Barriers to Access and Adherence to ARVs

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Background

South Africa’s Western Cape Province has been in the forefront of the rollout of antiretroviral (ARV) treatment since 2003, and is widely held as a model for the rest of the country to follow. Despite this, barriers to access and adherence to antiretroviral (ART) treatment have been identified as issues of major concern in the Western Cape Province. Such barriers, much like the diseases being treated, are the result of the complex intertwining of political, economic, social-cultural, gender, and biological factors.

Methodology

A patient-centred ethnographic study is underway which assesses the nature and extent of HIV and AIDS treatment initiation and barriers to adherence at three field sites in the Western Cape Province. The views of Health Care Professionals (including Doctors, nurses, counsellors and home-based carers) are also included.

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Ethical approval was obtained from UWC, NUI Maynooth and the Western Cape Provincial Department of Health.

Patient Participants

Participants are recruited through ARV clinics, PHC clinics and by introduction through NGO Home Based Carers. Semi-structured interviews are conducted in the language of choice of the participant (English, Afrikaans or isiXhosa) on the basis of informed consent. With their permission, Clinic patients are ‘shadowed’ for six weeks, followed by follow-up and transcribed in full and translated into English before coding and analysis using ATLAS.ti qualitative analysis software.

Preliminary Findings – Off-label Use of ARVs:

Home Based Carers report that there is a market in the area for the sale of ARVs. These include sales to:

- Patients who are ill but do not want to attend the clinic
- Patients who don’t trust clinic staff/have confidentiality issues with clinic
- Patients who are illegal immigrants
- Drug-users who take them for recreational purposes.

(Researcher Field Notes, Nov. 2009)

“The guy is taking the pills to… drugs… to drugs. Every time he’s sick he come to take here… then he just break out the door and taking the pills. At [another suburb] where they have an ARV clinic and then the gangs wait outside. When you go inside and then they know ARV clinic HIV patients going in there they’ll rob you from your tablets when you come out.” (Home Based Carer)

“There was one time he [boyfriend] smoked my pills. My pills! I don’t keep my pills there any more. My pills are at my Mother’s now… They stay there now. See, its just one little pill… a little white one. He smokes that, there. These little pills. These… he smokes it. [points to the picture on the wall]. He smokes that.. He says he wants to die. He says he wants to die. So I say, ‘but you can’t die (kill yourself) with my pills. Take your pills and die with them.’” (Mary, 32)

Preliminary Findings – Social Grant

Patients who meet certain medical criteria (including, but not limited to, a CD4 count <200) may qualify for a Social Grant of R900 (c. €90 per month), renewable every six-months on the recommendation of their Doctor. For some patients this grant represents their sole income and keeping the grant becomes all-important for their family’s survival.

“... and people will, will not take their ARVs to keep them under 200. Because they often come to me and say ‘yes, now-now you made me better and now what, now I'm without food.” (Nurse Co-ordinator, Home-based Carers)

“Must be taking your tablets because life, yes... then big problem because at home got no food. Must be take your tablets?  Doctor tell me CD4 count is high. It's two hundred five (205), two hundred forty (240)… so I do not qualify for grant.” (Ursula, 39)

“I told them, I don’t get pay so I won’t take the pills.” (Josie, 41)

Preliminary Findings – Branding of Resources

Access to clinics for treatment is difficult in resource-poor settings where transport is limited. While each sub-district in the region has its own ART site, these may be some 30 miles from patients in need of their services. In addition, separate public services may lack the necessary co-ordination required to enable access. Patients are reluctant to use buses or mini-buses that be readily identified as ‘clinic’ transport.

“Today I had to stand on the road and hike…. sometimes [it takes] 3 to 5 hours. Like now today I walk so 7 o’clock, I also come here before 11. And then I have to hike back again. We have to take chances because we don’t have our own transport”. (Amos, 34)

“...we make an appointment for the patient, the patient receives the appointment so he knows about the appointment, and we even have a bus who would take them to [ARV Clinic] and bring them back here which is free of charge and then they don’t turn up.” (Sr. J, Clinic Manager, Rural PHC)