Chapter 10

Stigma When There Is No Other Option: Understanding How Poverty Fuels Discrimination toward People Living with HIV in Zambia

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Introduction

Based on qualitative fieldwork in urban and rural Zambia (see Bond et al. 2003), this chapter aims to demonstrate that HIV-related stigma and discrimination are fueled by the practicalities of limited resources and narrow options and, in this wider context of poverty and household fatigue, that the poor, women, orphans, and rural dwellers are particularly vulnerable to HIV-related stigma and discrimination. It is apparent that a significant proportion of discriminatory actions are caused by the fact that HIV and AIDS can be so very hard to manage in the context of poverty. Significant differences between the urban and rural sites that emerged in our material, with overall less stigma manifested in the urban site and more pronounced stigma in the rural site, suggest that it is possible to alleviate household stress and reduce this type of stigma and discrimination by providing services and support.

Poverty and stigma have a peculiar relationship: it is easy to “understand” decisions in the context of poverty that result in discriminatory actions, for example, a decision to withdraw orphans from education because the household cannot afford to educate them. The decisions themselves are not always stigma per se, but the actions are experienced as stigmatizing. For example, orphans feel stigmatized by being out of school, and, the consequences of the actions can be damaging. And often the decisions are voiced through a language of attribution and blame.

The Wider Context

The intersections between poverty and stigma related to HIV and AIDS reinforce the fact that stigma cannot be isolated from other social processes and phenomena and that it must be understood in the context of other things happening (Wallman 1988), including, in Zambia, a process of "community unraveling" (Scudder 1983), hunger, deprivation, and limited capacity to cope (Bond 1998). Zambian society is staggering under the weight of economic hardship, the impact of HIV, poor education and health services, and widening inequality. These stresses are reflected in rising incidences of violence, alcohol abuse, accusations of Satanism and witchcraft, and family breakdown. As Whiteside and de Waal (see Barnett and Whiteside 2002) highlight in their "new variant famine" argument, HIV compounded with other problems, such as hunger, is a lethal combination.

These wider stresses lend themselves to the process of stigma. Others have written convincingly about how stigma is "allowed" to unfold within a context of inequitable power relations (Link and Phelan 2001), where stigma plays the role of separating "us" (the morally upright and socially pure) from "them" (the deviant and impure) and reinforces social stereotypes. This chapter aims to demonstrate the synergy between "diverse forms of inequality and stigma" (Parker and Aggleton 2003), as evident in the added vulnerability of the poor, women, and orphans to the dimension of stigma under the lens in this chapter. Castro and Farmer (2005) write, "poverty, already representing an almost universal stigma, will be the primary reason that poor people living with HIV suffer from greater AIDS-related stigma," and "social forces determine not only risk of HIV infection but also risk of AIDS-related stigma." But this chapter aims to make one additional point: that in the context of poverty, people stigmatize people living with HIV and AIDS because they have no other option.

What Is Stigma?

Stigma is a spoiled identity resulting from "an attribute that is deeply discrediting" (Goffman 1963), though, as Goffman further points out, it is a language of relationships, not attributes, that is really needed (Goffman 1963). A person's whole identity can be tainted by an attribute. Disease stigma is "negative social 'baggage' associated with a disease" (Deacon, Stephney, and Prosalendis 2005). In relation to HIV, stigma is the social process of combining the assumed presence of HIV virus in a person or group with "a perceived notion of culpability" (Scrambler 2004). As suggested above, HIV stigma is also often layered on preexisting stigma toward marginal or powerless groups (Herek and Glunt 1988; Parker and Aggleton 2003). The critical elements of HIV-related stigma to consider are causes of stigma, experiences of stigma, consequences of stigma, and strategies to cope with stigma.

The dimension of stigma being examined here is poverty as a cause of stigma. The experiences of stigma catalyzed by poverty revolve around experiences of devaluation, exclusion, and disadvantage (Sartorius 2004), which may be internalized in the forms of self-hatred, self-isolation, and shame (Alonzo and Reynolds 1995). Family members may also find they are "all obliged to share some of the discredit of the stigmatized person to whom they are related" (Goffman 1963).

