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Comparative Perspectives on Living With HIV/AIDS in Late Life

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Abstract

The effects of HIV/AIDS on different societies spanning the globe are only beginning to be described. This article describes HIV/AIDS's emerging impact and consequences for families and societies around the globe, with a primary focus on middle-aged and older members. It first provides the current data on the evolving international profile of the HIV/AIDS epidemic. Then, using primary sources and published data, it explores three contrasting nation/state settings (Uganda, Thailand, and India) to describe the cultural, social structural, and family consequences of HIV/AIDS. Findings include identification of emerging and potential strains on core cultural practices related to social integration at the community and family levels, as well as shifts in normative role relationships between multiple generations. Direct and indirect challenges to core moral and ethical issues beyond those simply related to infectious disease prevention and treatment are also identified. Finally, this article draws on these explorations to formulate several key priorities for future research and practice related to HIV/AIDS among older adults.

The fact that HIV/AIDS has had a global impact is seldom questioned, yet we are only beginning to explore and learn how it is reshaping the structure of different societies and the later life experiences of peoples around the world. Important insights into the experiences of living with HIV/AIDS can be gained from a global perspective. Cross-national research enables us to appreciate better the particular forms and manifestations that we take for granted in the United States but that are just one among several possible from the perspective of the global laboratory of human social organization.

We currently face a fundamental scientific and public health need to sharpen our definition of the basic issues and analytic constructs used to define the relevant questions and salient units to measure. The importance of these contributions cannot be overstated. A cross-cultural perspective, although limited in this case by the need to generalize from state-level data, helps to identify the most appropriate analytic units; that is, it suggests what to measure and sample for as a corrective to past questions that were circumscribed by concerns with how many and how often to measure using known factors. We need new concepts as well as

new data that will provide insights into the limits of our existing data sets and assist in their reanalysis. It is time to remap the scope of what we regard as the relevant factors and issues that define the universe of living with HIV/AIDS at the individual and societal levels. We will suggest such a reformulation through focusing on the impact of HIV/AIDS on the elderly, a perspective rarely assumed in writing and research on the epidemic, and by using this perspective to consider the epidemic in three cultural settings: Uganda, Thailand, and India.

The HIV/AIDS epidemic has had a major impact on health in the United States, but the greatest impact has been felt internationally. As of January 1, 1996, 9,223,000 individuals had died of HIV/AIDS, 7,610,000 of whom lived in Sub-Saharan Africa (Mann and Tarantola 1997). As of this same date, there were 10,375,000 infected individuals (Mann and Tarantola 1997). Although 90% of HIV/AIDS deaths occur in people younger than age 49 (UNAIDS 1997), the immediate familial and long-term systemic impact on the elderly is considerable.

One of the more significant implications for our purposes is the likelihood that in countries with high prevalence rates, for at least a time (projections suggest the year 2020), life expectancy will be significantly reduced. Already in Uganda, the expected age at death has fallen by 20 years (Piot 1997) to 39.9 for men and 40.6 for women, suggesting the possibility that for these hard-hit countries, there will be a greatly reduced elderly population due to high death rates among the middle aged, the future elderly. This is directly attributable to the deaths caused by HIV/AIDS. Furthermore, the epidemic is already altering the population profile because women of reproductive age are dying, thereby removing their potential fertility from the population (Mann, Tarantola, and Netter 1992) and because women are voluntarily limiting their fertility in countries such as Botswana (Tlou 1995).

To review the impact of the epidemic on the elderly, we have selected three countries with instructive similarities and differences that represent three different experiences with HIV/AIDS. Comparative data are drawn from the following:

1. Uganda, which has one of the highest HIV/AIDS prevalence rates in Sub-Saharan Africa and therefore in the world (as of 1995, there were l.9 million people with HIV/AIDS or 9% of the population [Savin 1997], but because of undercounting, some sources estimate the number may be considerably higher [National AIDS Documentation and Information Centre Publication (NADICP) 1996]);
2. Thailand, whose seroprevalence rate is currently the highest in Asia, with 2% of the adult population infected; and
3. India, which is still in an early stage of the epidemic but whose absolute numbers of infected are the greatest in the world (although less than 1% of the population [Piot 1997]) and is expected to experience the most extensive impact of the epidemic in the world.

In each of these three countries, the epidemic has taken different forms, depending on sexual practices and beliefs about sexual pollution, general health practices, and the broader

geopolitical and socioeconomic contexts that structure the spread of the disease. Its impact on families and communities is experienced differently depending on local kinship organization, residence patterns, traditions for child rearing, care of the elderly, and mortuary rituals.

These three countries share or will share a long-term systemic impact of the removal of a society's most productive members: the middle aged. Unlike most epidemics or natural disasters that kill the weakest members of a population, the youngest and oldest, HIV/AIDS primarily attacks the strongest, the central actors in the cultural, social, and economic life of a society. To the extent possible, given current data sources, we will examine the long-range impact of the epidemic on the various societies in question and the implications this has for the elderly in the future.

All the countries under discussion have mobilized public health programs aimed at prevention of and education about HIV/AIDS, with varying degrees of success. We will look beyond the early questions concerning prevention to understand the impact of the epidemic on the basic cultures of people living with HIV/AIDS.

