

Curing Stigma — The Limits of Antiretroviral Access

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Once physically incapacitated by their disease, many people with human immunodeficiency virus (HIV) infection or AIDS have found new life, thanks to the increasing availability of antiretroviral drugs. But for many patients in sub-Saharan African countries, the devastating physical effects have been replaced by debilitating psychological conditions: social isolation and the condemnation of their family, friends, and society.

I met Ama at the Fevers Unit of Korle Bu Teaching Hospital, an HIV–AIDS clinic in Accra, Ghana, where I had gone to interview patients about their experiences taking antiretroviral medications. Having been infected, and then abandoned, by her husband a few years earlier, Ama now struggled to support herself and her four-year-old daughter Abena with sporadic odd jobs and occasional rations of rice and grains from a support group at the clinic.

Despite having been taken in by her family, Ama and her daughter, who is HIV-negative, found themselves confined to a single cramped room in the corner of her family's home, forbidden by her relatives even to enter the kitchen — a painful reflection of her society's view of people infected with HIV.

Though Ama was somewhat worried about her health, caring

for Abena and being accepted by her family remained her principal concerns. Her estrangement from her relatives pained her immensely — perhaps more so than receiving the diagnosis of HIV infection. She wanted acceptance from her family, and she wanted Abena to know her grandparents, uncles, and aunts and to be coddled and loved by them.

Ama's concerns were echoed by many other patients during my time at the Fevers Unit. I met an endless flood of dispirited and exasperated questions: Why has my family left me? Who will marry me? How can I have a baby?

In many societies, the stigma associated with HIV infection can mean rejection by family, friends, and the larger community. Finding a potential mate becomes a nearly impossible task, usually feasible only if one's HIV status remains undisclosed. The prospect of giving birth and raising children seems like a hopeless dream for those unwilling to take the chance of infecting their babies.

In Ghana, where life revolves around the family unit and children are treasured, many patients felt that their lives were incomplete or empty. Although they might regain strength and vigor when given antiretroviral medication, the facets of life that many patients valued most remained

elusive; unable to participate in the social and cultural rituals of their community, they felt disappointed and disillusioned. Antiretrovirals were not, after all, the remedy to all their troubles.

Such isolation undoubtedly complicates patients' clinical care and health. Psychosocial stressors have been known to worsen health outcomes, and the lack of adequate social supports can lead to lower rates of adherence to medication and can place patients at risk for depression. Unfortunately, there is rarely time to address these weighty issues at a clinic where more than 100 patients are seen each day.

Tackling stigma poses challenges, since it is often based in deeply entrenched social and cultural beliefs. Yet if not addressed with appropriate education, it will continue to have far-reaching and destructive effects. As Ama herself recognized, antiretroviral drugs might keep her healthy, but ultimately, it was caring for her daughter and reuniting with her family that would keep her whole.

(Names and identifying details have been changed to protect the patient's privacy.)

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