Caring for the Caregivers: Models of HIV/AIDS Care and Treatment Provision for Health Care Workers in Southern Africa

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Rollout of antiretroviral therapy (ART) has been successfully initiated in many countries, but concerns have been raised about the ability to meet treatment needs in areas where there is a high prevalence of human immunodeficiency virus (HIV) infection/acquired immunodeficiency syndrome (AIDS) and where there are severe deficits in human-resource capacity. Many health care workers in resource-poor areas are experiencing burnout, struggling with external and internal stigma, failing to access HIV testing and treatment early, and subsequently becoming sick and dying of AIDS. Although the human-resource deficit is a well-recognized problem, little has been written about the programs that have been established to provide treatment for HIV-infected health care workers. In the present article, we describe staff care programs at McCord Hospital in Durban, South Africa; Mseleni Hospital in northern KwaZulu-Natal, South Africa; and the Tshedisa Institute in Gaborone, Botswana. These programs provide convenient, confidential, and holistic care for HIV-infected health care workers and health care workers affected by caring for HIV-infected patients. All 3 programs have noted that, among health care workers, there is increasing acceptance of counseling, testing, and treatment. We propose that there is an urgent need for the development of HIV/AIDS care and treatment programs for health care workers that remove barriers to access, provide confidentiality in testing, are conveniently located, and are integrated with tuberculosis programs and other treatment services.

The burden of HIV/AIDS in areas where its prevalence is high is enormous, and the impact of HIV/AIDS on society and on health care delivery has been well described [1, 2]. The urgent need for treatment, as well as for prevention, has been recognized [3]. Many countries have begun the daunting task of rolling out antiretroviral therapy (ART) to large portions of their population. To do this, they need not only finances but sufficient human resources. Deficits in human-resource capacity threaten to undermine the scaling up of treatment. Although concern has been raised about the need for more health care workers, a comprehensive human-resource strategy has not been implemented in the countries in southern Africa that are burdened with the highest prevalence of HIV infection. As ART provision is scaled up, the critical question of who will do the job becomes paramount [4].

HEALTH CARE WORKER BURNOUT

The emotional burden of the HIV/AIDS epidemic on the health care workers who must function in struggling health systems where workloads are high and resources are minimal is significant. In hospital wards, a high percentage of patients are young adults and children who are ill and dying of AIDS. There are critical staff and bed shortages, and the tuberculosis (TB) epidemic
is growing. Health care facilities are attempting to provide services to prevent mother-to-child transmission of HIV in areas where it is estimated that the antenatal seroprevalence is ≥40% [5]. The rollout of ART to large numbers of adults and children, along with the necessary counseling, adherence, and monitoring support that must accompany treatment services, has added to the workload. In some countries, the burden of HIV/AIDS is compounded by a lack of support from senior doctors and administrators. Ambiguity and a lack of political leadership from governments are also problems in some areas. The tremendous burden of caring for ill individuals under these circumstances has led to high incidences of compassion fatigue, posttraumatic stress, depression, and burnout [6]. As a result of emotional strain, many health care workers either emigrate to developed nations, where there may be less work-related stress, or leave the profession entirely.

HIV INFECTION IN HEALTH CARE WORKERS

Although burnout is a concern, one of the greatest threats to the capacity of health care systems to deliver treatment for HIV infection in high-prevalence areas may be the illness and death of the HIV-infected health care workers themselves. Dan Ncayiyana of the University of Cape Town (Cape Town, South Africa) commented on this threat by saying, “We are going to run out of people before we run out of money” [7, p. 584]. Although much has been written about the prevention of occupationally acquired HIV infection, it is widely acknowledged that, for the vast majority of health care workers in areas where the prevalence of HIV infection is high, the infection is actually community acquired. Therefore, the prevalence of HIV infection among health care workers should be similar to that in the community in which they live. Even so, there are few recently published surveys documenting the prevalence of HIV infection among health care workers in the developing world.