Method

There are many difficulties in defining what is considered to be old age in traditional cultures, particularly those facing pandemics such as tuberculosis (TB) or HIV/AIDS. For the purposes of this article, the elderly will be defined using local definitions. Typically, this references life-cycle stage as in India, where adults are categorized as elders when their oldest son marries, which, given the early age at marriage, could mean one is old in the early 40s. When no such clear-cut cultural label comparable to the Western status of elder is available, as in Uganda, we will use the age of 50, which, given the shorter length of life in many non-Western countries, is taken as an appropriate approximation of the life stage that in industrialized countries is associated with age 65. Whenever possible, it will be important to use categories that correspond more closely to socially defined status rather than to simple chronology. The United States marker of 65 for old age was established in the policy debate that proceeded the enactment of Social Security. It had its roots in the pension systems of Europe and has far less social relevance to the countries under consideration.

In this discussion, we refer to entire nations rather than to the several possible cultures embraced within each one. It must be recognized that most countries embrace numerous cultural groups, ethnic traditions, and language groups. For example, India alone has more than 500 language groups. These factors structure group and individual experiences of the disease. Discussion of a country as a whole inevitably requires generalizations.

In the countries reviewed below, we will consider first the risk of HIV/AIDS infection for older people, and ask, "What is the risk of older people contracting HIV?" Then we will explore the likely experience of living out old age with a highly stigmatized disease and ask the question, "What are the experiences and societal impact of the diffusion of HIV across the entire life span?" Attention then shifts to the intergenerational impact of the epidemic in terms of the responsibilities the elderly assume for providing care for the dying, for fostering

orphans left by the epidemic, and for attending to their own needs in the absence of adult caregiving children. Here we ask, "How are traditional forms of caregiving and fosterage responding to and interpreting the challenge created by HIV/AIDS?" We conclude each section by asking, "What is the impact of HIV/AIDS on the processes of community reintegration following the death of a member?"

Because of the lack of published materials on this topic, we used a variety of data sources. The data sources for these discussions include searches of the available published literature, interviews with experts in the field, epidemiological data posted on the Web, interviews with local practitioners in the countries under consideration, and communication with representatives of international agencies such as the World Bank, the Centers for Disease Control and Prevention, the U.S. Agency for International Development, and the World Health Organization (WHO). Because the epidemic is at different stages in the countries under review, the data sources on which the case studies are based are not always comparable. The first and second authors drew from their ongoing study of African Americans and HIV/AIDS to formulate the questions guiding this study.

Approaches to Cross-Cultural Comparison in HIV/AIDS

Although there are similarities across the three cases, it should be noted that from a comparative perspective, each cultural system represents some unique and distinct dimensions. Such cultural specificity limits our ability to conduct strictly structured comparisons between the cultures. Despite the challenges posed by these limits, cross-cultural comparisons can provide valuable insights into identifying the impact of contextual variables on behavior and assessing the relative impact of different variables in explaining the experience of people who are HIV+ and the impact of the disease on the family and social group. Spira and colleagues (1998), writing in an editorial for the *American Journal of Public Health*, argue that cross-cultural comparisons can improve public health policies by relating the study of behavior to the sociocultural and political context, thus "denaturalizing" behavior and challenging the cultural categories typically used in epidemiological research.

UGANDA

Uganda, with one of the world's most advanced HIV/AIDS epidemics, demonstrates the potential systemic impact of a wide-scale epidemic on a whole society. These systemic impacts will change the role the elderly play in Ugandan society and their experience of old age and redefine the nature of old age for some time to come.

Elderly at Risk/or HIV Infection—In contrast to many South Asian countries such as India, Uganda has no specific beliefs proscribing sexuality among the elderly. To the contrary, in this area there is the belief that sex with a younger person will rejuvenate an elder (Tlou 1995). This belief and the behavior associated with it may contribute to putting the elderly at risk because the incidence among young adults is much higher than among the elderly.

To date, older people have not been the target of prevention campaigns (Rwabuhemba, personal communication, 1998). However, a promising pattern has been identified for the late middle aged men, those between ages 40 to 49. Between 1989 and 1995, condom use increased 50% in this age group (Kagimu and Marum 1996).

Experience and Societal Impact of HIV/AIDS—Ugandan elderly do not appear to be subject to increased AIDS stigma due to their age in part because of the extensive public education campaign aimed at reducing the stigma. Nevertheless, elderly who die from AIDS most likely will not experience the Ugandan version of the "good death." This is characterized by considerable dignity—often impossible with the diarrhea and/or dementia that can accompany AIDS—and the presence of family and friends whose attendance on the dying person may be diminished because of the still extant stigma.

Although HIV/AIDS mortality and morbidity are centered on young adults and the middle aged, by attacking this key group, the disease disrupts relationships both within and between other generations. When their adult children die, the parents are left with the responsibility of raising their grandchildren and assuming their children's other social and ritual duties. The elderly face additional responsibilities with fewer material and cultural resources in the household and the greater society to meet the crisis. The impact of these disruptions of traditional relationships on individual households depends on both the stage in the family cycle at which the disruptions occur as well as the socioeconomic resources to which a household has access (Barnett and Blaikie 1992). For example, a rural family with young children and two sick parents with no relatives who contribute to the household's well-being will experience considerably more HIV/AIDS-related deprivation than one with older children who can contribute to the family's subsistence needs, or a family with a relative who receives a steady salary and sends regular cash contributions.

The impact on individual households and families and their elderly will vary depending on where the afflicted household is in its developmental cycle and on what resources are available. The impact on the elderly will also vary depending on the gender of the afflicted person, with the sickness and death of daughters having a greater impact on grandparents—particularly grandmothers, who will assume most of the caregiving responsibilities for their daughter's children. In the case of a son's death, his wife will assume primary responsibility for the children, seeking supplemental support from grandparents if it is available.

