

HEALTH AND WELLNESS **FOR ALL: MAMELANI** **PROJECTS' WELLNESS** **PROGRAMME**

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It is estimated that in South Africa, nearly 600 people die per day of HIV and AIDS related causes.¹ Though efforts to curb transmission of the HI virus have been numerous, the number of people infected continues to rise at an alarming rate. In order to help reduce transmission rates, and improve quality of life for those living with the virus, there is a pressing need for effective health education to support care and treatment efforts. Mamelani Projects, a Cape Town-based public health non-governmental organization (NGO), runs a Wellness Programme that empowers individuals to take greater control over their bodies and health through self-care health education and psychosocial support. It aims to strengthen effectiveness of existing health care systems by helping people make better-informed decisions about how to access services and how to stay healthy, while emphasizing local resourcefulness among low-income communities.

Situation on the ground

The public health challenges facing South Africa, a country grappling with the legacy of apartheid and staggering inequality, are vast. It has an HIV prevalence rate of 18.8% and 5.54 million were estimated to be living with the virus in 2005.² Most prominently, the HIV health crisis is characterized

by a public health system that is thin on the ground; high levels of food insecurity; limited access to treatment and care; lack of information about prevention and management of symptoms; and finally, mixed messaging around HIV/AIDS treatment options,³ accompanied by stigma and social inequality. Consequentially, low-income communities are faced with the double burden of illness and poverty. Since most poor communities receive care from overcrowded clinics and emergency rooms, health education and psychosocial support are luxuries the health care system cannot afford.

Mamelani Projects' Wellness Programme: Supporting health care systems

While health education was traditionally the role of staff at public clinics, pressures on the resource-strained medical establishment prevent people from getting sufficient information to help prevent illness and maintain good health and, additionally, pose barriers to early testing. Nurses who are meant to see 35 patients per day are being forced to see up to 90.⁴ Scores of cases of illness go unnoticed. A study in a community of high HIV prevalence in Cape Town estimated that 63% of community adult cases with pulmonary tuberculosis remained unrecognized by the health services.⁵ Thus, the inaccessibility of health care facilities contributes to low levels of testing and a delayed response time to symptoms.

Mamelani Projects' Wellness Programme attempts to fill this gap by educating people about wellness and available health services in order to get the most effective care possible. It provides low-cost, practical information about how to boost the immune system and nutrition security; how to identify a range of illnesses; on correct usage of medication and treatments; and on the medicinal and nutritional value of locally available foods and home remedies. Facilitators educate groups on all available treatment options for commonly experienced illnesses and ailments, covering medical, traditional, as well as home-based care options.⁶ Importantly, it encourages people who are unaware of their HIV status to get tested as soon as possible, while emphasizing that HIV is not a death sentence. Reducing the incidence of both opportunistic infections and HIV-associated morbidity and mortality requires both early testing and improved access to prevention and care services. Thus, improving nutritional status, and increasing response time to infections and avoiding unhealthy activities may strengthen the immune system and delay disease progression.

Health education for all

Mamelani believes that every human being has the right and responsibility to have a basic understanding of how their body works and what steps can be taken to stay healthy. The workshops are tailored to the needs of low-income families and are taught in Xhosa. They stress the importance of wellness to the general population, without isolating HIV services or people infected by the virus. HIV education is integrated with wellness information in an attempt to reduce stigma associated with the disease, and to emphasize that it is everyone's responsibility – whether they be HIV positive or not – to be aware of how to prevent infection and how to stay healthy.

The following comment made by a participant demonstrates the power of health education to transform the way people view their role in managing their bodies and improving their health:

“I always thought that these things about our bodies were only for the doctors to understand. I never thought I could understand these things. But now, after the workshops, I am curious, because I can see that I can also understand these things. This knowledge is really powerful to me because now I can make the right decisions.”

By teaching people about their bodies, ways of staying healthy and their various options in responding to illness, people are able to view their bodies and their relationship to illness in a more positive light. Mamelani shows people that they can take control of their health by first understanding that they have the right and responsibility to gain insight into information that is traditionally perceived to be within the domain of the medical establishment. Mamelani facilitates this learning process by providing information and guiding people through the difficult challenges that they face in implementing this knowledge into their daily lives.