In the early years of the epidemic, epidemiological studies performed in Zaire found that the prevalence of HIV infection among health care workers increased from 6.4% to 8.6% between 1984 and 1986 [8, 9]. More recently, an anonymous survey involving 595 health care workers across race groups in 4 different provinces in South Africa found an overall HIV infection prevalence of 15.7%, compared with an estimated prevalence of 15.5% among adults in South Africa [10]. In addition, in both Malawi and South Africa, there were reports of an increasing incidence of TB among health care workers throughout the 1990s. The increasing incidence of HIV infection among health care workers was speculated to be the cause of this increase [11, 12]. The most recent HIV prevalence study surveyed a cohort of 77 doctors who graduated from Makerere University in Kampala, Uganda, in 1984. The authors found that, by 2004, 11 doctors had died of AIDS, and 5 of 6 suicides were thought to be related to a known or suspected diagnosis of HIV infection [13].

CARING FOR THE CAREGIVER PROGRAMS

If countries do not implement programs to combat staff burnout and avert deaths due to HIV/AIDS, widespread access to ART will never be achieved. However, because there exist few well-established HIV infection treatment programs geared toward health care workers, the optimal administrative and financial structure of such initiatives is uncertain. An analysis has been published of the financial cost of establishing a comprehensive treatment program for health care workers in South Africa. This study found that the estimated cost would be between R6000 (US $838) and R9000 (US $1256) per person per annum [14]. In addition to having concerns about financial needs, health care workers have articulated concerns about the lack of management guidance to establish treatment programs for health care workers. Nurse managers in South Africa acknowledge that caring for HIV-infected nurses is a critical component of their work, particularly in KwaZulu-Natal, the South African province with the highest rate of HIV infection. Although staff care is important, nurse managers have noted that there are no formal policies regarding the management of HIV/AIDS among staff in the workplace [15]. These concerns echo the urgent need for establishment of a comprehensive plan and program development to support HIV-infected health care workers in countries with a high prevalence of HIV infection. The following overviews provide some insight into successful models of health care worker–oriented HIV infection treatment programs.

McCord Hospital. McCord Hospital is a government-subsidized urban facility located in Durban. Health care for staff is provided free of charge at the staff clinic. In late 2001, after several staff members died of AIDS, the clinic began to provide ART to staff who were in desperate need of treatment. The program was introduced with the full support of management, staff, and unions. HIV care is integrated with other comprehensive services provided at the staff clinic, including acute conditions and chronic conditions, such as TB. The clinic also affords patients confidentiality, because it is separate from the general ART clinic. All HIV-related counseling and blood taking, including HIV testing and CD4 cell count determination, is performed at the staff clinic by the staff doctor. Adherence training is done during the course of consultations, making access to voluntary counseling and testing (VCT) and ART seamless and convenient [16].

McCord Hospital employs ~540 staff, including 170 student nurses who study for 2 years. With an assumed HIV infection prevalence of 20%, it was estimated that one-third, or 35, of the HIV-infected staff members would have CD4 cell counts
of <200 cells/mm³ and would need to be receiving ART at any one time. This number would presumably increase each year. Before institution of the program, few staff (6–11 per year) were accessing VCT. Since the program started in late 2001, increasing numbers of staff have been accessing VCT every year, from 38 in 2002 to 118 in 2005. Since 2002, 45 staff members have started receiving ART, and, currently, 25 staff members, who are still employed at the hospital (including the child of one staff member), are enrolled in the ART program at the staff clinic.

There has been a great improvement in the morale among staff at the hospital, with staff now able to see their colleagues showing clinical improvement instead of dying. A number of staff receiving ART have disclosed their status to friends, colleagues, and patients, to encourage others to undergo testing and start receiving treatment. Nurses and lay counselors have started small group discussions with other staff members about ART, overcoming the stigma of HIV/AIDS, and the need for early testing. The psychology department at the hospital has been involved in holding ongoing debriefing sessions for clinicians working in the medical wards and HIV clinic. In addition, support groups for nurses that address the emotional burden of providing care for dying patients, particularly adolescents and children, have been critical to increasing morale.