Response of Traditional Forms of Caregiving and Fosterge to HIV—The extent of the HIV epidemic and the impact it has had on the middle aged have disrupted the family system of caregiving and fosterage. Traditionally, care for the sick has been shared among the wider and dispersed family. The sick person may be cared for by different relatives at different times, moving from one to another (McGrath et al. 1994). Ties between urban and rural relatives remain strong, and it is to rural areas that many people with HIV/AIDS retreat for care and anonymity (WHO 1994). This is the pattern despite the fact that the northern and eastern regions, where most of the HIV cases are concentrated, are also the poorest areas of the country (NADICP 1996). The burden of this care remains considerable, unfortunately; in rural areas, nongovernment organizations (NGO) that have sponsored home and hospice

care programs designed to support family caregivers of persons with HIV (PWH) have been the least effective (NADICP 1996).

For at least two reasons, the dispersed family faces challenges. The dispersed family organizations typically function to match different types of resources to different kinds of needs and have encountered serious obstacles in their ability to meet the challenge of HIV/AIDS. Because the wasting and weakness associated with HIV/AIDS make travel difficult, sick individuals are unable to move among various family caregivers, hence disrupting the sharing of burden. In addition, HIV has reduced the number of kin caregivers available due to HIV-related losses, further attenuating the support available.

The National AIDS Documentation and Information Center (NADIC) of Uganda estimates that by the year 2002, Uganda will have 2,034,000 orphans younger than age 15 (NADICP 1996). Grandparents assume the care for HIV/AIDS orphans at the death of both parents or at the death of the mother, but in the latter case, the father typically remains involved in the care. In discussing the challenges posed by care for orphaned grandchildren in Uganda, Savin (1997) illustrates the problem by describing the case of Nelson and Nabokza Kobogoza as not uncommon. They have cared for 18 of their grandchildren, all of whom have been orphaned by HIV/AIDS. They are caring for 12 now, and Naboloza fears she will soon have more children to care for. Her remaining son-in-law recently died from AIDS and she knows her daughter “will probably feel sick soon” (Savin 1997:12).

Caring for orphaned grandchildren represents a significant strain (Prebble 1994; Ankrah 1994). Grandparents must provide subsistence for the children, schooling fees, and supervision. In many cases, the elderly assuming these responsibilities are challenged even to care for themselves, especially after losing the contributions of their adult child, the orphans’ parent.

For Ugandan grandparents to assume the role of parent presents a role conflict. As in most cultures, the traditional role of grandparent is one of indulgence and affection. They may not be suited to provide a disciplined environment for the children, especially those attending school, the demands of which may be foreign to their grandparents (Prebble 1994). An illustration of grandparents’ difficulty in coping with these responsibilities is that fact that orphans in grandparent-headed households represent the greatest percentage of children asked to leave school for discipline problems (Prebble 1994).

Grandparent care is not a unique response to the HIV/AIDS epidemic. Children are frequently sent to live with different relatives for varying periods of time. This pattern, however, assumes the parents’ continued participation in both the supervision of the children and their material support. The removal of both parents by death is a new crisis with which the extended family is trying to cope. Other family members, also hard-hit by the epidemic, may have few resources to share with grandparents, who often assume foster care for several children at the same time. However, the extended family system of care is responding to this unprecedented challenge, and as of 1994, less than 1% of all orphans were in orphanages (WHO 1994).

Community Integration and HIV/AIDS Mortality—With the removal of so many young and middle-aged adults from the population, the elderly find themselves in the position of having to reassume many social and ritual duties they had relinquished (Ankrah 1994). This includes exercising family and extended kinship group leadership and accepting various responsibilities in the local community.

The impact of the removal of the middle-aged person from the workforce and the change this creates in the producer/consumer ratio have a long-term impact on the quality of life for household members (Barnett and Blaikie 1992). Mosi: HIV/AIDS deaths have been in the nonagricultural sector.[1] These deaths affect agricultural households by reducing the amount of remittances sent by laboring relatives. Household members are forced to plant cash crops for currency, hence reducing the nutritional content of home gardens (Kagimu and Marum 1996). When the disease strikes agricultural workers, the reduction in the number of household producers leads to less diversity in agricultural crops, inattention to garden maintenance, and loss of cash crops while potentially increasing the number of consumers through the addition of sick adults and orphans to households (Barnett and Blaikie 1992). As households reorganize their resources to meet these increased demands, reallocation may take place in such ways as pulling children out of school to work in gardens and to save money on school fees. Loss of educated youth will have a long-term impact on both quality of life and economic productivity of society as a whole (Mann, Tarantola, and Netter 1992).

Another unrecognized social impact of HIV that is highlighted by comparative research is in the area of community funerals and mourning periods. Funerals have changed significantly since the start of the epidemic. Funerals are universally important since they serve to mobilize community support for the bereaved and facilitate repair to the sense of social disruption to the fabric of community life. Traditional funerals lasted seven days. Family, neighbors, and friends participated, typically losing several days of work. The cost to the family was significant. Current reports indicate that funerals last only one and a half to three days (Ankrah 1994; Barnett and Blaikie 1992). Those close to the grieving restrict their participation to support during the vigil the night before the burial. Such a shortening of funerals, a key cultural medium for coming to terms with grief, can have serious negative consequences in the ability of mourners to adapt and come to terms with their loss (Geertz 1973).

