

AIDS in Africa: Blurring the Boundaries Between Life and Art

By Sandra L. Bertman

In Africa, the reality of AIDS is bleak. The social stigma, the poverty, the disinterest or apathy are “deafening,” to borrow a phrase from Craig Demmer (this issue).

In 2001 and 2002, I had the rare opportunity to co-facilitate a series of conferences and workshops in Namibia and Botswana, whose overall theme was burnout—“Caring for Ourselves in Order to Take Care of Others.” In these African countries, I heard directly from practitioners that every level of caregiver felt completely overwhelmed by those dying of AIDS.

Public hospitals, filled with patients suffering from pneumonia, chronic diarrhea, and tuberculosis, were evidence enough of the steep rise in AIDS cases (Cameron, 2003). An American doctor, David Cameron, who teaches family medicine in Pretoria University, has observed a change in doctors and nurses in South Africa. The fear and apprehension of the 1990’s is now replaced by hopelessness and apathy. All too apt are these haunting lines of a poem by Robert Lowell (1977):

*The resident doctor said,
“We are not deep in ideas, imagination or enthusiasm—
how can we help you?”
I asked,
“These days of only poems and depression—
what can I do with them?
Will they help me to notice
what I cannot bear to look at?”*
(pg. 117)

For those caretakers at our workshops who were seeking respite from their exhaustion and burnout, we tried to generate some “ideas, imagination, or enthusiasm” by introducing easily understood techniques involving the arts, focusing on verbal and visual images. Among the techniques we used was one called a “visual case study” in which participants interact directly with a work of art.

A Visual Case Study

Art images express truth in ways ordinary words cannot. The arts not only help us “notice what [we] cannot bear to look at,” but also afford a safe space and time in which to ponder human suffering without subjecting another person, or oneself, to embarrassment or shame. Blurring the boundaries between life and art, images compel us to witness reflectively.

At one such workshop using the visual case study method, we concentrated on a

woodcut by a contemporary Namibian artist, Lindley Hoaeb (Figure 1). With a larger-than-life color transparency of it projected on the screen, participants jotted down what the woodcut meant to them. Then volunteers read their written notes, spawning animated discussion.

Some participants wrote straightforward descriptions of the woodcut—as a grouping of four or five figures. Even simple objective details led to narrative possibilities. For example, consider the shadowy outline of man with a hat, in profile on the left. He appeared to be looking away, perhaps distancing himself from the group of a woman and three children. One participant speculated, “Could the white shadow with a hat represent the doctor turning on his heels? His role, after all, is to treat patients. The truth might be he has nothing medically to offer. Nothing.” Others argued that the patient’s social situation or spiritual well being was not the doctor’s responsibility. Another participant suggested the man was the husband and children’s father—the kind of man who throws his wife out because he finds she has AIDS (cf. Demmer, this issue).

The title of the woodcut, “The Husband’s Responsibility,” gave us further clues about the artist’s intended meaning, clues about the shadowy father typically missing from the family. It hints of the social and political realities of AIDS in Africa: widespread heterosexual transmission; young people and children infected and dying of the disease; family burdens falling on the young mother and, when she dies, on the aunts, cousins, grandmother, and extended family.

Cognizant of cultural mores, workshop participants acknowledged the ever-present embarrassment and secrecy and denial about AIDS, “an unspoken rule of silence that permeates all interactions” (Demmer, this issue). How then does a clinician broach the subject with patients, even with close friends or fellow workers? Our discussion of the woodcut not only shattered the “deafening” silence, it made us feel, among ourselves, a special bond of closeness and community—as if we understood one another.

Of course, learning more about the African culture puts a different spin on how one understands the woodcut. Nonfiction sources (Cameron, 2003; Demmer, this issue) informed me that Hoaeb’s woodcut image is quite accurate as documentation of the AIDS tragedy. In this context, the boundaries between life and art become blurred—if nonexistent.

Continued on page 5



Figure 1.
“The Husband’s Responsibility,”
by Lindley Hoaeb (2000). Woodcut.
Used with permission of the artist.
All rights reserved.

The Truths of Fiction

Contemporary novels, too, flesh out the deafening silence and further document the cultural context. The protagonist of Unity Dow's (2000) riveting novel, *Far and Beyond*, describes the degradation of women: their service as "mere vessels for use by men;" the "sanctioned humiliation" of the marriage ceremonies; and the isolation of their suffering. Conscience? Husband's responsibility? The African culture traditionally has given the male wide latitude to dominate his woman, to leave her, to sleep with a virgin in the hope of curing his AIDS (a commonly held belief), or to abandon his family.