Mseleni Hospital. Mseleni Hospital, a government-supported hospital in a remote rural area of KwaZulu-Natal, employs ~450 health care workers. HIV infection prevalences among the staff are not known, but whole-community surveys performed in a neighboring area revealed a prevalence of 17% (V. Fredlund, Mseleni Hospital, unpublished data). With no accurate HIV infection prevalence data for staff at Mseleni Hospital, assumptions were made that if 20% of the staff were HIV infected and approximately one third of these had a CD4 cell count <200 cells/mm³, then ~30 staff would need to be receiving ART at present and the number would increase every year. Health care for staff is provided through the staff clinic. In addition, some staff members choose to obtain medical care through local private practitioners. ART for staff has been available free of charge through the staff clinic since 2005. Counseling and testing of staff are done by a number of people, including a well-respected and trusted lay counselor who has publicly declared that he is HIV positive and is receiving ART. A professional nurse counselor on the staff also assists with VCT. Like the staff clinic at McCord Hospital, the staff clinic at Mseleni Hospital was initiated in response to the overwhelming need to provide care and treatment to caregivers faced with fear and stigma. Currently, 35 staff members are receiving ART. There has also been a growing openness among staff, who are now less afraid to disclose their infection status and share details of their treatment with colleagues. For instance, staff members have elected to use their own names, as opposed to anonymous codes, on blood test reports. However, there are still some staff members, particularly laborers such as groundsmen and maintenance assistants, who are not optimally accessing VCT and ART. Ongoing efforts are focused on increasing awareness, particularly in that group.

Tshedisa Institute. The Tshedisa ("tshedisa" means "to rejuvenate or give life" in Setswana) Institute in Gaborone, Botswana, is an independent, privately funded health care facility specifically designed to meet the emotional, physical, and spiritual needs of health care providers in the city. It was established, in May 2006, by physicians working at the HIV/AIDS clinic at Princess Marina Hospital, a 550-bed facility in Gaborone. The facility was established in response to the growing number of coworkers who were dying of or in need of treatment for HIV infection and who refused to come forward and receive treatment at the existing in-house staff clinics. The program focuses on health care workers who are HIV infected and/or are affected by caring for individuals with HIV infection and who are experiencing stress, compassion fatigue, and burnout. It encourages health care providers to appreciate the importance of looking after their own wholeness and well-being in addition to those of their patients. The Tshedisa Institute offers holistic health services, including one-on-one counseling, support groups, creative arts therapy (e.g., dance, yoga, visual arts, poetry, and creative writing), comprehensive HIV/AIDS testing and treatment, general medical checkups, and a quiet garden for staff to enjoy. Certificate courses in such skills as stress management, cognitive behavioral therapy, and group counseling are also offered for health care workers. The Tshedisa Institute is centrally located in Gaborone and is within walking distance of Princess Marina Hospital. Since the inception of the program, services uptake has been significant, with 204 health care workers presenting for HIV testing. Of those tested, 12% were found to be HIV positive. Seventeen staff members have started receiving ART, and many more are participating in one-on-one counseling or weekly creative art therapy classes.

KEYS TO PROGRAMMATIC SUCCESS

Recognition of the need for a health care worker program was critical to program implementation and success in each of the examples provided above. Each of these institutions acknowledged the unique stress and the barriers to accessing HIV care faced by health care workers. In response, each developed slightly different models of HIV care and treatment for staff. Two programs are in-house programs, whereas the other is an independent program that is located in close proximity to the hospital. All 3 programs are convenient and offer integrated, comprehensive services. Lack of confidentiality is usually seen as a major drawback of in-house programs, but, certainly, the experience at McCord Hospital and Mseleni Hospital has shown that, on the contrary, a well-managed in-
house program has led to positive reinforcement and improved morale, as staff observe clinical improvement in their colleagues and become aware of where to access treatment. The successful treatment of staff in both of these institutions has also contributed to a decrease in stigma and a greater willingness to discuss HIV infection status and treatment. A recent survey of access to HIV care for employees of 64 large, private companies in South Africa showed that in-house disease management programs achieved higher uptake of services for their employees than did private medical insurance and externally managed programs [17].

Critical to programmatic success is the involvement of well-respected and trusted staff members as counselors, clinicians, and advocates of the program. This is essential to encouraging staff to utilize the program and is a positive force to combat fear and stigma. Finally, each program provides holistic, comprehensive care. The Tshedisa Institute, in particular, is tackling burnout among health care workers by use of counseling services and creative arts classes. In addition, incorporating HIV services for health care workers into comprehensive health care services instead of within specialized ART clinics normalizes this disease and reduces stigma. All 3 programs have demonstrated that health care workers will access HIV testing, care, and treatment if it is offered in a manner that addresses the unique barriers that they face.

**CHALLENGES TO IMPLEMENTATION**

There are several challenges to providing HIV care for health care workers in areas with a high prevalence of HIV infection. More information on the prevalence of HIV infection and the incidence of TB among health care workers in countries with the highest burden of HIV infection needs to be obtained so that the problem can be met with an appropriate response and so that the efficacy of programs, once established, can be measured. Very little is known about morbidity, absenteeism, and mortality rates among health care workers in these areas. Even less has been published about successful programs to help health care workers access HIV care.