Background to the Study

The Zambian research "Understanding HIV and AIDS-Related Stigma and Resulting Discrimination" was part of a multicountry study led by the International Centre for Research on Women (ICRW)[1] in collaboration with local partners in Ethiopia, Vietnam, Tanzania, and Zambia, which aimed to disentangle stigma and discrimination in an effort to provide entry points for programmers to reduce stigma; it was carried out from 2001 to 2004 (see Nyblade et al. 2003; Ogden and Nyblade 2005).

It is of significance that in this multicountry study, the relationship between poverty and stigma emerged most strongly in the Zambian material where poverty indices and HIV prevalence combined were the highest out of the four countries, and where household fatigue was the most evident.

Poverty in Zambia

Within the SADC region, by 2002, Zambia had the highest level of income poverty and the fourth largest level of human poverty (following Angola, Mozambique, and Malawi) (World Bank 2002). By 1998, overall national poverty stood at 72.9 percent of the population, with 57.9 percent classified as being in extreme poverty (LCS 1998; World Bank 2002). Poverty levels were highest in the rural area, although this disparity was narrowing by the late 1990s because of a rise in urban poverty; by 1998, 36.2 percent of the urban population were in extreme poverty compared to 70.9 percent of the rural population. Certain groups were more visibly poor than others, including small-scale farmers, large households, female-headed households, and women in general. Lusaka had the second highest concentration of the poor (World Bank 2002).

HIV in Zambia

Prevalence rates in adults aged 15–49 years were estimated to be 21.5 percent in 2002, with variations between urban and rural areas, and around one in four households had experienced an HIV-related death (UNAIDS 2002). Young women aged 15–19 were five times more likely to be infected than young men in the same age group (CBOH 1999), and in 2002, 5 percent of rural and 7 percent of the urban population were estimated to have taken an HIV test (Zambia Sexual Behaviour Survey 2002). As a result of HIV, the numbers of orphans were estimated to be at least 690,000, and at least 40 percent of households were looking after one or more orphans (UNICEF 1999; UNAIDS 2002). The number of orphans was highest in rural areas, in small-scale farming households, and in low-cost areas, where poverty indices were also the highest (World Bank 2002). In 2002, there were many more HIV/AIDS programs in urban areas than rural areas (CBOH 1999).

The Research Sites: Rural and Urban Microcosms of Wider Trends

In Zambia, seven months of qualitative research was carried out in 2002 in two adjacent high-density urban compounds in Lusaka, the capital city, and in a rural constituency in Choma district, Southern Province. Lusaka and Southern Provinces have the highest HIV prevalence in Zambia (CSO 2003), and in Lusaka and Southern Provinces, at least 18 percent and 17 percent, respectively, of the child population are estimated to be orphans (UNICEF 1999).

One of the Lusaka sites (Kamwala) is a planned residential area with a population of 30,000, government primary and secondary schools, a clinic (with voluntary counseling and testing services), piped water, and, with residents who are a mixture of middle-class in formal employment and working class whose income is derived from the informal economy. The other adjacent site is a shanty compound (illegal until 1995) called Misisi, with a population of 23,000, poor-quality housing, no government services, and with residents mostly involved in the informal economy, including clandestine activities. A demographic survey in the shanty compound revealed an extremely high level of adult mortality with HIV largely responsible (Kelly et al. 1998). As one resident barber in the study describes the area, “Very few children go to school, and very few people go for work. . . . People are failing to meet eating needs because they fail to find money.”

Community-based organizations (CBOs), nongovernmental organizations (NGOs), and research activities related to HIV and AIDS are quite extensive in both compounds, especially the shanty compound, and include home-based care (HBC), a hospice, an orphanage, and a community school.

The rural site is called Mbabala, lying 30 kilometers to the northeast of Choma town in Southern Province. The population numbers around 15,000 people (mostly one ethnic group, the Tonga), and there are 36 villages, 21 resettlement schemes and commercial farms, seven schools, and one health center (with no VCT services at the time of the study). In Choma town, there is a district hospital and, further to the north, a mission hospital. The 2001/02 farming season was difficult because of late rains, and the harvest was poor. People are mainly farming and trading (in fish, farm products, and charcoal). CBO and NGO activities related to HIV and AIDS were slowly being introduced, but there was no active HBC. At one primary school accessed by four villages in the area, 72 of 350 pupils were orphans (21 double orphans), giving an indication of the orphan burden in the area.

