

Oral presentation

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Why do HIV negative mothers refuse to participate in a clinical research involving HIV positive mothers in Cameroon?

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Background

Adhesion of participants is critical for clinical study recruitment and success. The PEDIACAM-ANRS 12140 survey, including babies born both to HIV positive mothers and HIV negative mothers started in Cameroon at the end of 2007 and is currently ongoing. The objectives are to evaluate the feasibility of early antiretroviral multitherapy on HIV infected infants and the humoral response to vaccines of the expanded program of immunization (EPI). HIV negative mothers are more numerous than expected to refuse to participate to this survey. It should be important to investigate reasons for refusal in order to improve recruitment and better understand attitudes of general population towards clinical research on HIV/AIDS. We present here the preliminary results on reasons for refusal and socio-demographic characteristic associated with early lost-to-follow up in HIV-negative mothers

Methods

Inclusion of children in the PEDIACAM survey is proposed to all HIV-infected mothers in participating maternities before the 7th day of life. Each time a child born to HIV infected mother is included (index child), we propose, the

survey to the following HIV-negative mothers who delivered in the same maternity with a child of same gender than index, until acceptance of one control mother.

Results

During the first year of the study, 9723 deliveries occurred in the three study sites, with a maternal HIV prevalence estimated at 6.6% (636). The preliminary data showed that two kind of initial refusal were reported: 1) the mother did not explicitly refuse but told that she has to obtain opinion of her family (husband, mother in law) prior to accept and never came back; 2) the mother refused for various reasons: fear of stigmatization due to the participation in a study involving HIV infected persons or practitioners known to take care of HIV patients; refusal to act as a guinea pig; lack of time for follow-up. Among HIV negative mothers who accepted initially to participate, 36% (211/582) of HIV negative mothers had not returned more than two weeks after the visit planned at 6 weeks of age, in spite of telephone recall. Early lost-to-follow up was not significantly associated with age, marital status, number of child alive and sex of the child. How-

ever, it was lower among high- than low-educated HIV negative mothers (21% vs 33%, $p = 0.003$).

Conclusion/perspectives

This study raises some of the obstacles to the participation of HIV negative mothers to clinical research, for the greater part due to their perception of HIV infection. Even after initial acceptance to participate, a high rate of parents did not return for first follow up. The anthropological study associated to PEDIACAM which will start in March 2009 may contribute to better understand representations of parents towards clinical care and research in HIV infection.

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