As if it is not bad enough to contract the often fatal disease, Africans have to bear an additional burden—the stigma of the whole community. Those who are healthy neither speak of AIDS nor acknowledge the disease even when it afflicts close friends or family members. Dow (2000) described the many ways around mentioning the dreaded disease, even at a funeral:

"Such vague words as 'long illness' always meant something was being hidden. Mara thought she heard someone say the word AIDS but she could not be sure. In any case she could not imagine anyone being courageous enough to utter that dreaded acronym, especially at a funeral; 'this disease,' 'the radio disease,' 'phamo kate,' or 'the disease with a short name' were the more acceptable synonyms." (pg. 12)

At her wedding, a wife is instructed she must cook, clean, wash for, and please her husband sexually, and never ask him where he has been.

"A husband may go chopping in a neighboring field. Only a wife with long ears will hear things she does not need to hear. A married woman must make sure the home fires do not burn out. There is no house without a leaking roof but you do not see women in the streets telling all and sundry of their problems." (Dow, 2000; pp. 150-151)

Demmer (this issue) speaks of wife beating and unfaithfulness. Mda (1995) stated, "Men are dogs, and are known to wander from time to time." (pg.18) So, women in general have the burden of keeping the family going and, when disease strikes, they have the responsibility of struggling on.

Settling Loose Ends

Several workshop participants' stories fixated on the woman's thoughts in Loeb's woodcut. The consensus was that most dying African women want to know their children will be cared for. They want to appoint guardians in advance, figure out economic support of children or elderly or ill, have loose ends settled, and the ease—the permission—to die.

In Dow's (2000) novel, the weak, bed-ridden young mother, Cecilia, musters strength to beg her friend to go to a government or social service office for women and children. "I want Bibi's father to pay child support. Before I die, I want to know someone will support her." Wincing with pain, knowing she has little time left to live she adds, "You have to do it fast . . . But I will not die until I am sure that something has been done." (pg. 166) In the novel, Cecilia encounters disastrous legal and bureaucratic roadblocks which might

have been avoided if direct answers to her questions had been forthcoming. At the close of our workshop, a task force was formed specifically to investigate the legal rights of women.

The Restorative Power of Art

This visual case study exercise opened participants to moments of insight and honesty with their own deep feelings, which may well be the first step to healing. Nurses and social workers from Botswana talked about the stigma of even working in an AIDS clinic. Some caretakers noted that keeping so completely busy might be a way of avoiding their own inner pain. Everyone acknowledged the contagion of grief, sadness, and stress. When their shift is over, these caretakers may be leaving a patient but walking into their own personal situation—and it might not be so different. They themselves, or someone in their household, may be infected. Can they admit it? To whom can they turn? Finding their bearings, the participants became spiritual companions to one another.

We concluded that the visual case study—reading closely what is happening in the woodcut, then reflecting on the complexities and ambivalences of what the image conveys—was a fine "booster shot." It improved one's ability to witness. It sharpened one's eyes and ears in clinical situations. Maybe more, this rehearsal or prelude helped participants to absorb, interpret, and respond to difficult moments with their patients, gave them practice in framing questions, and suggested a repertoire of responses for "staying present" with patients without having to fix, remedy, or relieve the suffering.

Appreciative of Lowell's (1977) insightful observation that some in healthcare are deficient of "imagination, enthusiasm, or ideas," we respectfully add this simple technique using the restorative power of art to our "treatments" for caregivers' physical and spiritual exhaustion: prayer, exercise, a walk in nature, a cup of coffee, or a visit with a friend, old or new, real or created (on canvas or in print). □

References

- Bertman, S.L. (in press). Staying present with suffering: Images still and moving. *Journal of HIV/AIDS & Social Services*.
- Cameron, D. (2003). Dying and living in South Africa, Christmas, 2002, *American Academy for Hospice and Palliative Medicine Bulletin*, 3, 8-9.
- Demmer, C. (October, November, December, 2003). The Twilight Zone: AIDS in South Africa, *The Forum*, 29, x-y.
- Dow, U. (2000). *Far and Beyond*. Gaborone, Botswana: Longman.
- Lowell, R. (1977). "Notice," in *Day by Day*. New York: Farrar, Straus and Giroux.
- Mda, Z. (1995). *Ways of Dying*. Capetown, South Africa: Oxford University Press.

About the Author

Sandra Bertman is Research Professor of Palliative Care at Boston College Graduate School of Social Work and curator of the Staying Soulful project for the American Academy for Hospice and Palliative Medicine. Founder of the Program of Medical Humanities and the Arts in Healthcare at University of Massachusetts Medical and Graduate Schools of Nursing, she authored the classic handbook, *Facing Death: Images, Insights and Interventions*, and edited the comprehensive anthology, *Grief and the Healing Arts: Creativity as Therapy*.