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The burden of illness caused by perinatal HIV infection in Canada has not been well defined. With the development of the Canadian Paediatric AIDS Research Group (CPAR), this national perspective becomes more feasible. The information is important in the development of health care services as well as providing directions for further research.

The surveys were performed with several objectives. First, we wanted to quantify the number of children in Canada known to be exposed to HIV by perinatal transmission. Second, we set out to collect demographic information such as risk group and racial origin of the affected families. Finally, we hoped to obtain an overview of current therapeutic practices in the management of infected children. This information would then serve as the groundwork for ongoing annual surveillance.

METHODS

Infectious Disease Departments in 15 tertiary care paediatric centres (Table 1) were contacted for our surveys. These centres provide regional care for Canada's ten provinces and territories. As of May 1992, 13 centres in seven provinces were found to be managing perinatally HIV exposed infants and children.

Information was collected through two surveys, the first in March 1991 seeking to capture information on all cases followed to that point, the second in May 1992 requesting an update on known cases and the addition of new cases presenting through the year.

The survey was conducted using a standard questionnaire which used initials as identifiers to prevent duplication of cases. Information on year of diagnosis, CDC classification, maternal racial origin, risk group and therapeutics was requested. Questionnaires were then forwarded to the Hospital for Sick Children for analysis.

The inclusion criterion for the study was HIV infection acquired by perinatal transmission. This included those infants with indeterminate infection (CDC Class P0) followed until status confirmed, as well as those with proven infection (CDC Class P1/P2). This was justified by the fact that seroreverting children and their families require the same care and support from the medical system in the first 12 to 18 months as those with proven infection (CDC P1/P2).

Cases from Quebec centres and Ontario centres were grouped by province. The smaller numbers of cases from other provinces were combined under the heading "Other".

Demographic information on racial origin was grouped under the headings Black, White, Other or Unknown. In the small sample (13/204) where country of origin rather than race was recorded, several assumptions were made. A mother from Africa (n=2) or Haiti (n=9) was considered...
black unless otherwise stated. Mothers from Canada (n=2) were considered white unless otherwise stated. Mothers from other countries or racial groups, including aboriginal North Americans, were included in the Other group. Risk factors for HIV acquisition were grouped as exposure through sexual contact, intravenous drug use (IDU), transfusion (TA) or unknown. Sexual contact was defined as exposure to known HIV-infected persons or to those with risk factors for HIV infection. When sexual contact and another risk factor were identified together, the second factor was recorded as primary risk.

**RESULTS**

As of May 1992, the total number of children managed for presumed or con-
Perinatal HIV Survey

Confirmed HIV infection in Canada was 220 (Figure 1). A breakdown by CDC classification and province is provided in Table II. The 106 current cases being followed up to May 1992 are also listed by CDC classification and province (Figure 2). Sixty-two new cases, or 28% of the total, were seen in the last year of the combined survey period (Figure 3). Quebec is the province with the largest number of cases, though its proportion of the total in Canada falls from 63% in March 1991 to 40% in May 1992. Conversely, the proportion of Ontario cases rose from 26% to 32% and the proportion of cases seen outside Ontario and Quebec (Other) rose from 11% to 28% of the combined total. The rate of increase in new cases for Ontario for April 1991-May 1992 was greater than Quebec at 33% versus 20% respectively (p<.003). Similarly the rate of increase outside Quebec and Ontario (Other) was greater than Quebec's at 50% versus 20% respectively (p<.001).

The 220 perinatally exposed children were born to 204 mothers. The breakdown of maternal racial origin is provided (Figure 4). Eleven mothers were recorded as racial origin other than black or white (Other); of these, six were Aboriginal Canadians, two were Hispanic and three were not specified. When Quebec is compared with the rest of Canada, the percentage of black mothers is significantly higher at 64% versus 25% (p<.001) (Figure 5).

Patterns of maternal risk behaviour indicate that sexual contact is the most common route of infection (68%) (Figure 6). The percentage attributed to intravenous drug use (IDU) is 24%. It should be noted however, that cases attributed to IDU may be overestimated. In the survey, when IDU and sex were both identified as risk factors, IDU was chosen as the primary risk. Transfusion-associated cases constitute 6% of the cases recorded.

