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HUMAN RIGHTS, MENTAL ILLNESS AND HIV: THE LUTHANDO NEUROPSYCHIATRIC HIV CLINIC IN SOWETO, SOUTH AFRICA

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ABSTRACT

HIV is the leading infectious killer of adults in the world today and a majority of persons with HIV live in southern Africa. Mental illness is common among patients with HIV. Persons with HIV and mental illness, however, are often denied access to HIV treatment for a variety of reasons, including presumed non-adherence, potential drug interactions, and lack of coordinated care. The exclusion of the mentally ill from HIV care is a concerning human rights issue. This paper discusses some of the human rights issues in the care of patients with mental illness and HIV and describes a successful model for integrated care developed at the Luthando Neuropsychiatric HIV Clinic in Soweto, South Africa. The Luthando clinic has provided care to more than 500 patients and has been shown to be a successful model for other programs to improve HIV care among the mentally ill.

BACKGROUND

HIV is the leading infectious killer of adults in the world today, and it is estimated that there are more than 33 million individuals living with HIV globally, of which 22.5 million live in southern Africa.^{1,2,3}

The country of South Africa has a general HIV seroprevalence of 18.8%, but the disease is disproportionately high among the poor black population living in urban areas.⁴ HIV prevention and treatment programs have been scaled up in South Africa, but it is estimated that only 10% of those in need of antiretroviral therapy (ART) actually receive treatment for their disease.⁵ Access to treatment and care is limited by the high number of patients, the limited number of providers, and medication shortfalls.⁶

Although it is true that any member of the general population can become infected with HIV, the burden of the disease is heavier among certain populations. Chief among these are patients who also suffer from mental illnesses.⁷ In South Africa, it is estimated that 26.5% of patients with mental illness also have HIV.⁸ In spite of the high levels of HIV and co-morbid mental illness, these individuals are often unable to access HIV therapy.⁹ This is largely due to the national HIV program's views that mentally ill patients are at high risk of default and poor adherence, and thus a lower priority for initiation of ART.^{10,11} Although not formally stated in policy documents, most practitioners are hesitant to provide HIV treatment to patients with co-morbid mental illness because they believe that such patients will be unable to adhere to their regimens; the possibility of drug interactions and that the use of efavirenz in these patients might aggravate the mental illness as a result of its neuropsychiatric side effects.^{12,13} These and other issues have resulted in severely limited access to HIV care and treatment for this vulnerable section of the population, many of whom go on to be exposed to the morbidity and

mortality associated with untreated HIV.¹⁴

Furthermore, evidence from recent trials has shown that HIV treatment can act as a viable HIV prevention strategy.¹⁵ While specific evidence in mentally ill populations is by and large still outstanding, evidence shows that patients with severe mental illness have high rates of HIV-related risk behavior, making them more vulnerable to HIV infection.¹⁶ A recent study showed that those patients with severe mental illness and with higher Colorado Symptom Index (CSI) scores had a significantly greater risk for HIV infection than those with lower scores. Thus, denying patients with mental illness access to HIV therapy may actually contribute to the spread of HIV in this population.

The exclusion of the mentally ill from HIV treatment practiced by many implementers of HIV treatment programs is done in violation of their human rights; the practice raises questions about the legality and morality of HIV care provided to the mentally ill.¹⁷ First, the mentally ill are considered to be a population requiring society's special protection in order to ensure their health and human rights.¹⁸ Global policies and mental health acts state that they are entitled to health care that is at a minimum equivalent to that received by the general population.¹⁹ Second, the mentally ill cannot be denied lifesaving medication as a group or population of individuals.²⁰ Finally, to presume non-adherence in mentally ill patients as a criteria for not initiating ART is discriminatory, especially in a setting where no adherence-enhancing strategies have been implemented. Clearly, these human rights issues, associated with the provision of HIV care among mentally ill patients in high-burden settings merits urgent action.