THAILAND

Elderly at Risk for HIV Infection—The experience of the elderly in the HIV/AIDS epidemic to date has primarily been as caregivers to adult children. This is largely a result of the relatively recent nature of the epidemic in this country. In 1997, the government reported a cumulative total of 55,443 cases; 84% of these had been reported between 1994 and 1996 (Ministry of Health [MOPH] 1997). A majority of these cases, 81%, are believed to be heterosexual transmission cases. As of 1997, the Thai government reported that only 5% of the total HIV/AIDS cases were among people age 50 and older. Of these, 89% were male (MOPH 1997).

[1]A study of the Rakai District, an HIV/AIDS sentinel district, reported that two-thirds of the deaths were among nonagricultural workers (Kagimu and Marum 1996).

Experience and Societal Impact of HIV/AIDS—Elderly who become infected are likely to experience a multiply devalued status. They are stigmatized for having HIV/AIDS. They are also demeaned for showing that they are sexually active and thus perceived as acting against culturally normative behavior associated with the status of elder. Buddhist influences on Thai culture lead HIV/AIDS to be constructed as the result of having acted immorally or improperly in the past or in past lives. HIV/AIDS is believed to be caused by bad karma, as well as by promiscuity and associating with things unclean (i.e., women's pollution) (Songwathana and Manderson 1997). Buddhism teaches that the individual is responsible for his or her fate; thus, acquiring HIV/AIDS is seen as the individual's responsibility. The negative acts that are thought to constitute a sufficient basis for HIV/AIDS retribution are not limited to this life. Due to the belief in rebirth, these acts may have occurred in a previous life and not have been atoned for. Characterizing the assignment of responsibility and blame is the Thai proverb "do good, receive good; do evil, receive evil." As one elderly caregiver (reported in Songwathana 1972:2) noted,

> My son was suffering from this disease because of his karma. I was always compassionate and sympathetic with his suffering because he was really ugly; he had dirty skin lesions. I knew he was going to die soon…. I felt that this is not only his karma, but also my *wan* (suffering). I have had little opportunity to make merit in my life; this may be because I did bad things too. (Pin, 59-year-old mother)

Elderly who acquire this highly stigmatized disease are more likely to be blamed for their own disease as opposed to attributing the causal actions to a former life. They are seen as having lived longer and had more opportunity to do good or evil than younger people who become sick. Elderly afflicted with HIV/AIDS engender social disgust. This disgust toward elderly with HIV/AIDS also makes it more stressful for the family to care for them (Songwathana 1997).

Response of Traditional Forms of Caregiving and Fosterage to HIV—The family is the main source of care for people who have HIV/AIDS. Mothers and wives are the most common family caregivers.[2] Because of the negative moral sanction associated with HIV/AIDS infection and the strong belief in its contagious nature, assuming care for someone with HIV/AIDS is often a difficult undertaking fraught with ambivalence.

> I am his *mae* (mother). Others can refuse care, but I cannot. Even though he was to blame as a bad person, he is still my son. Whatever he did in the past was part of my suffering too. If I reject him I would be *khon hap* (bad person) and also be blamed by others. So I want to do my best to give him happiness in the last period of his life, although I have little assistance. He would have no one to care for him if I didn't. (Pin, 59-year-old mother) (Songwathana 1997:6)

Caregiving for an adult child with a stigmatized disease can be difficult for older mothers. They report financial strain, lack of adequate education to provide the care, and the need for

[2]Older sisters, especially the eldest, will assume the care for a sibling with HIV/AIDS. The sibling set in Thai society is organized hierarchically. Siblings are referred to by their gender and birth order (e.g., first eldest sister, second eldest sister, third youngest sister). This structure carries with it rights and obligations. In cases of need, even in adulthood, siblings will call on these relations for help—for example, nursing a sibling with HIV/AIDS if the mother is unable to provide care (Songwathana n.d.).

formal and informal support in their assumption of caregiving and foster care responsibilities (Kaewkantha and Langkarpint 1996). Songwathana (1997) found considerable concern about HIV/AIDS transmission among caregivers. The high rate of illiteracy among older women may contribute to their fear of contagion. This fear, in some cases, led to somatizing, with the caregivers expressing HIV/AIDS symptomatology. In an in-depth interview study by Songwathana (1998) ($N = 13$) of older caregivers, 2 of the caregivers, both women, reported experiencing HIV/AIDS symptoms. The caregivers believed they had acquired the disease from their sick children and that they, the caregiver, would soon die from it. There was no reason for the interviewer to believe that these women had actually been exposed to HIV/AIDS. Instead, they appear to be unclear concerning HIV/AIDS transmission but also plagued by the belief that the bad fortune that led to their child acquiring the disease probably extended to the mothers having HIV/AIDS also. This fear can be seen in the following quotes. One mother commented,

> Although everyone fears contagion, I am not afraid. If I am infected by him, it doesn't matter because I am old. I always think that if it [HIV/AIDS] happens to me, I have no choice; that is my karma and suffering. (Chim, 58-year-old mother) (Songwathana 1997:6)

Another mother could not overcome her fear of contagion:

> I feel that I have lost control of my life since I began taking care of him [her son]. I feel guilty that he wanted me to give him a hug, but I didn't until he died. (Pin, 59-year-old mother) (Songwathana 1997:4)

But caregiving is not simply experienced as burdensome or frightening. As we know from research in gerontology in the United States (see Abel 1991; Sankar 1991), caregiving is a complex undertaking involving many different feelings and meanings. Thai caregivers are no less complex in their approach to the work. Along with feelings of strain and fear of contagion, they express the belief that this experience will allow them to fulfill the culturally valued task of release of *dukkha* (attachment) and hence to build merit. Dukkha is a Buddhist concept referring to the strong attachments and desires that are believed to be at the root of worldly suffering. Women are thought to have fewer opportunities to release dukkha because, unlike men who can become monks, they tend to remain in the world tending to the needs of others. This type of caregiving is viewed as so onerous and painful, however, that people who undertake it are believed to improve their karma and thus release their dukkha.