As the TB epidemic grows in the community in countries with a high prevalence of HIV infection, so does the incidence of TB among health care workers. In McCord Hospital, the incidence of TB among staff for the years 2003–2006 was ~2600 cases/100,000 staff/year (K.E.U., unpublished data), which is 2–3 times the incidence noted in the local population of ~1000 cases/100,000 staff/year [18]. Of the 45 staff members who started receiving ART through the staff HIV program, 20 required TB treatment as well. This is a substantial clinical challenge. There are diagnostic difficulties associated with many cases of smear-negative and extrapulmonary TB, as well as potential drug interactions between TB drugs and ART drugs. In addition, the treatment of TB in immunocompromised patients may need to be prolonged and individualized. In South Africa, the TB program is run by a separate health department with separate clinics, and coordination of treatment for TB and HIV infection can be difficult. In addition, there is much that needs to be done in the area of infection control to protect health care workers from contracting TB from their patients.

Lastly, health care workers are not immune to the stigma surrounding HIV/AIDS. Raviola et al. [6] describe a sobering picture of the tremendous burden carried by resident doctors in Kenyan hospitals, as well as the silence, fear, and hopelessness surrounding a diagnosis of HIV infection in their patients or themselves. Mortality data for a cohort of Ugandan doctors showed that, of 22 doctors who died, 11 died of AIDS, and 5 committed suicide because of a known or suspected HIV diagnosis [12]. The external stigma is obvious; there is a risk of gossip, discrimination, and hostility from others if health care workers are known to be HIV infected. The internal stigma is not so obvious and is much more difficult to address. In a lecture in Durban in May 2006, Edwin Cameron ascribed the death of a legal colleague from AIDS as being due to a “paralysing dread of confronting HIV that was located not in others but within himself” [19]. He further described this internal stigma as “fear, self-disablement, and feelings of contamination, self rejection and self loathing” [19]. This internal stigma results in “paralysed inaction, postponement, delay, denial and death” [19]. The effects of this internal stigma, when added to the burnout experienced by many health care workers, contribute to enormous barriers for health care workers accessing HIV care. The fear of disclosure to colleagues within the small community atmosphere of a hospital, if confidentiality is not protected, can make the barriers seem insurmountable.

**RECOMMENDATIONS**

Health departments and individual health institutions need to gather up-to-date information on HIV/AIDS prevalence, morbidity, and mortality among their own staff through anonymous surveys. This gathering of information needs to be integrated with programs that offer VCT to all staff in an environment that is confidential and supportive of access to treatment. Possible opportunities to increase testing would be to offer VCT within the hepatitis B virus vaccination program or during an annual physical examination. Clear information needs to be given to staff to reinforce that testing is in no way associated with further employment prospects and that results are not known to management. Senior management needs to be proactive and openly supportive of early testing.

TB prevention strategies for health care workers need to include infection control measures, such as ventilation, UV lights, the use of N-95 masks in any departments managing patients with TB [20], and routine provision of TB prophylaxis to HIV-positive health care workers [21]. Furthermore, the
treatment of TB among staff needs to be handled by the same clinic that provides HIV testing and treatment, so that treatment decisions are coordinated.

Programs to provide HIV care and treatment for health care workers are an urgent necessity. The provision of medical insurance and reliance on individuals accessing care in the private sector are not enough. Programs should be located in house or close to the place of work so that the service is recognized and easily accessible. Counseling services must be offered to help prevent burnout. Edwin Cameron’s plea was for us to normalize this disease and to remove the barriers to testing and treatment [18]. Insistence on formal pretest counseling with a counselor is a barrier. Any health care provider should be prepared to provide counseling and testing for HIV infection. The referral of staff to other institutions for HIV care because of confidentiality creates barriers, and every effort should be made to provide convenient alternatives. The fracturing of health care provision between different providers (e.g., staff clinic, HIV counselor, TB clinic, and general ART clinic) also creates barriers for health care workers. Care and treatment for health care workers should be convenient, holistic, and integrated into one clinic. Finally, the provision of HIV care and treatment for health care workers must become a public health priority, or universal access to ART in high-prevalence countries will remain an unmet goal.

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References