The denial of lifesaving treatment to the mentally ill is a major human rights abuse that is in violation of numerous international charters and documents that protect all individuals' right to health. The most notable articulation of this right is Article 12 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR). As stated in General Comment 14, "Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity." In this statement from the

UN Committee on Economic, Social, and Cultural Rights clearly articulates that denying people or groups of people access to the means to achieve health is a serious human rights concern.²¹ Excluding the mentally ill from lifesaving HIV treatment is also in violation of rights, pursuant to the ICESCR, the African (Banjul) Charter on Human and People's Rights. Specific to persons living on the African continent, the document states, "Every individual shall have the right to enjoy the best attainable state of physical and mental health. States parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick."²² Although there is no official policy excluding the mentally ill from HIV treatment in South Africa, the use of "presumed non-compliance" as a reason to deny therapy violates the African Charter.

Finally, people with mental illness are considered a disabled population; as such, the protection of their rights and health falls under the Convention on the Rights of Persons with Disabilities, which states that persons with disabilities have the right to enjoy full equity under the law. This includes access to health care.²³ South Africa is a signatory to this convention.

In an attempt to address some of these concerns, a team of psychiatrists working at Chris Hani Baragwanath Academic Hospital (CHBAH) in Soweto, South Africa, developed a program to treat HIV among patients with mental illness. The program, known as the Luthando clinic, has provided lifesaving HIV therapy to more than 500 individuals in the last two years. The aim of this paper is to describe the historical development of the program and its attempts to deal with the concerns that have limited access to ART to mentally ill patients. It also presents lessons learned, in the interest of helping other programs provide care for patients with HIV and co-morbid mental illness.

METHODS

Located on the southern border of Soweto, CHBAH has 2,964 beds, making it the largest acute hospital in the world. It is the only public hospital in the Soweto region, and serves 6 million people from the surrounding areas. The urban area of Soweto is home to

Figure 1: The Luthando Neuropsychiatric HIV Clinic



more than 1.3 million people and was incorporated into the city of Johannesburg in 2002. The name derives from its formal designation, “South Western Township,” which developed as city and state authorities evicted black South Africans from Johannesburg city proper. Soweto’s population is primarily black and many residents live in poor socioeconomic circumstances.

In terms of mental health, CHBAH has psychiatric wards with 150 beds dedicated to inpatient psychiatric care. Luthando Clinic is a part of CHBAH that serves as an outpatient care center for persons with HIV and mental illness. It was started in 2008 and is currently the only clinic in Johannesburg providing integrated mental health and HIV care. The majority of patients seen at Luthando clinic are referred from the hospital’s inpatient psychiatric wards.

Two methodologies were used to generate the data

in this report. First, an operational assessment of the program history, development, and services provided was performed to describe the Luthando Neuropsychiatric HIV clinic. Operational assessments have been widely described in the medical literature as a way to study and report program-related outcomes.²⁴ Attention was also given to the provision of integrated services for patients with HIV and mental illness as well as strategies used to promote adherence. Second, a retrospective database review was done among all patients with mental illness and HIV who received care at the Luthando Neuropsychiatric HIV Clinic between 2008 and 2010. This review included assessing data on age, gender, clinical variables, and adherence-related variables. A descriptive analysis of this data was performed and is reported in this paper.

Figure 2: Objectives of the Luthando Neuropsychiatric HIV Clinic

The mission of the Luthando Neuropsychiatric HIV Clinic is to improve the lives and health of people living with mental illness and HIV. The objectives of the project are to:

- Improve the quality of life of mentally ill HIV-positive patients through the implementation of community focused HIV/AIDS interventions
- Improve access of mentally ill patients to HIV/AIDS comprehensive care
- Enhance HIV prevention among mentally ill patients
- Improve the care and holistic treatment of HIV-positive mentally ill patients
- Improve adherence to ART through structured programs with FSA, IGA, support groups, and compliance therapy
- Strengthen the capacity of the psychiatric community to access care and treatment for psychiatric HIV-positive patients
- Improve human rights advocacy among mentally ill HIV-positive patients
- Collaborate with government, hospital, and community psychiatric HIV services and other stakeholders
- Promote partnership building between Luthando and other organizations
- Strengthen Luthando's institutional capacity for efficiency and effective delivery of project goals/objectives
- Provide capacity building for partners to increase awareness and advocate for HIV/AIDS psychiatric care
- Acquire baseline information concerning prevention, care, and holistic treatment of HIV-positive psychiatric patients
- Conduct research to inform project activities