Therapeutic information, particularly concerning cases early in the survey period, is incomplete. The information presented represents a snapshot of current therapeutics (Table III). Forty-five percent of CDC Class P1 patients are receiving some HIV-related therapy; this rises to 97% for those with CDC Class P2 disease.
DISCUSSION

We recognize several limitations of these surveys. Working with a small total number of cases restricted our analysis to the national trends. With some exceptions, we were unable to make comparisons between the provinces or risk-factor subgroups at this time. As well, data were collected retrospectively from 13 different centres. Date of birth was not routinely recorded in the questionnaire. This precluded analysis of cases by birth cohort. Variations in the recording of country versus race for maternal origin necessitated certain assumptions as outlined in the Methods section. The retrieval of other missing information was difficult, particularly for earlier cases. Because records were clinically focused, additional data on socioeconomic status, the use of non-prescription drugs other than by the intravenous route, and other social issues were infrequently recorded and therefore could not be analyzed. The survey form has been modified for ongoing surveillance to include date of birth and expanded demographic, clinical and therapeutic information.

Paediatric infectious disease departments in tertiary care centres were chosen as those most likely to be involved in perinatal HIV care. Perinatal HIV infection is a new disease entity and, as such, few practitioners at the community level have managed cases in isolation. It has been the experience of the research group that children with recognized exposure are referred to tertiary care centres for some component of their diagnosis and care. The centres in this survey provide this paediatric tertiary care for all provinces and territories in the country. It is possible that a small number of cases may have been missed because they were never referred to a tertiary care centre. However, the potentially much larger group are the undiagnosed cases. Therefore this survey is not a prevalence survey of perinatal HIV infection but a survey of diagnosed cases of perinatal HIV infection.

Despite these limitations, several points are worthy of discussion. These surveys are the first attempt to quantify and qualify the burden of perinatal HIV infection in Canada. The response rate was 100% for the paediatric centres surveyed. The surveys show that previously reported national figures for perinatal AIDS have been underestimated, under-reporting of AIDS cases is a recognized problem. They also show that the number of newly recognized cases of perinatal HIV exposure has been rising. Fully 28% of the total Canadian case load presented in the last year of the survey period. This may be due to increased recognition of perinatal HIV or to a real increase in the number of exposed infants. The relative importance of these two factors is unknown at this point. It is currently estimated that 15-30% of exposed infants will acquire infection by perinatal transmission. If we apply similar rates to our population, one would expect the 111 confirmed cases (P1+P2+dead) to be accompanied by at least 350 exposed but uninfected infants (P0 or seroconverters). Clearly, the majority of these infants have not yet been identified. The Canadian Paediatric Society is currently developing a policy statement on perinatal HIV antibody screening with recommendations to promote identification of HIV-positive pregnant women. The guidelines are expected to be similar to those already developed by the American Academy of Pediatrics in 1992.

Several points have been noted in the collection of case information over time. Early cases were clustered in the urban areas of Montreal and Toronto. Increasingly, smaller centres in Quebec, Ontario and other provinces are being identified as sources of new cases. Cases among Aboriginal Canadians have been identified. Poverty, substance abuse and other social problems make this group particularly vulnerable to the rapid spread of HIV. Prevention of spread necessitates that educational strategies and programs for medical care be tailored to their needs.

Aspects of HIV infection in Canada have often mirrored demographic trends seen in the United States. This survey identifies certain differences between the perinatally infected groups. In many parts of the U.S., perinatal infection is concentrated among inner city, IV drug using, black and Hispanic populations. HIV infection compounds other medical problems faced by these children, problems that may affect overall prognosis. These include intrauterine drug exposure, other congenital infections, prematurity and malnutrition as well as limited access to the health care system. The Canadian experience indicates a more heterogeneous patient population. To date we have not seen the high proportion of intravenous drug-related cases that has been noted in parts of the United States. Sexual contact rather than intravenous drug use is the primary risk factor. In addition, our survey indicates that most symptomatic patients are receiving therapy of some type. With the exception of some earlier cases lost to follow-up, ongoing care and family support have been comprehensive. The impact of these factors on prognosis will become more apparent over time.

Some general observations about current therapeutic practices can be made. Our survey indicates widespread use of anti-retrovirals in symptomatic children. PCP prophylaxis is also widely used. Trimethoprim-sulpha is most frequently administered, though experience with intravenous and aerosolized Pentamidine is reported. Prophylaxis against bacterial infection with IVIG is also reported. To date, specific national guidelines for paediatric HIV therapies have not been created.

In conclusion, although the surveys suffer from diagnostic bias and referral bias, the information collected adds much to the information from the AIDS reporting system, which is the only other source for national statistics on perinatal HIV infection. Through annual surveys, we hope to establish a system of regular data collection for infants and children with perinatal HIV infection. This will allow continued evaluation of the changing demographic profile, therapeutic practices and outcome of these children in Canada.

REFERENCES


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