

## Construction of illness and its implications for Adherence to Medication (Case study of Antiretroviral Therapy in Uganda)

### Abstract

Three decades since the first HIV cases were identified in Uganda there is no known cure for this disease. Though already available in resource rich settings, ARVs were introduced in Uganda's public health care delivery system in 2003. The introduction of ARVs, offered under a comprehensive package called antiretroviral therapy (ART) came with several structural challenges. While structural challenges are valid and real to a sustainable ART program this study chose to focus on a social science issue that also affects adherence to ART. The study focused on interrogating how patients' construction of illness influences their adherence to ART. Using ART and HIV as disease this study shows how patients' construction of illness affects adherence to medicine.

Interpretivist theories of symbolic interactionism and social constructionism were used to unravel and understand patients' construction of their illness. In-depth interviews and life stories were conducted with 51 ART patients recruited at the ISS clinic, Mbarara national referral and Iganga hospital respectively following exit client interviews. Data was collected in four phases and a pre-formative phase between October, 2007 and December, 2010.

Findings show that ART patients had constructions of HIV according to phases. Pre-ART constructions highlighted HIV as a death sentence disease, was contracted regrettably through immorality and basically confined in urban centres. However, constructions change during the post-ART era to "a normal disease like any other health condition" and "disease (morbidity associated) when not treated".

ART patients' construction of their illness during the pre-ART era reflected death and symptomatology. These constructions however change during the post-ART era to "normalization of disease", functional ability, symptomatology and belief in ARVs. What is clear about constructions between pre- and post- ART eras is the shift from constructions of hopelessness and resignation to hope and optimism. ART patients' constructions of illness were shaped by their lived experience (with the disease). Social support and other community members also played a role in patients' constructions. Patients who had a bad experience with HIV constructed their illness reflecting this phase of their lives.

The longer one spent on medication (ART) the better the adherence levels. Among adherers however, patients who constructed their illness as being normal due to the availability of drugs and their efficacy were better adherers. In a few cases the availability of ARVs led to treatment optimism and constructions of their situation as not being bad and led some patients to either sub-optimally adhere or not to adhere at all.

This study provides four lessons for adherence to medication. One, individual patient's construction of illness is informed by personal lived experience and other players who contribute to the overall social constructions. Two, all patients have a self indication of what they want to achieve (in life) and how they are to achieve it. Three, patients' lived experiences contributes to their construction of illness and consequently how seriously they will take their medication. And lastly, patients wield power on how well a medication will work. For some patients, doctors' instructions and regimen requirements do not necessarily translate into adherence to medication.