A man living with HIV in the area describes the predicament households face when a household member falls sick as follows: "When someone is sick and the family is poor, there are talks over what to eat, small things that need money. This brings problems in the family. Where will the family get the money?"

Methodology

In each site, a series of participatory and community trust building activities were the starting point for the research. These included a stigma workshop with local representatives, community mapping, a stigma transect walk, free listing of terms used for people living with HIV and AIDS, picture discussions, and timelines of TB and HIV. Following a week of these activities, semistructured key informant interviews, and focus-group discussions were carried out with a representative range of community members (TB patients, people living with HIV/AIDS [PLWHA], youth, children, religious leaders, health professionals, caregivers, educators, farmers, employers, and NGO representatives). In total, 68 key-informant interviews and 53 focus group discussions (FGDs) were held.

In addition, eight one-day participatory workshops were held (four urban, four rural) with 72 children. The children were drawn from out-of-school children; school-going (government and community) children; children living with HIV and AIDS; and street children. And in the urban site, six rounds of interviews with 13 households affected by tuberculosis and HIV and AIDS were carried out.

The data were analyzed thematically and managed using QSR N6 software qualitative data package.

Key Dimensions of the Intersections of Poverty and Stigma

People Living with HIV and AIDS Are a Burden in the Context of Poverty

In a "biting economy" (15-year-old boy, urban), people living with HIV and AIDS are considered a "burden" according to respondents because they are not able to contribute to household income when they are sick and they undermine the income generation and progress of the household. During periods of illness, they soak up money, energy, and time. Both they and relatives who come to visit them take up space.

People living with HIV and AIDS are perceived as a burden for other reasons not related to poverty (for example, an emotional burden), but it was largely the economic burden that respondents in these communities focused on.

In order to meet the needs of people living with HIV and AIDS, households fall back on informal coping strategies (selling assets, borrowing, stealing) and can feel overwhelmed to the breaking point. "Your resources are milked," explained rural men farmers. In order to pay for treatment, food, surf (to wash linen), and water,[2] respondents often reported spending money and selling assets and sometimes reported borrowing money or goods or even telling lies and stealing, as young men in the rural site describe, "A lot of money or wealth will be wasted during that nursing period, and, as a result of the illness, you tend to borrow a lot and tell lies."

Sometimes there is simply "no means" of getting money and/or food; these are households where there is often little (and sometimes nothing) to eat or where people are already eating "unrecommendable food." For such households to repeatedly look after a chronically sick household member is unmanageable; as captured by an urban social worker, "people in this area are living under poverty, I can say. Very few people can manage to look after these people [living with HIV and AIDS] if you look at the current situation. As now, people are just feeding on unrecommendable food *ka pamela* per day, *chiwawa,* and *impwa.*[3] They think that if they start again looking after those people they are actually putting themselves in problems."

Complaints about demands for "special food" from people living with HIV and AIDS included "demands" for "chicken," "meat," "fruits out of season," and "tomatoes." Sometimes the treatment that is considered unaffordable is panadol (a painkiller), as described by gatekeepers in rural Zambia: "If I am poor, for example, I will not even afford to buy a panadol for K100,[4] but the rich go very fast and buy medicine, even if there is no cure." As an urban bus owner pointed out, the needs of people living with HIV and AIDS are often not budgeted for, and "a week's supply becomes days only." There is often a desperate concern that you cannot meet the special needs of the sick and that you are unable, if poor, to "accept them fully" (young women, urban). You can want to take them to the hospital, buy the medicine they are prescribed, and buy them the food they ask for, but you just do not have the money.

Relatives from the village (especially men) who come to visit the sick are an added burden, requiring additional food, space, needs, and transport expenses. Space in the house is very often limited. This is especially true if the visitors are men, said urban pregnant women, "the men will just come for luxury and other stuff. Men are a burden." If it is your spouse who is dying or who dies, there is the burden of being the only breadwinner: "both breadwinner and a widow, the burden is very much there" (health workers, urban).

But, even in the context of absolute poverty, there are certain relationships that withstand the strain, in particular parent–child relationships, because as rural elders proclaim, "you cannot throw away your own." People whom you "belong" to (chiefly close blood relatives) are obliged to care for you, especially in the village.