Importance of nutrition education for health care

Due to the high level of poverty and unhealthy consumption patterns, many South Africans have low levels of immunity, making them more susceptible to HIV and to the symptoms associated with the virus. Nutrition should be integrated into care because it strengthens the body's ability to ward off diseases and symptoms that are commonly associated with the HI virus.⁷ People living with HIV experience increased physical energy expend-

iture,⁸ drops in food intake,⁹ nutrient mal-absorption and loss, and altered metabolism that bring about weight loss and wasting, a common symptom of AIDS.¹⁰ Further, anti-retroviral treatment (ARV) reduces the rate of viral replication, while nutrition “provides the body with what it needs to create new immune cells, and thus do its part in fighting infections.”¹¹ Thus, limited access to proper nutrition and financial constraints affect an individual’s adherence to the medication.¹² Good nutrition helps the body achieve the full benefits of ARVs; nutrition and ARVs work in tandem to sustain the immune system in different, though complementary ways. Supporting nutrition security of people living with HIV, especially when they are asymptomatic, may prolong the period of time before HIV develops into full-blown AIDS.

Another indication of the need for health education and nutrition-based responses to high rates of HIV, AIDS, tuberculosis (TB) and other illnesses is the rate of re-treatment for people on treatment. According to a study by the Human Sciences Research Council on major infectious diseases in the Western Cape, it was found that in areas with poor access to health facilities, re-treatment cases are the result of increased susceptibility brought on by advanced immuno-suppression. This is due in part because HIV creates an environment where the risk of reactivation of latent TB disease is exacerbated by a compromised immune system. Thus, the nutritional implications of HIV and TB are also critical due to the high co-infection rate. There is a greater risk of infection progressing straight to primary disease in instances of immune deficiency.¹³

The wellness workshop addresses how the immune system works, how different illnesses affect the body, how to respond to the symptoms of opportunistic infections, and how improved nutrition can strengthen the immune response at every stage of disease progression, including enhanced drug effectiveness. This information makes the workshop most useful for people who test positive but have not developed full-blown AIDS because a strong immune system prolongs the time before ARVs become necessary.

The component of the workshops which focuses on nutrition guides participants through a number of activities to demonstrate the importance of eating balanced meals using nutritious, locally available foods without incurring excess cost. For example, the Mamelani Wellness Programme promotes increased consumption of selenium, which is widely known to be vital for immune functioning. Selenium is found in beef, chicken liver, sunflower seeds, Brazil nuts and aloe (an indigenous South African succulent).

Facilitators demonstrate how to make aloe juice, which is locally grown and easily accessible. Mamelani also provides Brazil nuts at a subsidized rate to participants in order to provide an alternative, low-cost source of selenium. In addition, they discuss practical strategies for maintaining a healthy body weight, while fighting misconceptions that lead to poor health. Finally, the workshops discuss cooking methods that ensure maximum nutritional intake.

The workshops place extra emphasis on food-based responses that can strengthen the immune system and help the body cope with symptoms. One HIV-positive participant claimed that she frequently suffered from mouth sores, which forced her to take excessive periods of leave from work to access health services from the clinics. She could not afford to spend time waiting in clinics each time she experienced a mouth sore, and would normally postpone accessing treatment until the pain was so unbearable that she was unable to eat. After attending the wellness workshops, she began chewing sour fig leaves to halt the progression of the mouth sores. Responding promptly saved valuable time and her immune system sustained less harm.

Supporting people beyond information

Disproportionate numbers of people affected by disease in South Africa come from impoverished backgrounds. Staying healthy and preventing illness is further challenged by the fact that many live in crowded, unhygienic living environments and often come from socially marginalized communities. To negotiate and cope with the multiple impacts of illness and poverty, such as stigma, isolation and loss of employment, Mamelani provides psychosocial support and care so that participants can focus on their health to the best of their abilities. Support takes the form of one-on-one counseling, referrals to other NGOs and by serving as patient advocates. An important feature of the organization is that all of the facilitators come from the communities they serve, and conduct the workshops in a manner that encourages respect and dialogue, as opposed to providing information in a top-down manner.