With the growth of urbanization in Thailand, rural grandparents have assumed considerable child-rearing responsibilities as parents migrate to cities in search of work. These responsibilities have been offset by the remittances sent home by working parents. However, as the HIV/AIDS epidemic spreads, the parents are dying, leaving grandparents with sole responsibility for the orphans and no additional financial support (*Global AIDS Report* 1996). According to Songwathana (1998), parents who are dying of AIDS and grandparents make decisions about foster care for the children together. Concern over the impact of the HIV/AIDS stigma that is associated with all household members leads parents to choose as a foster parent the relative with the most HIV/AIDS experience, as well as adequate material

resources and proximity to the orphans. Thus, paternal as well as maternal grandparents may be selected as foster parents. Grandparents who do assume care typically receive material support from living adult children (Songwathana 1998).

In situations where there is no relative or suitable adult who is familiar with and therefore unafraid of HIV/AIDS, children may be abandoned. In response to the problem of abandoned children, government and nongovernment orphanages have been established in the north where the epidemic is widespread. A government-supported foster care program is also in place, but it reports difficulty in finding families to care for HIV/AIDS orphans (Songwathana 1998).

A Thai Department of Public Health Administration study (N = 116 rural households with a recent HIV/AIDS death, 100 households in the same area with a recent non-HIV/AIDS death, and 108 local households with no record of a recent death) on the economic impact of HIV/AIDS on the elderly found a significant impact (Kongsin 1995). In almost half of the households, the PWH had provided significant care and support for an elder family member. In 41% of these cases, other extended family members were able to assume care for the elder, but 57% were left to care for themselves, and 2% ended up in orphanages or temples (Kongsin 1995).

Community Integration and HIV/AIDS Mortality—The epidemic is having an immediate impact on household economy and potential implications for the larger sphere of social production and reproduction. In trying to assess the financial impact of the HIV/AIDS epidemic, Kongsin (1995) compared households with an HIV/AIDS death, households with a non-HIV/AIDS death, and households with no recent deaths in rural areas. He found that HIV/AIDS deaths have a disproportionate impact on the households where they occur. The average yearly income for such a household was 66% of those experiencing death from other causes and 53% of those with no death. The costs of caring for an HIV/AIDS patient at home were 10% higher than the costs of caring for a non-HIV/AIDS patient. The impact of these deaths extends beyond the immediate household. Because 30 is the average age at death from HIV/AIDS, as compared to 40 years old for non-HIV/AIDS deaths, HIV/AIDS deaths mean the loss of 30 years of adult productive labor to the general population. For non-HIV/AIDS deaths, the loss is on average 20 years. Finally, the losses are likely to be long term because children are being removed from school, and hence the training needed to enhance their earning ability to help families cope with the economic losses caused by the deaths is stopped (Kongsin 1995).

Mortuary rituals have been significantly disrupted because of the stigma associated with HIV/AIDS (Songwathana 1998). In many cases, the kin and social network refuse to participate in the standard two- to three-day funeral. Although this lowers the cost of the funeral by about 22% compared to non-HIV/AIDS funerals, which last longer and have more people in attendance (Kongsin 1995), the social reintegration function of the mortuary ritual is also diminished by this change. The long-term consequences of this have yet to be determined.

INDIA

The HIV/AIDS epidemic in India has quickly become the world's largest. It is estimated that India will have more than 5 million infected people by the year 2000 (Bollinger, Tripathy, and Quinn 1995). Although prevalence is very difficult to determine due to unreliable data (Mane 1997), surveillance data from sentinel populations such as commercial sex workers (CSWs) show an alarmingly rapid increase[3] and, as of late 1997, stand at 50% (Gangakhedkar et al. 1997). Public health efforts to prevent the spread of the epidemic remain at an early stage and have had a minimal impact. Financial resources are limited for these efforts (Mane 1997). The public education system has few resources to devote to the effort, and the media continue to stigmatize those with the disease (Mane 1997). The fact that the epidemic has primarily affected the lower classes and the poorly educated, who represent little social investment, may have contributed to the slow response to the disease.

To date, heterosexual sex is the main mode of transmission, and with the existence of high-risk sexual practices such as male-to-male sex denied,[4] the epidemic is likely to continue its rapid spread.[5] Given that most men who engage in male-to-male sex are also married (Khan 1993), bisexual transmission may play a significant role in the epidemic.