The quality of the past relationship, reciprocal relationships, individual character, and the household status of the sick person also influence care and stigma. It makes such a difference whether the person with HIV and AIDS is an old friend, family member, neighbor, stranger, or someone you never much liked anyway (Bond 2002). "It depends on how the patient used to relate to you before he or she got sick," explain urban TB patients, "If you were not good, you easily become a burden." An urban headmaster makes the same point even more bluntly: "There are some people even when they were okay they were so useless to the family and when such people are found in a situation, yes they are considered a burden." It was evident that how you get treated depends partly on your household status, with previous breadwinners less likely to be stigmatized, and more junior or marginal members more likely to be stigmatized.

Spiraling Poverty, Needs, and Neglect

Caregivers are not able to work while people living with HIV and AIDS are extremely sick. When illness reaches a "climax," it is "very involving, programs come to a standstill" (young men, rural), "your day-to-day duties are disrupted" (young women, rural), "progress and incomes are disturbed" (hospice worker, urban), and, "they shatter all your plans and activities" (secondary school children, urban). Over time, when spiraling poverty is pitted against spiraling needs, "poverty flows in" (pastor, rural), and this can lead to spiraling neglect. It is an illness that "takes too long" (politician rural), involves "very special care" (bar owner, urban), and "even when they are supposed to die it takes time" (community health workers, rural). Underlying this fatigue is the knowledge that HIV is an incurable disease and that no matter what you do, the patient will eventually die. The fact that the illness takes a long time drags households down, and the more you continue to look after a patient, the more money you lose. An NGO manager comments that even if you thought you could manage to care, you gradually lose patience and can eventually give up. Even urban health workers lament, "it can be an added burden, it is too much and especially when they become more sick and when they carry on to get more and more sick, it can become difficult." Rural secondary school girls relay the burden of treatment costs: “booking taxis taking the person to the clinic if the person is very sick. The hospital costs nowadays are very high, and the food [costs]. When the person dies you find that all the money was spent on the sick person.”

The language used by households in relation to caring for people living with HIV and AIDS included: “no, I cannot bear with this kind of problem” (NGO manager, rural); “tiresome” (bar owner, urban); “it is burdensome” (traditional healer, rural).

Over time, as fatigue sets in and poverty worsens, households are likely to develop negative attitudes toward people living with HIV and AIDS, who are then more likely to experience different forms of stigma. They are accused of wasting time and money, and basic needs such as treatment, clean clothes, linen, food, and emotional support are not always met or are even cut out. Some people are sent elsewhere including, for urban dwellers, back to the village. Households say they are “not prepared to handle” (health worker, urban) the people living with HIV and AIDS. Young urban men relay, “If someone has been looking after an HIV-positive person for a long time, he will think ‘I am just wasting my time. Why should I care for this person? He is just spending my money for nothing; after all, he will die.’ . . . After a long time the care will drastically change.”

Respondents reported that sometimes you actually want the patient to die or are advised to let the patient die. Traditional healers and young men in the urban area concur that resources are saved for the funeral over and above treatment and care; “other relatives who are spending on that person would advise you to do it roughly so that he dies; then they spend on the funeral” (traditional healers, urban); “They [the caregivers] will start preparing for the funeral and raising money for the coffin instead of buying food and some stuff” (young men, urban).

Powerlessness of Poor People Living with HIV and AIDS

The powerlessness, marginality, and vulnerability of poor people living with HIV and AIDS who are sick was widely acknowledged and attributed to the fact that they have nothing to offer and are therefore “overlooked” (young men, urban). Similar to street kids, children out of school, and sex workers, they are almost invisible and unaccounted for, as reflected in the following quotes: “you who is dog poor, they [community] just pass by you, not looking at you” (TB patients, men, rural); “(people living with HIV and AIDS) are unwanted and unprotected. . . . If there is no-one to help them, the poor die” (young women, urban); “Because of the hunger situation, it is a problem. You find that when one is poor, there are a few to nurse him” (gatekeepers, rural).

