MAKERERE UNIVERSITY

Department of Health Policy, Planning and Management, School of Public Health,
College of Health Sciences, Makerere University
Department of Public Health Sciences, Division of Global Health (IHCAR),
Karolinska Institutet

Lost in Transition- Pre-Anti Retroviral Care and Delayed Initiation of Antiretroviral Therapy in Uganda

ACADEMIC THESIS
The public defence for the degree of Doctor of Philosophy at Karolinska Institutet and Makerere University will be held at Makerere College of Health Sciences, Davies Lecture Theatre
Friday May 6th, 2011, 9.00 AM.

AKADEMISK AVHANDLING som för avläggande av gemensam medicine doktorsexamen (*Doctor of Philosophy, Faculty of Medicine, PhD*) vid Karolinska Institutet och Makerere University offentligen försvaras på det engelska språket i Makerere College of Health Sciences, Davies Lecture Theatre Fredag 6:e maj , 2011, kl 9.00

Muhamadi Lubega

Supervisors:
Professor Stefan Peterson
Department of Public Health Sciences
Division of Global Health (IHCAR)
Karolinska Institutet, Stockholm

Assoc Professor George William Pariyo
Dep. Health Policy, Planning and Management
School of Public Health
College of Health Sciences
Makerere University, Kampala

Assoc Professor Anna Mia Ekström
Department of Public Health Sciences
Division of Global Health (IHCAR)
Karolinska Institutet, Stockholm

Dr Tumwesigye Mbona Nazarius PhD
Dep. Epidemiology and Biostatistics
School of Public Health
College of Health Sciences
Makerere University, Kampala

Faculty Opponent:
Professor Per Olof Östergren
Lund University, Dept of Clinical Sciences/Public health
Malmö. Sweden

Examination Board:
Assoc Professor Carina Källestål
Dept of Women's and Children's Health
Uppsala University, Sweden

Assoc Professor Anne Katahoire
Child Health and Development Centre
Makerere University, Kampala

Assoc Professor Stephen Lawoko
Department of Public Health Sciences
Division of Social Medicine
Karolinska Institutet, Stockholm

Kampala and Stockholm 2011

ABSTRACT

Background: Comprehensive HIV care aims at providing care and support, from HIV counselling and testing, through pre-antiretroviral (pre-ARV) care to antiretroviral therapy (ART). However, many people living with HIV (PLHIV) do not start treatment or are lost to follow-up during pre-ARV care, and subsequently initiate ART very late, with a high risk of HIV/AIDS-related mortality. Determinants of uptake/retention of PLHIV under pre-ARV care and delayed ART initiation in Uganda, where HIV and ART awareness are presumably high, are not sufficiently understood.

Main aim: To investigate uptake and loss to follow-up of PLHIV under pre-ARV care and delayed ART initiation in order to inform policy and strategic planning for improved comprehensive HIV/AIDS care.

Methods: Four studies (I-IV) were conducted in Iganga district, eastern Uganda. Study I used key informant interviews (KIIs) with five health workers and 10 in-depth interviews (IDIs) with PLHIV, as well as six focus group discussions (FGDs) with caretakers of the PLHIV to explore reasons for loss to follow-up under pre-ARV care. Study II was a randomised controlled trial involving 400 participants, to evaluate the effect of extended counselling on uptake of pre-ARV care. Study III used 20 IDIs with clients on ART and 10 FGDs with caretakers of ART clients to understand reasons for delayed ART initiation. Study IV was a case-control study involving 152 cases (clients who initiated ART at CD4 < 50 cells/µl) and 202 controls (clients who initiated ART at CD4 50-200 cells/µl) to assess risk factors for very late initiation of ART. Content analysis was used for qualitative data, and univariate, bivariate and multivariate analysis for quantitative data.

Results: Reasons for dropping out of pre-ARV care included inadequate post-test counselling to PLHIV and competition from traditional/spiritual healers. Other reasons included transportation costs, long waiting time, lack of incentives to seek pre-ARV care by PLHIV who perceived themselves to be healthy, and gender inequality (I). PLHIV who underwent counselling by staff trained in basic counselling skills, combined with home visits by community network support agents, were 1.8 times more likely to take up pre-ARV care compared to PLHIV who received the standard care (RR 1.8; 95% CI 1.4-2.1) (II). ARV stock-outs, inadequate pre-ARV care and perceived lack of staff confidentiality were system barriers to timely ART initiation. Weak family/social support and misconceptions about ARVs were cited as individual/community barriers to timely ART initiation (III). Seeking care from traditional/spiritual healers before attending formal care (AOR 7.8; 95% CI 3.7-16.4), lack of pre-ARV care (AOR 4.6; 95% CI 2.3-9.3), subsistence farming (AOR 6.3; 95% CI 3.1-13.0) and lack of family/social support (AOR 3.3; 95% CI 1.6-6.6) were crucial risk factors for very late ART initiation (IV). Higher age (AOR 0.9; 95% CI 0.8-0.9) and being female (AOR 0.4; 95% CI 0.2-0.8) were protective factors against very late initiation of ART (IV).

Discussion: Adequate post-test counselling for newly diagnosed PLHIV, combined with follow-up care by network support agents, could help retain PLHIV under pre-ARV care and allow timely initiation of ART. Trained and supervised traditional/spiritual healers could complement government efforts in offering some components of pre-ARV care. ART services should be made more affordable, accessible and user-friendly to enhance timely ART initiation. Other system deficiencies, such as stock-outs of cotrimoxazole and ARVs and lack of adequate staff also need to be addressed. There is a need for social mobilisation to address gender inequality, stigma and misconceptions about ARVs and to boost social support for PLHIV.

Key words: counselling, community support agents, pre-ARV care, traditional healers, HIV, antiretroviral treatment, adherence, Uganda