Elderly at Risk for HIV Infection—As of 1998, it does not appear that many people age 50 and older have contracted HIV/AIDS (only 1.9% of the total, according to some figures) (Bharat 1994). Certain factors suggest that the elderly may be at low risk. Cultural factors may play a role in protecting the elderly from HIV/AIDS transmission. Hindu society in India has a clearly articulated and widely shared sense of the cultural life course. Life is made up of distinct developmental stages, each with its own appropriate code of conduct, immediate and long-term goals, and suitable rewards (Vatuk 1990). The "elderly" are those whose eldest son has married and brought home his wife to live in the parental home. The arrival of the daughter-in-law signals that the parents are to begin their withdrawal from a

[3]The seroprevalence rate of HIV/AIDS among commercial sex workers (CSWs) in Bombay, Pune, Madras, and Vellore, where the epidemic is most prevalent, increased from 1% to 3% in 1987-1988 to 25% to 40% in 1992 (Bollinger, Tripathy, and Quinn 1995). Despite the fact that prostitution is illegal, there are at least 50,000 CSWs in Bombay alone. The seroprevalence rate in patients at sexually transmitted disease clinics has increased from .3% in 1988 to 10% to 14% in 1992 (Bollinger, Tripathy, and Quinn 1995). As in Africa, the disease is mainly transmitted heterosexually. It is likely, however, that male-to-male sex accounts for a greater proportion of the transmissions than acknowledged. Because homosexuality is illegal, surveillance figures concerning male-to-male transmissions are unreliable (Bartlett 1995), but it is thought to be higher than officially reported (Rodrigues et al. 1995).

[4]Reliable data on male-to-male sex are extremely sparse. One study (N = 1,200) (Khan 1993) of men in India and men of Indian descent in London drew its respondents from readers of a male sexuality newsletter and respondents to a hotline on the same issue. This study reports on patterns of sexuality that have implications for HIV/AIDS spread to the elderly. Most of the respondents in the study were married and continued to have sex with their wives, who did not know of their male-male sexual encounters. Only 2 in the sample had told their wives of their practices. All continued to engage in male-to-male sex after marriage but preferred to have multiple partners to ensure that no emotional bonds would develop that could destabilize the marriage. Men older than age 60 report, on average, eight different male sexual partners per year. Men in this age group and those ages 45 to 60 report the lowest level of knowledge about HIV/AIDS transmission or about safe-sex practices. Furthermore, 60% of the men report having sex with members of their extended family and having male-to-male sexual encounters in the home. This suggests the possibility of multiple HIV/AIDS infections within the same family, reducing the family's ability to cope with HIV/AIDS caregiving and to sustain its responsibility to care for the elderly parents. The reliability of this study is unclear.

[5]India has a transsexual subpopulation known as *hijra* and *ali*, who are involved in the commercial sex trade. They only constitute a small proportion of the CSWs in cities, but in rural areas and small towns, they are often the only available CSWs (Asthana and Oostvogels 1996). Studies done in rural areas suggest that bisexuality is more common than officially recognized (Bollinger, Tripathy, and Quinn 1995). Thus, male-to-male sexual contact may be a significant but unacknowledged mode of transmission.

HIV/AIDS is also spread through injection drug use and through transfusions. The injection drug transmission is mostly restricted to Manipur in the northeast, near the source of heroin in Mynmar. Transfusion poses a serious threat because the blood supply is not routinely screened for HIV despite the availability of the means to do so (Bollinger, Tripathy, and Quinn 1995). A study in Bombay found that 86% of commercial blood donors screened for HIV were infected (Bollinger, Tripathy, and Quinn 1995).

life that includes sensuous pleasure and that is focused on concerns of this world and to begin preparing themselves for the spiritual journey that is involved in old age and ultimately death. A central part of this process is the culturally prescribed end of the spousal sexual relationship. Sex between older people is strongly frowned upon and thought disgusting; it is also difficult to achieve because the son and his bride take the parents' bedroom upon their marriage, with the parents moving to the common room to sleep (Vatuk 1985). Older women and men are supposed to dress simply and modestly, never fashionably, or they will be ridiculed as still interested in sex. Renouncing sex and any sensuous pleasure is seen as a key part of successful late-life development. Data gathered by Khan (1993) suggest that men who engage in male-to-male sex remain sexually active well into late life. The majority of these men are married, and it is not clear whether the prohibition against marital sex will limit transmission to older women. The fact that 13.6% of married monogamous women visiting a sexually transmitted disease clinic were found to be HIV+ (Gangakhedkar et al. 1997) underlies the possible risk to older women.

Experience and Societal Impact of HIV—Elderly who do contract HIV/AIDS can be expected to share in the widespread stigma associated with it. There is little effective public education to counteract the HIV/AIDS stigma. Sobering studies of HIV/AIDS knowledge and attitudes cited in Bollinger, Tripathy, and Quinn (1995) of college (Hiramani 1992) and medical students (Vasundhra 1993) demonstrate a low level of knowledge of the disease; for example, only 33% of college students know how to prevent HIV/AIDS, 40% of physicians did not know HIV caused AIDS, and 25% of them thought it could be transmitted by casual contact. In a more recent study, Poddar, Poddar, and Mandel (1996) found that 59% (n = 206) of respondent residents of a Calcutta slum knew of HIV/AIDS but only .5% to 11% (.5 =full knowledge, 11 =partial knowledge) knew how to prevent it. They conclude that no serious attempts at educating groups at high risk have been made. The stigma is so extreme that there is reportedly widespread abuse by low-level health workers who blackmail people who test positive concerning their diagnosis (Baria 1997).

The elderly who do become infected are likely to experience the rejection and disgust associated with the infection. The disgust may be more intense because it is associated with "promiscuous" sex, at a time in life when the individual, according to the culturally prescribed life course, is supposed to have withdrawn from sexual activity and desire. In the absence of accurate data on sexual practices, it seems safe to speculate that the elderly, as we are discovering is true of elderly in most cultures, are more sexually active than previously thought, which appears to be confirmed by Khan's (1993) data. Given the current hostility, fear, ignorance, and rejection surrounding HIV/AIDS, even among health professionals and the educated (Pais 1996), it is unlikely that cases of transfusion transmission will be treated differently.