The situation of the poor was a sharp contrast to that of the rich. As urban secondary school children candidly observed, "The poor live 1 year, the rich 10." There is a strong sense that having HIV and AIDS is very different for people with money, that their money buys them more space to hide, allows them to live longer, helps cushion the impact, and allows them to more easily find support and love. People living with HIV and AIDS who are poor (living in either dense, urban conditions or in small, rural communities) have less space to hide from stigma when they are sick, they are sick more often, and they "die faster" or "when they are not supposed to" (headman, rural) and occasionally alone. Respondents commented that poor people's funerals are more likely to be shorter, cheaper, and to involve "less crying" (man living with HIV and AIDS, rural). Poor people are more likely to accept humiliation: "the poor keep quiet and accept any treatment" (secondary school pupils, rural).

In the urban area, primary school children mentioned how the rich could exchange their "contaminated blood" for clean blood,[5] and, a number of other respondents mentioned how the rich could go outside the country for treatment. A few respondents mentioned the rich being able to buy antiretrovirals; for example rural secondary school girls remarked, "Since they introduced these ARVs,[6] the rich man can easily manage to get them while the poor can't because they cost a lot of money."

A businesswoman in town commented that the differential treatment of the rich and poor "starts from hospital up to homes." There was evidence that the rich received preferential treatment in clinics, and the ulterior motive of looking after the rich was often mentioned: "people are after his wealth" (primary school boys, rural). Indeed, the rich were reputed to have no problem in finding bedside caregivers, "but if it's a poor person, this one has just a pair of Tropicals [flip-flops]; what can he leave behind? So they abandon him" (secondary school boys, rural). So for people living with HIV and AIDS, as a rural headman so vividly described, "the disease becomes deeper and deeper." Pregnant urban women bluntly state, "With the rich, you find even if he has soiled linen, many people will be willing to wash them, while for the poor, they will just leave everything, being there is no soap, a lack of water nowadays, and the person will be sleeping on dirty linen, and the disease will be even worse."

Poverty, Orphans, and HIV- and AIDS-Related Stigma

As the children's research in Zambia demonstrated (see Clay, Bond, and Nyblade 2003), orphans often experience differential treatment in the household. One of the main causes of this is being an orphan in a poor society. To take in additional children when "the economy is very bad and mostly families are failing. . . . is really heavy" (women TB patients, rural). Their "needs are always a second priority" (development officer, rural), and poor guardians are forced, or decide, to withdraw education, adequate food, and clothing from orphans. Orphans are regarded to be "wasting money" (secondary school girls, rural). You can "have the heart of looking after the children (orphans), but how?" exclaims an urban nursery school teacher. A woman in an urban household admits, "Small ones who can't do things on their own are especially a burden."

An urban headmaster pits duty against poverty: "In our Zambian society, it is our custom to look after people; if my brother has died, it is my duty to look after his children, but because of these economic changes, we are not able to look after the children, because of the economy." An urban peer educator sees it as a choice between educating your own children or looking after orphans: "Yes, they are seen as a burden because it's not possible for one to spend a lot of money on medicine, transport, food, instead of using it on one's own children for school."

Even your own children can be considered a burden in the context of poverty. An ex-TB patient in the household study explains how when he was sick, "my son was a burden because I was not working," and rural women TB patients explain how "Parents don't have enough to give to their own children."

Women, Poverty, and HIV- and AIDS-Related Stigma

Respondents considered women more vulnerable to deepening poverty and stigma. Women have less income-generating power, so if their husband is sick, the "financial problem in the house will be very big, they finish all the money and will end up selling furniture" (secondary school girls, rural), and the wife "will take all the responsibilities" (traditional healers, rural). Urban TB patients think that women are also more dependent than men on relatives for money, and the relatives "easily get fed up, complain, and later stop [giving help]." A member of a drama group in Misisi pointed out that when husbands are sick, women are sometimes forced into sex work in order to raise money for their husband's medicine.

The burden of caring for the sick falls largely on women, and this takes time away from caring for children and earning their own money because their "duty becomes only taking care of that sick person" (community health workers, rural).

If their husband dies first, women and children will often suffer. A widow in the household study said that she worried after her husband died and his business closed that she would not "have the means to look after the children." In the event, she moved out of the house they lived in and owned and rented it to give her an income. The custom of property grabbing[7] can leave women and children in abject poverty; as explained by urban gatekeepers, "usually what I have seen when the man dies, the woman is mistreated, the relatives of the man would want to grab everything from the woman, even forgetting the children. They will sometimes even call her names, or she will be blamed that she is the causer. But when it is the woman who has died, the family from the woman will not bother the man."