RESULTS

Early program history

From 2002 to 2008, the lead author of this paper conducted continuous assessments looking at access to ART among the mentally ill in Johannesburg. The assessments consistently showed that mentally ill patients reported a great deal of difficulty in accessing ART. In 2008, a team of mental health providers came up with the idea of an integrated HIV and mental health clinic, and the Luthando project was born. Persons living with HIV and mental illness named the clinic "Luthando," which translates from Zulu into English as "love." CHBAH's Department

of Psychiatry provided a small space for the clinic; the facility consisted of one chair and one table, as well as an open waiting area. Patients had little privacy. A team of three psychiatrists underwent intensive HIV training and became certified to provide ART. The training included a doctors' initiation and rollout course taught by HIV experts through the Aurum Institute. As members of the local HIV clinicians' society, the psychiatrists received monthly updates and lectures. HIV clinicians and the Department of Infectious Diseases also provided the psychiatrists with on-site supervision within CHBAH. During the first six months of the program, these three psychiatrists served as the only staff in Luthando; it quickly became apparent to these providers that more

resources were needed. They decided that the early Luthando setup was not an acceptable way to deliver quality services and felt the marginalized patients were not receiving an acceptable standard of care. Furthermore, psychosocial assistance and support was also urgently needed. Thus, the project sought additional funding support.

Program development

Support was sought and obtained from a variety of partners, including the Aurum Institute and Bristol-Myers Squibb's Secure the Future corporate philanthropy program. With this funding, the team converted a condemned ward into the current Luthando site (Figure 1). The ward was cleaned, renovated, painted, and fumigated. In addition to improved waiting areas and increased clinic space for privacy, office space was also constructed to facilitate the running of the clinic. Additional medical staff were hired, including a medical officer and nurse. A data manager and office assistant were hired with funds provided by the Aurum Institute and Secure the Future. In 2009, the hospital administration provided Luthando with a cleaner.

As it began to grow, the Luthando Neuropsychiatric HIV clinic also developed its goals and objectives. The main objectives are focused on improving the quality of life of patients with the co-morbidities of HIV and mental illnesses. The specific objectives are outlined in the box in Figure 2.

To date, the clinic provides care to 603 mentally ill patients with HIV. The staff consists of two psychiatrists, one medical officer, two nursing assistants, a data manager, a general office assistant, and a cleaner. The clinic is open three days a week, and each week the staff sees approximately 100 patients.

Services provided

Multiple services are offered at the Luthando Neuropsychiatric HIV Clinic. As noted previously, most patients are referred to Luthando from the inpatient psychiatric wards at CHBAH. Thus, the clinic provides vital ongoing mental health care. Patients are seen for a variety of mental health issues including psychosis, bipolar mood disorder, depression, anxiety, and behavioral problems. Psychiatrists,

mental health nurses, and trained therapists follow up with patients. The hospital pharmacy provides a range of psychiatric medications, including typical and atypical antipsychotics, selective serotonin reuptake inhibitors, mood stabilizers, and benzodiazepines. Antiretroviral therapy is provided through the HAST (HIV and AIDS, STIs, and TB) directorate, a division of the Department of Health dedicated to HIV and sexually transmitted diseases.

The clinic also provides HIV testing and treatment. Since many HIV providers are either too burdened to accept these patients, worried about the issues of obtaining consent for testing, or decide not to start mentally ill patients on ART, the psychiatrists at Luthando were trained as ART providers. They offer ART to the patients at Luthando and have access to first- and second-line ART regimens. In addition to ART provision, Luthando offers diagnostic and monitoring services, including laboratory analysis, radiographs, and sputum analysis for TB. All of the diagnostic and monitoring services are provided through the laboratory at CHBAH, which is operated by the National Health Laboratory Services.

