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Christian Kind, Pediatric AIDS Group of Switzerland (PAGS)

Neonatologie Frauenklinik, Kantonsspital, St. Gallen

Vertically transmitted HIV infection: How representative are data from a voluntary registry?

Since October 1986 the Swiss Neonatal HIV Study maintains a national database of prospective data on children born to HIV-infected mothers.[1] Participating physicians register data on all children with known maternal seropositivity they encounter, if possible starting from birth. All Swiss pediatricians with interest in HIV infection participate in the study and all pediatric HIV clinics have reported all their patients.

During the years 1986 to 1992 new children of HIV-infected mothers have been registered at a rather constant number of around 50 per year of birth. The geographical distribution of these new registrations did not show significant changes.[2]

The question of interest in this presentation is: can these data from voluntary registrations provide an estimate of the real prevalence of HIV-infected parturients in Switzerland?

A clue to the number of children of HIV-infected mothers not detected and registered at birth is given by the incidence of children receiving a diagnosis of symptomatic HIV infection without their mothers' seropositivity being known previously. As in the cohort of children of HIV-infected mothers followed up from birth the number of patients with symptomatic HIV infection and the number of asymptomatic children is known for any year of birth, a corresponding number of undetected asymptomatic children can be postulated for every child being registered because of symptomatic HIV infection. From this a hypothetical total number of children of HIV infected mothers can be calculated for every year of birth and hence the prevalence by dividing by the annual number of live births.

Results of these calculations are given in the table. This method of estimation is based on two assumptions:

- All children with symptomatic HIV infection will get registered after some time.
- For a given year of birth the proportion of children with diagnosed symptomatic HIV infection is the same in the cohort followed up from birth as in the – unknown – total population.

The first assumption could be violated in two ways. Firstly some children with diagnosed symptomatic infection could not be registered. This will occur most probably only rarely, as it is very likely that at the presenttime a child with symptomatic HIV infection will be

Yob	P	sP	sL	T	Prevalence	Detection rate
1986	39	3	5	104	0.14%	50%
1987	40	4	2	60	0.08%	82%
1988	37	5	4	67	0.09%	76%
1989	45	10	2	54	0.07%	94%
1990	50	2	1	75	0.09%	72%
1991	42	7	1	48	0.06%	96%

Table 1. *Estimation of prevalence of HIV infection in Swiss parturients.*

Yob: Year of birth, P: number of children of HIV-infected mothers followed up from birth, sP: number of children with symptomatic HIV infection in P, sL: number of symptomatic children detected and registered because of symptoms, T: total number of children of HIV-infected mothers. [T = (sP + sL)* (P/sP)]. Prevalence is T divided by the annual number of live births: Detection rate: number of children registered into the study divided by T.

seen by a pediatrician with special interest in HIV infection. All these specialists meet regularly in the Pediatric AIDS Group of Switzerland (PAGS) and participate in the Neonatal HIV Study. Completion of the registry is actively sought by the study secretariat at regular intervals.

Secondly some children with symptomatic HIV infection might go undetected. This could certainly happen in the case of young infants dying rapidly from an overwhelming infectious disease without showing definite symptoms in the previous weeks. This course was observed in about 10% of infected infants in the cohort followed up from birth. Violation of the first assumption leads to an underestimation of true prevalence by 10% to 25% per missed symptomatic child.

The second assumption would be violated if the same factors in the mother (e.g. poor health) would increase the probability of inclusion of the child in the study and the probability of early development of symptomatic infection in the child. This would lead to an underestimation of true prevalence. On the other hand it is likely that mild symptomatic HIV infection will be diagnosed much earlier in children with known maternal seropositivity than in others. This would lead again to an underestimation. This last problem will however become less serious with higher age of the children, as the great majority of HIV infected children develop symptoms during the first year of life. Prevalence estimates for the years of birth 1986 to 1988 can thus be regarded with more confidence in this respect.

A further concern about the validity of these estimates lies in the small numbers involved that could lead to large random errors. A way to look at this problem is to repeat the estimations at different points in time and observe the fluctuations for a given year of birth, which stem from new infants developing symptoms in the cohort followed up from birth and from newly diagnosed symptomatic HIV infection from the general population (Figure 1). During a three year period individual estimates have fluctuated to a maximum of 18% around the average, which seems surprisingly stable.

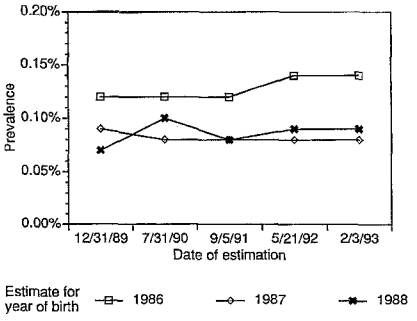

Figure 1. *Stability of the prevalence estimate over time. Prevalence estimates for three different years of birth are shown for five estimations at different dates during a three year period.*

Conclusions

The voluntary registry of the Neonatal HIV Study allows a rough estimate of the prevalence of HIV infection in Swiss parturients of 0.1%.

However validation of this estimate by unlinked anonymous screening of newborns is necessary.

References

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