rosenberg PS, Biggar RJ, Goedert JJ, Gail MH. Backcalculation of the number with human immunodeficiency virus infection in the USA. *Am J Epidemiol* 1991; 133: 276–285.
 18. Hser YI. Population estimates of intravenous drug users and HIV infection in Los Angeles County. *Int J Addict* 1993; 28: 695–709.
 19. Selwyn PA, Alcabes P, Hartel D, et al. Clinical manifestations and predictors of disease progression in drug users with human immunodeficiency virus infection. *N Engl J Med* 1992; 327: 1697–1703 [Erratum in *N Engl J Med* 1993; 328: 671].
 20. Houweling H, Heisterkamp SH, van Wijngaarden JK, Wiessing LG, Coutinho RA, Jager JC. Analyse van de AIDS-epidemie in Nederland, 1982–1993 [Analysis of the AIDS epidemic in the Netherlands, 1982–1993]. *Ned Tijdschr Geneesk* 1994; 138: 1954–1959.
 21. Van den Hoek JAR, van Haastrecht HJA, Coutinho RA. Risk reduction among intravenous drug users in Amsterdam under the influence of AIDS. *Am J Public Health* 1989; 79: 1355–1357.
 22. van Ameijden EJC, van den Hoek JAR, Coutinho RA. Injecting risk behavior among drug users in Amsterdam, 1986 to 1992, and its relationship to AIDS prevention programs. *Am J Public Health* 1994; 84: 275–281.
 23. Hartgers C, van Santen GW, van Haastrecht HJA, van den Hoek JAR, van den Akker R, Coutinho RA. De HIV-prevalentie onder druggebruikers die methadon verstrekt krijgen bij de drugsafdeling van de GG & GD te Amsterdam [HIV-prevalence among drug users who participate in methadone programmes of the Amsterdam Municipal Health Service]. *Tijdschr Soc Gezondheidsz* 1992; 70: 275–279.

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