Abandonment of antiretroviral therapy: A potential barrier to scale-up in sub-Saharan Africa

Over the past 4 years, antiretroviral therapy (ART) services in Zambia have expanded at an unprecedented rate. Approximately 130 000 Zambians have initiated ART nationwide, with over 48 000 in the capital city of Lusaka alone. Proper identification of patients failing therapy is a challenge because of limited diagnostic capabilities and laboratory facilities, yet accurate diagnosis is critical given the poor availability of salvage therapies. Barriers commonly reported in sub-Saharan Africa include transportation, hunger, and clinic waiting times. We describe another potentially important barrier: preferences for traditional medicines and/or alternative AIDS remedies.

In Lusaka we have documented 3 cases in which the patient initially demonstrated significant clinical and immunological improvement after starting ART. These improvements began to wane over time, despite continued adherence to clinical visits, drug collection and laboratory monitoring, until the patients were diagnosed with virological treatment failure. It was only after intensive counselling and clinical investigations that the true reason behind the HIV disease progression was revealed. Two patients had abandoned ART in search of a local herbal remedy. The third had stopped ART and sought to cure AIDS through prayer. Although all three agreed to re-start ART, only one of them made a full recovery. One patient died and the other remains bed-ridden.

We believe this phenomenon is noteworthy with regard to the degree of deception that surrounds the patient’s decision to discontinue ART. In each of the above cases the patient undertook extraordinary measures to convince health care providers of their continued adherence, including timely clinical visits and pharmacy refills. We do not believe that this behaviour is linked to the selling of antiretroviral drugs for financial gain, as has been suggested by anecdotal reports; all ART is provided free of charge in the Lusaka public health sector. Instead, patient motivation appears to be linked to experimentation with traditional medicines or alternative ‘AIDS cures’. Similar deception has been observed among patients in the context of HIV-related care in previous work.

In one trial, we found that 28% of women who reported adherence to nevirapine prophylaxis for perinatal HIV prevention did not have detectable levels of the drug in cord blood following delivery. The reasons behind this remain poorly understood.

Individual patient response to ART during scale-up in sub-Saharan Africa is generally favourable in terms of immune recovery, viral suppression, survival, and quality of life. Despite these clear successes, however, there exists a degree of scepticism regarding HIV care, including ART, both among patients and within communities. The most prominent example has been among regional governments, with their calls for an ‘African’ solution to the epidemic. Similar sentiments have been described in individual patients in behavioral studies. Under these circumstances, traditional medicines and local ‘AIDS cures’ may have heightened appeal.

As in many African countries, the long history of traditional medicine use in Zambia is linked to strong cultural values and belief systems. Despite the acceptability of these remedies to the general population, practitioners of Western-style medicine often view traditional practices unfavourably because they lack rigorous evidence of safety or efficacy. For this reason, patients may conceal use of traditional medications because they fear being ridiculed or shamed. This concern has been evident in our work in Lusaka; 54% of antenatal attendees believed they would receive worse clinical care if they admitted to use of traditional medicines. We believe that abandonment of ART – and the deception surrounding it – may develop at the intersection of these very different medical cultures. For a proportion of patients, the resolution for these conflicting cultural values is to stop ART in favour of traditional medicines while appearing to continue with long-term care – without ever disclosing these actions to their health care providers.

At present the pervasiveness of this phenomenon is unknown, and because of its secretive nature it may be difficult to determine. From a public health perspective, better understanding of the timing of this phenomenon in the course of therapy is important. Some patients, knowing that ART is not a cure, may abandon therapy to seek out alternative remedies early in the course of therapy. Others may become impatient with the prospect of lifelong treatment and succumb to social, peer or family pressure later on. Interestingly, the patients we have described were among the earliest to enrol into HIV care in the Lusaka public health sector. Since that time increasing numbers of traditional or alternative medicines are being promoted as HIV/AIDS remedies or cures, so it can be expected that the frequency of this phenomenon may increase.

Targeted educational campaigns are critically needed to address these issues directly within communities. Leadership is needed from individual governments as well as national and international health bodies to support the use of only rigorously tested products, as has been advocated by the World Health Organization. Stronger collaborations between traditional and Western-style health practitioners should also be considered. Many countries in Africa are beginning to recognise the role that traditional healers can play in bringing HIV counselling and care to the millions of people who require it, especially in settings of severe health provider shortages. Clinicians should also consider this phenomenon as they manage their patients. Patient-centred adherence counselling,
along with non-judgemental approaches to non-Western medical practices, appear to be low-cost interventions that may prevent the incorrect diagnosis of regimen failure and improve the long-term outcomes of patients with HIV.

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