



Measuring HIV Symptom Distress in a Rural Zulu Community

SOUTH AFRICA



KwaZulu-Natal

Human suffering from the HIV/AIDS epidemic in South Africa has reached unprecedented proportions. In 1998, an estimated 50 percent of all new infections in Sub-Saharan Africa occurred in South Africa. The HIV prevalence rate in the impoverished area of KwaZulu-Natal, where Wilbur Downs Fellow Erin Shawn, RN conducted her research in the summer of 2002 is conservatively estimated at 36 percent. According to Erin, the vast majority of people infected have no access to antiretroviral treatment, making palliative care the only treatment available.

Palliative care is the combination of active and compassionate therapies to comfort and support individuals and families living with a life threatening illness. The crucial element is the relief of all pain—physical, psychological, spiritual, and social. In order to evaluate the effectiveness of a palliative program, it is necessary to be able to measure the range and severity of patient symptoms. Erin's project was titled "Measuring HIV Symptom Distress in a Rural Zulu Community." She conducted a cross sectional descriptive study of the range and severity of symptoms experienced by 64 KwaZulu-Natal AIDS patients receiving palliative care services from South Coast Hospice, a non-profit organization that cares for AIDS patients in the region.

Symptom distress in HIV-positive Africans has not yet been studied. Erin's study is the first of its kind to evaluate the Zulu community using the HIV Symptom List (HIV-SL) and the HIV Symptom Profile (HIV-SP), two survey instruments that were developed to assess and monitor symptom distress of people living with HIV. Erin's study will be able to provide insight into the frequency and severity of symptoms, and the range of distress experienced by the subjects. "This study will offer patients and caregivers the opportunity

to collaborate in assessment and treatment of symptom distress, subsequently improving palliative care services for this population," explained Erin.

Erin conducted her interviews in participants' homes, travelling to small townships, squatters' camps, and rural communities with one of four local South Coast Hospice caregivers who provided her with linguistic translation and familiarized her with the Zulu culture. "South Africa is a country of contrasts," said Erin. "It is so beautiful and yet there is so much suffering from poverty and the AIDS epidemic. The disparities are appalling; fancy shopping malls in Durban with squatter camps 20 km away. There are so many people dying of AIDS, yet people of privilege who are not involved in health care do not want to see or accept how serious the epidemic is."

After data collection was completed, Erin prepared a preliminary report for the South Coast Hospice. She is currently conducting further statistical analysis with assistance from YSN Professors Ann Williams and Marjorie Funk.

Recalling her summer experience in a story titled, "Sanibonani," Erin wrote: "I have seen young women dying, leaving their children to their mother who is already caring for grandchildren left behind by another daughter. Horrific opportunistic infections, frail bodies, young people with no hope. As a doctor I met here shared, 'I come with two ears and one mouth. I listen more than I speak.' That is what this study has been for me. However, it is so hard to listen and not be able to do much in return. All I can hope is that my findings will help hospice and help people who are suffering from HIV."