The combination of being a woman breadwinner and a widow[8] is brutal, and it is harder for widows both to raise enough money to get by and to remarry. Women, and more especially aunts and stepmothers, were cited by children as perpetuating abuse against orphans, reflecting the immense stress they are under (Clay, Bond, and Nyblade 2003). Urban traditional healers commented that women "shout" at their husband and children "because of HIV."

If poor women themselves fall sick, they are more vulnerable to "being chased" back to their parents, deserted or neglected by husbands, especially if they fall sick first or if they learn of their HIV-positive status first. A rural traditional healer commented that an HIV-positive woman, "will be isolated like a hoe without a person to use it." Rural community health workers commented how household chores grind to a halt when a woman is sick because "not all that a woman does can be done by a man, so it will be at a standstill."

Within poor communities, there is understanding, even coercion, around sex work until women or girls are thought to have HIV and AIDS, at which stage they are chastised, rejected, and blamed, or the mother is blamed for her daughter's transgressions and assumed status. As urban TB patients in Misisi wryly remarked, "For women, people like pinpointing their mothers that they are the ones who used to send them so that she brings money, especially in Misisi." At that stage, the focus is not on the poverty but how she got infected, and she and the mother are blamed for having transgressed. School children were aware of sex as a survival strategy, and how women are blamed if they fall sick. Looking at a picture of a woman seated surrounded by people with their backs to her, urban primary school children commented, "she was naughty, so everyone is reminding others what she used to do for money, and no-one is willing to help her out." Secondary school boys in the same urban site related how "Nowadays, the biggest problem is poverty. You find in a family no-one works or goes to work, so she (the mother) will decide to go and have a temporal affair so she can raise some money."

If women have no close family to return to, they are deeply vulnerable to neglect; as conveyed by urban traditional healers, "If you don't have a mother, no children, you will have problems. Relatives don't usually help. I say so because I witnessed this myself. A woman was sick, her husband ran away from her, she had no children, and only her relatives were there. If you don't have relatives, some women are buried very dirty, masked with feces."

In poor communities, sex workers are extremely vulnerable to not being cared for when they are sick, as illustrated in the following quote from one urban sex worker: "We have no support or visits from neighbors because they regard us as outcasts or 'not human beings' because of our business. . . . If I then get sick, they wouldn't even give me water if I needed it. . . . They always wish us to die. . . . It's not our wish to be sex workers, but it's due to poverty." The only case respondents in town recalled of a woman who died uncared for was of a sex worker, whose death was noticed by neighbors only once her body started to decompose, attracting flies and rats.

Poverty, Blame, and Stigma

Within explanations of poverty, underlying judgments often creep in to justify the stigmatizing actions. The implication is that poor people living with HIV and AIDS, especially poor women and children, are blamed[9] for their predicament. As a nutritionist in the urban area describes, "People are killing their own children very fast. They leave them to die slowly, painfully because they insult them and say bad names—'You alone went making money' and all sorts of words, which makes the patient have depression. They stop buying medicine . . . saying 'we can't manage. . . . If you want this type of food, you have to eat what we have because we have no money. We never costed but you costed all these, all the problems you have brought into this house!' Others are shunned very much."

Often it seems as though people are also aware of what they are doing, almost as though they are justifying why death has selected one person and not another. And there is recognition that blaming and complaining adversely affect the patient.

Rural Poverty and Stigma

Some urban families do not have rural ties, but for those that do (especially the more recent migrants), there is a trend for people suspected to have HIV and AIDS, and orphans, being sent back to the village.[10] A rural traditional healer commented, "the village is now the dumping ground," and young rural men said that people in town were "throwing" the problem to the village. The motives for doing this include spiritual connections,[11] close family ties in the village, and the tradition of care in the village, what rural gatekeepers called being cared for in "your own circles." But other motives are more discriminatory: wanting to grab property in the town; wanting to get rid of the problem; not having enough money to cope; and that funerals are cheaper in the village, where people often die at home and can be buried just in a blanket or a homemade coffin, saving hospital, mortuary, transport, and coffin costs.