Response of Traditional Forms of Caregiving and Fosterage to HIV—Most care for chronic disease as well as the frailty of old age is provided by the family at home. Although there is little published research on caregiving patterns for people with HIV/AIDS in India, anecdotal evidence suggests that it is still so new and relatively dispersed, given the overall size of the population, that care for someone with HIV/AIDS is difficult to provide

given how highly stigmatized the disease is. Because of the stigma, families appear reluctant to provide care and, if they do so, it is provided secretly (Bharat 1995). This is to protect other family members from the shared stigma. The popular press reports many examples of "middle class," "well-educated" families rejecting and financially cutting off family members who have HIV/AIDS and leaving them to die alone and in poverty (e.g., Baria 1997; Baweja and Katiyar 1992; Thapa and Rattanani 1995; Ahuja 1992; Katiyar 1995). This rejection can extend to include the entire nuclear family of the infected individual. Thus, if a husband has HIV/AIDS, he and his wife and children may be forced to leave the extended family because of the social disgrace and fear that the HIV/AIDS stigma will affect the whole family. In such cases, the wife is typically blamed as the cause of the disease. *India Today*, the main news magazine of India, reports that families are forced to keep the presence of HIV/AIDS family members a deep secret because public knowledge of a HIV/AIDS family member can affect the marriage prospects of other siblings and thus, possibly, the whole family's economic situation (Baria 1997).

Because India is a patrilineal society, care for orphans is the responsibility of the father's family. But here, too, the children share the parents' stigma. Children born to an HIV+ woman are believed to be cursed by their mother's fate. Grandparents assuming care for these orphans can expect to encounter serious problems in securing an education or in making a marriage for the child. Older children in the family are thought to share in the contagion. HIV orphans are sometimes abandoned.

As of 1998, it does not appear that the care of HIV/AIDS orphans has had a significant impact on the life of the elderly; the number of orphans is still too small. Family size continues to be large in India, with those age 65+ comprising only 3.8% of the population (Favereau 1995). With a dependency ratio of 8:1 for those age 65+, population figures are reported in increments of 15 to 64 and 65+; thus, no figures are available for those age 50 and older; it is likely that the elderly can find substitute children to replace those sons and daughters-in-law who are lost to HIV/AIDS. However, should the epidemic spread, this dependency ratio suggests potential problems in orphan care.

Community Integration and HIV Mortality—The widespread systemic impact of HIV/AIDS mortality on community and cultural functioning is yet to be felt. Although absolute numbers of people with HIV/AIDS are high, they are too widely dispersed to make an impact beyond the immediate family level. Indeed, the very size of India's population has led many into a false sense of security. Business and industry, for example, assess the possible impact of the epidemic on the workforce as minimal given that the epidemic is localized among the poor, who form a large pool of available workers (Ganesh and Sundaraman 1997). Unfortunately, it is precisely these large numbers that have raised concerns about the extent of the epidemic. Indian epidemiologists warn that a situation similar to Sub-Saharan Africa could develop. The average age at death from HIV/AIDS is 33 for men and 31 for women (Chacko et al. 1995). Death at this age results in the loss of 20 to 30 productive years. The loss will have a negative impact beyond those household members dependent on the labor of the middle aged, the young, and the elderly to the society as a whole (Srikanth et al. 1997).

The Indian family structure continues to be strongly patriarchal, with senior males retaining considerable respect and control within the family. Whether such a system will facilitate or inhibit the family and community response to sickness and death among the middle aged remains to be seen.

The emerging public education response has had little impact on the epidemic or on reducing the HIV/AIDS stigma (Mane 1997), which continues to be so extreme that people are afraid to be tested for the disease (Spratt, personal communication, 1998). HIV/AIDS is associated with marginal populations such as CSWs and *hijras* (castrated men who live as women and frequently engage in commercial sex work) (Mane 1997) and more generally is blamed on women who already occupy a devalued status in India society. This suggests that the impact of the epidemic, when it is felt, could accentuate existing social inequalities.

Hindus view the preparation for death as the final stage of life. Unlike many Western cultures, death is frequently discussed as people consider their lives and coming deaths (Vatuk 1996). To die suddenly, the ideal death for many American elderly, is seen as a great tragedy because the dying person should be alert and surrounded by family to whom the dying person gives last instructions. The funeral is a time of rejoicing over a good life, a "colorful and celebratory procession and joyous feast in congratulatory appreciation of a life well lived and a death well died" (Vatuk 1996:123). It is likely that dying from a highly stigmatized disease will disrupt if not destroy this process, causing distress for all involved.

DISCUSSION AND IMPUCATIONS FOR RESEARCH

Culturally comparative knowledge contributes to our study of HIV/AIDS by revealing the sociocultural fabric within which HIV/AIDS is socially defined, represented, and managed. That knowledge is vital to helping public health workers tailor programs of prevention and support in terms that are understandable for various societies. We identify four specific areas in need of further research based on the work we conducted to prepare the preceding discussion: quality of life for people with HIV/AIDS, outcomes desired by families and communities, prevention, and the impact of the epidemic on social organizations.

