

Case Management of HIV-Infected Children in Missouri

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Synopsis

The early referral of HIV-exposed children and their mothers to coordinated medical and social services has become increasingly important. In July 1989, the Missouri Department of Health initiated the Service Coordination Program to provide individualized referral (case management) for Missouri residents who were reported to have acquired immunodeficiency syndrome (AIDS) or HIV infection. The purpose of the Service Coordination Program is to assist persons in accessing medical and social services. The authors describe the characteristics of the 36 children (18 enrolled in the Service Coordination Program, and 18 not enrolled) reported to the Missouri Department of Health through September 1992. Although more detailed evaluations are necessary, preliminary data suggest that opportunities for early intervention may be facilitated by the Service Coordination Program if the child's HIV status is recognized early.

There is increasing emphasis on early intervention for persons infected with the human immunodeficiency virus (HIV) (1,2). Children who are HIV-infected present additional challenges for caretakers and health care providers. The majority of children acquired HIV infection vertically from their mothers, and diagnosis of HIV infection is complicated by the presence of maternal antibodies before 15-18 months of age (3,4). In many children, disease progression is much more rapid than in adults and adolescents (5-7). These factors make the referral of HIV-exposed children and their mothers to coordinated medical and social services especially important.

Confidential reporting of HIV infection was initiated in Missouri in 1987. In July 1989, the Missouri Department of Health (MDOH) implemented a Service Coordination Program (SCP) to provide individualized referral (case management) for Missouri residents who were reported to have acquired immunodeficiency syndrome (AIDS) or HIV infection. The purpose of the SCP is to assist persons in accessing medical and social services. People are referred to SCP from a variety of sources, including the HIV-AIDS surveillance program, counseling and testing sites, and care providers.

Methods

To compare children who were enrolled in SCP with those who were not, we reviewed 36 children with HIV or AIDS reported to the MDOH through September 1992. Excluded were children with hemophilia who receive assistance through existing programs and children who died prior to 1990 when SCP became widely available. SCP, medical, and social service records were reviewed for each child with HIV or AIDS. The involvement of mothers and other family members in SCP, partner notification, drug treatment, and support services was also reviewed.

Results

Characteristics of the 18 SCP enrollees and the 18 not enrolled are summarized (see table). Nonenrolled children may have been referred to SCP, but they were not enrolled for such reasons as the refusal of mothers or caretakers to join SCP or loss to followup. In addition, 17 of 36 mothers (47.2 percent) were also enrolled in the SCP.

The children's ages at diagnosis varied widely; the range was 1 to 116 months.

Demographic and transmission categories of 36 HIV-infected children in Missouri by enrollment status in the Service Coordination Program

Category	Enrolled		Not enrolled		Total	
	Number	Percent	Number	Percent	Number	Percent
Total	18	...	18	...	36	...
Race:						
African American.....	9	50.0	14	77.8	23	63.9
White.....	9	50.0	4	22.2	13	36.1
Sex:						
Male.....	9	50.0	11	61.1	20	55.6
Female.....	9	50.0	7	38.9	16	44.4
Mode of transmission:						
Perinatal.....	18	100.0	17	94.4	35	97.2
Transfusion.....	0	...	1	5.6	1	2.8

Category	HIV	AIDS
Number of children enrolled in SCP.....	10	8
Median age at diagnosis (months).....	5.5	13
Age range at diagnosis (months).....	1-63	4-38
Number of children not enrolled in SCP ...	11	7
Median age at diagnosis (months).....	6.5	20.0
Age range at diagnosis (months).....	1-116	3-58

Higher proportions of SCP enrollees than non-enrollees had a CD4 count documented (78 percent versus 56 percent, $P=.16$). Among children with HIV, the median initial CD4+ absolute count recorded was 1,565 cells per microliter (μl) (range 168-6,623) for 8 SCP enrollees, compared with 603 cells per μl (range 300-2,909) for 4 nonenrollees tested. Among children with AIDS, the median initial CD4+ count was 603 cells per μl (range 175-1,778) for 6 SCP enrollees, and it was 226 cells per μl (range 11-1,725) for 6 nonenrollees tested.

Overall, higher proportions of SCP enrollees than nonenrollees had received antiretroviral therapy—88 percent versus 44 percent, $P=.04$ —or PCP prophylaxis, or both; of children with AIDS, the proportion was 100 percent versus 57 percent, $P=.08$. Among children who had age-adjusted CD4+ count and percentage data available that indicated a need for therapy (8,9), all SCP enrollees received antiretroviral therapy and PCP prophylaxis, while 83 percent of the nonenrollees received antiretroviral therapy and 60 percent, PCP prophylaxis.

Conclusion

These data suggest that opportunities for early intervention may be facilitated by SCP if the child's HIV status is recognized early. Since SCP services were available to all children who were reported with HIV or AIDS, differences between participants and others may also reflect the motivation or ability of the mothers or other family members to keep appointments and followup.

As early intervention programs, such as the Missouri SCP, are implemented more widely, formal evaluations should be conducted concurrently with service provision to identify the most effective ways of providing services for HIV-infected persons. As the ability to treat HIV infection and its complications improves, there will be greater needs for early identification. In addition to maximizing the effectiveness of prevention, early intervention may delay HIV disease progression, prevent opportunistic infections, and provide screening for other diseases such as tuberculosis (1,2,4,8-10).

References

1. Jewett, J. F., and Hecht, F. M.: Preventive health care for adults with HIV infection. *JAMA* 269: 1144-1153, Mar. 3, 1993.
2. Francis, D. P., et al.: Targeting AIDS prevention and treatment toward HIV-1 infected persons: the concept of early intervention. *JAMA* 262: 2572-2576, Nov. 10, 1989.
3. Husson, R. N., Comeau, A. M., and Hoff, R.: Diagnosis of HIV infection in infants and children. *Pediatrics* 86: 1-10 (1990).
4. Rogers, M. F., Ou, C., Kilbourne, B., and Schochetman, G.: Advances and problems in the diagnosis of human immunodeficiency virus infection in infants. *Pediatr Infect Dis J* 10: 523-531 (1991).
5. Centers for Disease Control and Prevention: HIV/AIDS surveillance report. February 1993, pp. 1-18.
6. Krasinski, K., Borkowsky, W., and Holzman, R. S.: Prognosis of human immunodeficiency virus in children and adolescents. *Pediatr Infect Dis J* 8: 216-220 (1989).
7. Thomas, P., Singh, T., Williams, R., and Blum, S.: Trends in survival for children reported with maternally transmitted acquired immunodeficiency syndrome in New York City, 1982 to 1989. *Pediatr Infect Dis J* 11: 34-39 (1992).
8. Guidelines for prophylaxis against *Pneumocystis carinii* pneumonia for children infected with human immunodeficiency virus. *MMWR Morb Mortal Wkly Rep* 40 (No. RR-2): 1-13, Mar. 15, 1991.
9. Pizzo, P. A., and Wilfert, C. M.: Antiretroviral therapy and medical management of the human immunodeficiency virus-infected child. *Pediatr Infect Dis J* 12: 513-522 (1993).
10. Guidelines for prophylaxis against *Pneumocystis carinii* pneumonia for persons infected with human immunodeficiency virus. *MMWR Morb Mortal Wkly Rep* 38 (No. S-5): 1-9, June 16, 1989.