Health education is an ongoing need, especially for people suffering from a chronic illness, and a virus for which there is no cure. Normally health professionals inform patients about wellness information under incredibly stressful circumstances (e.g. after getting tested), resulting in

critical information about what to eat, and how to prolong the period before treatment is required, often being compromised. Thus, wellness workshops are conducted once a week for six weeks in order to give participants enough time to become comfortable with the facilitators, build trust with the group, and to absorb the information fully. One participant expressed her level of comfort in the workshop in the following way: “You always feel free to ask anything when you attend the workshop, about your health and even about the fears you have about the community.” This climate of respect is necessary in order for participants to feel comfortable to discuss complicated and sensitive issues.

While the wellness workshops aim to empower people to take their health and lives into their own hands, Mamelani understands that many people live in situations where they are not fully in control of their decisions, irrespective of how much they know about their responsibilities to their health. One client, who was on ARVs, was struggling to follow her treatment regimen because she lived with relatives who pressured her to share her food with the family, thus compromising her ability to meet her special dietary needs. She often arrived home to find that the groceries she had purchased had already been consumed. The facilitator suggested that she eat smaller meals outside of the home and offered her emotional support until she was ready to speak with the family, in order to make them sensitive to the importance of her dietary needs. After speaking to the family, it was suggested that she would share certain staples, but that specific food items would not be shared. The deeply engrained Xhosa cultural norm of sharing all resources equally made separating this individual’s food from the rest of the family’s a difficult adjustment. However, after some time, the family became more accommodating, despite the extra financial burden and the break from traditional consumption patterns in the home.

In certain cases, facilitators take a more proactive role by serving as patient advocates. One participant approached Mamelani because her child’s clinic card was burnt in a shack fire. Though the child was on treatment, the hospital refused to dispense the child’s ARVs without the clinic card and instead sent her back to her local clinic, where she would need to start the application process for accessing ARVs all over again. By the time the Mamelani facilitator came to know about the case, the child had not been able to access treatment for two weeks. The facilitator responded immediately by reporting the child’s situation to the management at the clinic,

to bypass the tedious reapplication process, so that the child could resume his treatment regimen as soon as possible. To respond to more specialized needs, Mamelani actively refers individuals to partner NGOs that deal with a host of issues, ranging from domestic violence, family conflict, food security, skills training and employment.

Conclusion

Mamelani's Wellness Programme responds to a range of needs faced by people struggling to cope with chronic illness. It understands that care for chronic ailments, such as HIV and TB, cannot be treated effectively through short-term inputs, but rather by empowering individuals to become informed about their health, and by supporting them through the various impacts of illness on their lives. One facilitator observed the following:

“Some people still cry when they are diagnosed with HIV. Some of our clients start drinking a lot and sleeping around because of anger. They feel angry towards their partners and blame them for their status. They do not talk about it and start to feel hatred and anger towards others. They experience fear – fear of dying, of losing their partners, of losing their jobs. They also experience confusion, not knowing what to do or what steps to take. Some people are still in denial, pretending as if nothing is wrong even if they are dying inside. They also experience stigma, feeling isolated from the family and friends. This is where Mamelani is helping – offering support and information. Knowledge is power. To know what steps can be taken and what the right thing to do is in order to stay healthy, shows people that they can stay strong and live positively for as long as possible before they progress to full blown AIDS. Even if someone is already on treatment, knowing what to eat and how to prepare healthy food can help with managing symptoms and adherence to treatment.”

Though South Africa has a strong commitment to human rights, it has a long way to go in order to ensure that people have access to essential services to protect the right to health. Mamelani understands that in order to help people effectively improve their health and seek needed services, the health care system must be supported by interventions that provide basic health education to ensure that people are able to take control over their

lives. Thus, the Mamelani Wellness Programme highlights the importance of health education as an entry point, in helping people at risk of illness and poverty live a better life by learning about their bodies, their rights in accessing health care, and their responsibilities to themselves and their communities.