Quality of Life for People With HIV/AIDS, HIV/AIDS Orphans, and Their Caregivers

For people with HIV/AIDS and for HIV/AIDS orphans, the caregivers are a central facet of quality of life. It is valuable to note that the caregivers can become "secondary victims"; they suffer by virtue of being identified with or working with family members with HIV/AIDS or orphans. Questions that address a caregiver's personal well-being and self-esteem are missing in the research to date. For example, how might traditional values or social roles for senior family members be used to lend prestige to the important work of nurturing or supporting families struggling with HIV/AIDS afflictions? Just as gerontologists have learned to question rather than accept the double- or multiple-jeopardy hypothesis about well-being in late life (e.g., being old, minority, and disabled necessarily lead to negative well-being), comparative research on HIV/AIDS needs to address with empirical data common presumptions about the inevitability and globally negative experience of living with or caring for someone with HIV. The case of Thai caregivers illustrates how multiple cultural explanations provide some positive avenues for caregivers to demonstrate that they

are fulfilling the positive cultural value of building merit despite the situational stigma of being identified with someone with AIDS.

Identify HIV/AIDS Outcomes Desired by People With HIV/AIDS, Their Families, and Communities

The global range of concepts about living and dying with HIV/AIDS highlights the need to specify the culturally defined goal of managing life and death with HIV/AIDS. In each culture surveyed, there were important differences in these definitions. For example, the notion of what was a good end for a person with AIDS is thought to differ. Indians desire a carefully considered, aware, and anticipated death, while Thai see their dying as the payment for wrong deeds that would gain them relief from suffering in a next life; and Ugandans seek a dignified death surrounded by family members. These differences underline the cultural content and structure of desired outcomes. A primary research agenda in the United States is to identify the priorities of the people living with HIV/AIDS as Americans and as members of families, particular ethnic traditions, and communities. In other words, the decision of whose desired outcomes will be legitimated may be a contentious one balanced between the life values and goals of the elderly, the people with HIV/AIDS, and public health officials and institutions.

The broad and pan-human experience of suffering that is highlighted by individuals and their families with HIV/AIDS is revealed by the cross-cultural perspective. The experience of suffering, although it takes different forms, shares some commonalties. These include shared experiences of stigma and social marginality. Similarly, there is a shared need for the mourning of normal life while living with HIV and for the loss of community and family members, which may be hindered by the shortening of funeral practices in many communities.

Prevention of HIV in Older Populations

Effective prevention messages are designed to address the social relationships, social and cultural forms or organizations, and cultural belief systems in which behavior is embedded. Understanding the cultural fabric within which sexual behavior is perceived will facilitate the development of more effective prevention campaigns. For example, in the cases at hand, a paramount challenge in India and Thailand will be to confront deep traditional beliefs and acknowledge that the elderly are sexually active. This must be a primary agenda item if we are to enable effective prevention programs.

Identify the Impact of the HIV/AIDS Epidemic at the Level of Social Organization and Cultural Identity

Mortuary ritual—HIV/AIDS has severely affected the population profile in high-prevalence countries. Emerging results clearly indicate that HIV/AIDS is beginning to fundamentally redefine some traditional forms of social and political organization. For example, we have highlighted change in traditional mortuary rituals due to increases in deaths and the financial costs of greater numbers of funerals. Funerals allow participants to reaffirm their social identity (Block and Perry 1982). A dramatic increase in the number of adult funerals has created a financial burden on individuals and communities in Uganda and

Thailand because the costs and time dedicated to lengthy mortuary and mourning rituals deplete the productive and resource base of a society. Traditional forms cannot be sustained. The quality of life is lessened. As a result, the key role played by funerals may be attenuated, creating identifiable areas of cultural strain, community disintegration, and increased individual marginalization. There is inadequate opportunity for mourning and recovery, which anthropological research has established are critical for reintegration of the bereaved into ongoing life. For the elderly, this limitation in the ability to mourn publicly and adequately for losses has a negative impact on late life.

Lost generation—The loss of so many young and middle-aged adults in countries such as Uganda has interrupted the cultural transition between generations. What is lost is a generation of wise, seasoned politicians and heads of families and organizations. Conversely, older generations are being forced to stay in positions of authority beyond the point when the next generation should have replaced them. This potentially fosters stagnation or rigidity in the political process. The normative transitions necessary to ensure a well-functioning political process may be inhibited.

Research and intervention priorities are needed to address this issue, including programs and practices that will counteract the problem by effectively supplementing and mentoring intergenerational activities.

Comparative Research

Cross-cultural comparisons can add to a systems- and meaning-centered framework for understanding the social impact of HIV/AIDS. As Spira et al. (1998) have recently reviewed, a host of important contributions as well as theoretical and methodological challenges are provided by comparative research. This approach is particularly important in HIV/AIDS research, where cultural values, beliefs, and practices are explicitly implicated in the spread and experience of the epidemic and, conversely, the epidemic is affecting the practice of cultures. Cultural practices related to community and family integration become strained, and shifts occur in normative role relationships between multiple generations.

HIV/AIDS challenges core moral and ethical issues beyond those simply related to infectious disease prevention and treatment. For example, health promotion precepts can conflict with those for disease prevention in cultures that believe an active sex life is needed to maintain vitality and quality of life in old age. Such ethical concerns are culture-specific filters through which public health issues are seen. It is precisely these objective cultural issues that act at the practical level to create barriers and resistance to effective implementation of research and prevention programs. We need to expand the research knowledge of the distinctive ethical and moral issues that each cultural tradition defines as relevant to the epidemic. Such data will advance our ability to design and implement effective prevention, treatment, and support programs.

Another contribution of cross-cultural research illustrated here is to identify how each culture defines the disease and its social consequences, the focus and ranges of concerns or fears, the styles of social and personal management of the epidemic, and the culturally desired outcomes.

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