As the patient population at Luthando began to grow, providers began to diagnose an increasing number with tuberculosis (TB). South Africa has one of the highest rates of TB in the world with an estimated prevalence of 407 cases per 100,000 people.²⁵ Furthermore, co-infection with TB and HIV is a major problem in South Africa; an estimated 70% of TB patients are also infected with HIV.²⁶ When it became clear that many of the Luthando patients suffered from three conditions—mental illness, HIV, and TB—and that many TB programs also overlooked persons with mental illness for concerns regarding adherence, the psychiatrists began to offer TB services as well. These include diagnosis (including drug susceptibility testing) and outpatient treatment.

Luthando also offers a range of psychosocial support services, which are primarily aimed at improving adherence and will be discussed in detail below.

Integrated services

One of the main objectives of the Luthando project is the provision of integrated care. In many clinics and hospitals in the region, patients must go to an

HIV center for their ART, a TB center for their TB diagnosis and treatment, and a mental health center for care for their mental illness. This provides fragmented care for patients. Providers at each of these centers may not be aware of the patients' comorbidities, or they may suspend necessary drugs due to interactions or adverse events with limited understandings of these medications and their interactions. Additionally, visiting three providers at three different locations can put further burden on patients and make it difficult for them to adhere to their treatment regimen. Luthando patients receive care for all their health issues in the same building from the same providers—a tremendous advantage for the population being served.

One notable component of the Luthando integrated service model is the provision of drugs for mental illness, HIV, and TB. Prior to the Luthando program, patients had to queue at one pharmacy for their psychiatric medication, at another for their ART, and then in the community for their TB medication. While it is a national agenda for patients to receive their TB treatment in the community, Luthando has been able to integrate ART and psychiatric medication into a single pharmacy with a shared database. This allows patients to receive all their medications in a single place and has been associated with high rates of medication pick-up.

Promoting adherence

Adherence to therapy is a major problem among patients with mental illness. This has largely been described as a problem for adherence to ART but can also include problems adhering to TB treatment as well as to treatment for mental illness itself. Thus Luthando has several projects aimed at improving psychosocial well-being and improving adherence.

An initial program of support groups was started using a traditional psychodynamic approach. A trained psychotherapist facilitated the support group. Here the group's goal was re-establishment of the normal development and removal of obstacles to the normal recovery processes. Attention was placed on transference, learning through experience, and conflict analysis. Attendance at these groups, however, was quite low. Both patients and providers felt they needed groups that were more social and included an activity. Furthermore, many patients were unable to earn incomes and lived in situations of deep poverty. Thus, two new programs were started in which

“group therapy” also included a social activity aimed at generating food and income for participants.

The first such program is a beading group. In this group, participants engage in crafting beaded art that they are able to sell to earn an income. Beads and supplies are provided through funding from the Secure the Future project, and the participants are taught how to do the beading. A trained occupational therapist leads these sessions. Participants are encouraged to attend, learn a new skill, and talk about issues that affect their health status and their ability to adhere. At the end of the group sessions, participants have a product that can generate income.

The second program, called the “Food Garden Security” initiative, focuses on food generation. Participants receive training in gardening techniques that can be used in their local settings. An expert in food security leads these sessions, along with a trained occupational therapist. Participants discuss life and health issues, and share strategies for maintaining their HIV and mental illness treatment programs.

Finally, an “adherence school” was developed. A course is taught once a week for two weeks to promote ongoing patient adherence; Luthando clinic staff prepares the manuals and presentations used in the course. This program also supports trained auxiliary social workers who are deployed into the field to trace patients defaulting on their treatment (those who have missed three or more months of therapy) and patients who have been lost to follow up (those who have not come to their monthly appointments). The auxiliary social workers then do home visits to promote compliance with therapy and encourage patients to attend their appointments.