- 1 'South Africa: AIDS Treatment Action' in *Africa Policy E-Journal*, 24 March 2003, available at <http://www.africaaction.org/docso3/taco3o3.htm>.
- 2 South African Department of Health, 'Broad Framework for HIV & AIDS and STI Strategic Plan for South Africa, 2007–2011' (Pretoria: Department of Health, 2006).
- 3 Key figures in the government have been denying the scale of the HIV epidemic and Dr. Mantombazana Edmie Tshabalala-Msimang, the former health minister, played a particularly damaging role in promulgating fallacious messages about how to respond to AIDS. The health minister persistently emphasized that AIDS should be treated with vegetables and good nutrition, while pointing out the high toxicity levels in anti-retroviral drugs. On the other hand, the Treatment Action Campaign (TAC) and health experts from around the world have rigorously been fighting the government to provide access to anti-retrovirals to people through the public health sector. Due to the confusing messaging and polarization around the debate between the government and the activists regarding the role of treatment and nutrition, many South Africans have been left with uncertainty about who to trust. As HIV and AIDS weaken the immune system, nutrition must be integrated into care and treatment for people who test positive. Thus, Mamelani Projects emphasizes the importance of testing, while educating people on what steps to take before they require treatment in order to prolong the period before treatment becomes necessary.
- 4 Aziz Hartley, 'Overworked Nurses Feel the Brunt', *Cape Times*, 15 April 2005.
- 5 Beverly Draper, Beverly, David Pienaar, Warren Parker and Thomas Rehle, 'Recommendations for Policy in the Western Cape Province for the Prevention of Major Infectious Diseases, including HIV/AIDS and Tuberculosis' (Western Cape: Human Sciences Research Council, 2007), at 27.
- 6 WHO, 'Traditional Medicine: Fact Sheet No. 134' (Revised May 2003), available at <http://www.who.int/mediacentre/factsheets/fs134/en/>. (In South

- Africa, 75% of people living with HIV/AIDS use traditional medicine / complimentary or alternative medicine (TM/CAM).)
- 7 HIV belongs to a group of retroviruses that affects the body by weakening the immune system, thereby making it more vulnerable to a host of different diseases and illnesses, such as TB, thrush, pneumonia, oral thrush, anaemia, as well as malnutrition. It is a slow acting virus and can remain in the body undetected for years; thus, it carries major long-term impacts that may not be detected early on. AIDS results when an HIV positive person contracts opportunistic infections (OIs) or when their CD4 count (a measure of the strength of the immune system) drops below 200 cells/mm. The length of time between HIV infection and AIDS depends on the strain of the virus, genetic factors, age, co-infections and the general health of the individual before and after infection.
 - 8 "Asymptomatic HIV-positive individuals require 10% more energy, and symptomatic HIV-positive individuals require 20%–30% more energy than HIV-negative individuals of the same age, sex, and physical activity level.": E. Piwoz, *Nutrition and HIV/AIDS: Evidence, Gaps and Priority Actions* (Washington, D. C.: Academy for Educational Development, 2004). Additionally, for HIV-infected children experiencing weight loss, energy needs are increased by 50–100%.
 - 9 Reduced food intake may be due to painful sores in the mouth or digestive track; depression, fatigue or other psychosocial problems; or lack of access to food or economic resources. The WHO recommends that effective ways of improving dietary intakes need development and documentation.
 - 10 Food and Nutrition Technical Assistance (FANTA) Project, *HIV/AIDS: A Guide for Nutritional Care and Support* (Second Edition, Washington, DC: Academy for Educational Development, 2004) at 14; E. Piwoz, *supra* note 8.
 - 11 David Patient and Nail Orr 'ART and Nutrition in HIV and AIDS', 5 *The Third Voice* (2006).
 - 12 People on ART who do not correctly follow drug regimens may experience more opportunistic infections and faster progression of the virus. Non-adherence may also produce drug-resistant strains of the virus, increasing the transmission of the virus to those who cannot be treated by existing medications. T. Castleman, E. Seumo-Fosso and B. Cogill. 'Food and Nutrition Implications of Antiretroviral Therapy in Resource Limited Settings' in Food and Nutritional Technical Assistance (FANTA) Project, *Technical Note No. 7*, (Washington, DC: Academy for Educational Development, 2004) at 11.
 - 13 Draper, *supra* note 5, at 22–26.