

From the Division of Global Health (IHCAR), Department of Public Health Sciences Karolinska Institutet

Motivations and Deterrents to Take Part in an HIV Vaccine Trial:

Experiences from study participants in Dar es Salaam, Tanzania

ACADEMIC THESIS

The public defence for the degree of Doctor of Philosophy at Karolinska Institutet will be held at Rockefeller Hall, Nobels väg 11, Solna Campus, Karolinska Institutet, SE-171 77 Stockholm, Sweden

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ABSTRACT

Background: As HIV infection continues to be a public health problem, development of an effective preventive HIV vaccine is a priority. For the ultimate development of an AIDS vaccine, clinical trials are being conducted throughout the world. However, the process of developing the vaccine does not only depend on identification of suitable trial candidates, but also requires knowledge of incentives to participate in the community where the trial is being conducted. Therefore, the studies presented in this thesis are components of a HIV/AIDS and HIV vaccine trial project in Dar es Salaam, Tanzania to address motivations and deterrents of participating in an HIV vaccine trial.

Aim: To examine the motivations and deterrents for participating in preventive HIV vaccine trials.

Methods: Data were collected from participants and volunteers who were considered for participation or participated in a phase I/II HIV vaccine trial. Four studies with different designs were conducted. In Study I, a semi-structured interview administered questionnaire was used to assess willingness to volunteer for a phase I/II HIV vaccine trial. A convenience sample of 329 individuals from the police force cohort was recruited for the study in 2005-2006. In Study II, focus group discussions were conducted to explore factors that would influence participation in an HIV vaccine trial among members of the police force in 2006-2007. In Study III, face-to-face interviews were used to identify reasons for declining to enrol in an HIV vaccine trial among those who agreed to enrol at the start and were randomized for the trial in 2007-2009. In Study IV, we used focus group discussions to evaluate the experiences of those who participated in the phase I/II trial in 2009.

Results: Willingness to volunteer for an HIV vaccine trial was associated with intention to tell others, positive outcome of the trial, personal decision and expectation of obtaining protection against HIV infection. Participation in an HIV vaccine trial would be negatively influenced by sexual partners, friends, family members, relatives or parents (significant others) and fear of vaccine side-effects. Personal fears and negative influences from significant others were the main reasons for declining to enrol in an HIV vaccine trial. Despite the negative comments from significant others, volunteers in the HIV vaccine trial managed to stay on until the end of the trial as a result of personal decision and trial-related interventions.

Conclusion: Personal decision is both a motivation to participate in an HIV vaccine trial and a reason to stay on until the end of trial. On the contrary, significant others are the deterrents to participation in the HIV vaccine trial and the reason for declining to enrol in the HIV vaccine trial. Awareness of these issues before trial implementation may help to maximize resource use and enhance retention of those who volunteer in the HIV vaccine trials.

Keywords: Willingness, phase I/II, HIV, vaccine trial, motivation, enrolment, participation, police officers, Tanzania

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