Descriptive patient data

Data were analyzed on 514 patients enrolled in the Luthando program. A majority (76%) of these patients are female and between the ages of 18-39 (69%). In addition to having HIV and mental illness, 17% of participants have active TB. Patients were in the late stages of their HIV disease upon enrollment, with 62% having WHO stage 4 disease. Fifty-nine percent of mental illness diagnoses seen in the clinic were considered secondary to HIV. These included mood and psychotic disorder due to general medical condition (HIV), psychotic disorder due to general medical condition (HIV), mood disorder due to gen-

eral medical condition (HIV), and HIV-associated neurocognitive disorders (HAND). Primary functional psychiatric disorders in order of prevalence were bipolar mood disorder type 1, major depressive disorder, and schizophrenia. Co-morbid substance abuse and substance-induced mood or psychotic disorders were rarely seen at the clinic, with less than 17% of patients diagnosed as such. Substances commonly seen are alcohol and cannabis abuse. Injection drug use does not feature amongst the substances commonly used in this setting.

A total of 467 patients in the program were available for outcome analysis. While 95% of the patients were adherent to their ART regimens, both by self-report and by pill counts, 38% of patients missed a clinical visit for two or more months. The clinic's "lost to follow up" rate is 11%. Among those patients who are no longer receiving care through Luthando, 25% moved to another catchment area, 20% were terminated as "non-adherent," 18% died, 8% requested to stop ART, 3% experienced drug interactions making them unable to continue ART, and 3% had adverse effects that limited their continuation of ART.

DISCUSSION AND FUTURE DIRECTIONS

While there are many factors associated with non-adherence to HIV treatment regimens (related to the treatment, patient, health care, and socio-economic situation), the Luthando Neuropsychiatric HIV Clinic has shown that HIV-positive patients with mental illness are able to take ART and to continue successfully with treatment. This finding is supported by other work in the field.^{27, 28} Luthando is also fostering global understanding of mental illnesses and HIV. Interventions are being developed for non-adherence among certain high-risk groups. For example, it has been shown that patients with depression are three times more likely to be non-adherent than non-depressed patients, and cognitive ability in HIV dementia has been shown to have a reciprocal relationship with ART adherence.^{29, 30} Thus, Luthando is now planning intensive interventions for people with depression and cognitive decline. Furthermore, evidence suggests that individuals with psychiatric disorders are significantly less likely to discontinue ART in the first and second years of treatment and mental health visits were associated with decreased risk of discontinuing ART.³¹ For this reason, an integrated approach such as the one at the Luthando Neuropsychiatric HIV Clinic has proven beneficial,

as evidenced by the "lost to follow up" rate, which is comparable with other general HIV clinics in the area.³² Not only does Luthando treat the patient holistically, but it also provides a non-stigmatizing setting in which marginalized patients can receive combined care.

Socio-economic circumstances made transportation to Luthando difficult for many patients, so the clinic expanded to a community site in the poor semi-urban district of Orange Farm, 45 kilometers from Soweto. There are plans to further develop this site, which falls under the jurisdiction of CHBAH, and to expand to other local community sites, thereby increasing service to the community's marginalized populations. Luthando will continue to play an important role in HIV prevention within the mentally ill population, and seeks to educate these patients while also playing a more active role in training mental health care practitioners and other health care staff. Improved advocacy among this marginalized population is a further main objective.

CONCLUSION

Persons with mental illness are a vulnerable population who merit special attention regarding health and human rights. In spite of the fact that mental illness and HIV are common co-morbidities, there are few global programs providing these patients with integrated services. In fact, most patients with HIV and mental illness are denied lifesaving ART because it is presumed that they will not be able to be adherent to their medications. This constitutes a human rights issue that requires immediate attention.

This report has several limitations. First, it involved a retrospective record review and thus is subject to all the biases that can occur with these types of studies. Second, the program described was targeted at an urban population living in Soweto and may not be generalizable to other populations. Finally, the operational assessment focused on integration of services and the promotion of adherence and may have overlooked other key operational issues present in the program.

In spite of these limitations, however, the data reported in this paper have important implications for addressing human rights and improving health care among persons with mental illness and HIV. First, patients with both these comorbidities can suc-

cessfully participate in care provided that they have the proper medical and social support. Second, psychiatrists and other mental health providers can be important care providers for both HIV and mental illness in settings that have a high burden of both diseases. Finally, The Luthando Neuropsychiatric HIV Clinic is an important model of how HIV care can be provided to a vulnerable population of mentally ill individuals. It is recommended that our model be replicated in other settings and we encourage other programs to follow suit.

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