The irony of this trend is that, in the face of limited food and services and support, people living with HIV and AIDS will die quicker in the village. There are stories of children resisting attempts to send a surviving parent to the village and comments about how people who are sick in town and return to the village will not have the friends in the village to support them (recognizing that it is especially hard to forge friendships when sick). Returning sick and in need of help to the village is not as life should be: people in the village look to urban kin to support them; as a pastor in the rural area explains, "In the village, we look forward to these people who are in town to help us, but if they come sick, it's an added load, it's a burden." And it is clear that those relatives who had supported rural kin while in town are much more likely to be cared for than those who did not and were "eating their money alone" (transporter, rural). Village kin also worry that they are not able to give their town relatives the lifestyle and food that they are used to.

Seasonal food scarcity and farming activities make it hard to care adequately when people living with HIV and AIDS are sick during the farming season:[12] farming activities cannot be postponed easily, and rural respondents complained bitterly about not being able to farm properly because of the care demanded by people living with HIV and AIDS.[13] Economic options are much more limited in the village, and it is harder to both generate and borrow cash in crisis. This is clear in the following quote from rural women farmers: "This patient at home has disturbed them. They don't finish the work at the fields properly. The patient also complains to them, saying that they take a long time to give him food. They will also say that, 'At the field that is where your food comes from.' They will blame the patient all the time."

Urban Poverty and Stigma

People in the village realize that it is better to be in town if you are HIV-positive and sick. They pinpointed institutional care in hospices, HIV and AIDS activities (clubs, NGOs, HBC), and more HIV and AIDS information as the advantages of being in town and said that people living with HIV and AIDS would live longer in town. There is also more cash in circulation in urban areas, and it is easier to borrow money or raise cash.

In the context of the extreme urban poverty of Misisi, if people are unable to cope with people living with HIV and AIDS, they can and do turn to the hospice, HBC, churches, a training center for girls, and the orphanage. Urban elders state, "If you cannot afford to look after an HIV patient nowadays, we have home-based care centers where they give support. These people will give assistance." There are simply more places to turn to when people can no longer cope at home. For example, urban respondents often mentioned taking patients to the hospice when they could not cope, as reflected in the following comment by urban gatekeepers: "financially, they would rather not keep them at home and will take them to the hospice if they are very sick."

In the urban sites, in comparison to the rural site, there was also more awareness of what people living with HIV and AIDS need, for example, their need for nutritious foods. People living with HIV and AIDS were more visible, and there were fewer cases in the data of extreme discrimination, more openness (including more discussion about disclosure), more awareness of the impact and hurt of stigma and discrimination, and fewer fears around casual transmission. Because these data are qualitative, evidence of reduced stigma in the urban sites emerges from the data but cannot be quantified.

However, looking after people living with HIV and AIDS does deepen poverty in town as well as in the village. It can stop people going to work or force them to take leave. Households may even employ someone to care for the sick person, or, if people are involved in the informal economy (stone crushing, trading), it can result in reduced business. It can be an excuse for relatives to come from the village, and these relatives, unless they are women caregivers, are regarded as an added burden.

Conclusion

This material demonstrates how the poor, orphans, and women are more susceptible to multiple stigmas and HIV-related stigma in Zambia. How HIV-related stigma deepens existing inequalities and exclusions has been expounded by other research and academics (Goffman 1963; Gilmore and Somerville 1994; Bharat 1999; Parker and Aggleton 2003) and is one of the core dimensions of HIV stigma worldwide (Ogden and Nyblade 2005). However, this chapter is making another simple but original point about the relationship between poverty and stigma, namely that the practicalities of poverty fuel stigmatizing actions and stigmatizing experiences. And the stigmatizers, poor and vulnerable themselves, and perhaps in an effort to distance themselves from the consequences of their actions, often adopt a language of blame when they make painful decisions about the allocation of resources. This blaming and shaming serves to deepen the stigma experiences by people living with HIV and AIDS in the context of poverty, and when (as often is the case) the stigmatizers are close relatives, the pain of the stigma experiences is even greater. Urban health workers, discussing how a family with no income and no other support cannot care for people with HIV and AIDS, comment, "you start complaining deep down in your heart, so even the patient won't get well because you are complaining."

However, indications of reduced levels of stigma in the urban site underline how it is possible to tackle this particular cause of stigma through a broader approach: through poverty reduction, women's empowerment, orphans' empowerment, and, through an increase in access to special HIV services (particularly in the rural areas) and to interventions that improve the practical and medical management of HIV. Our material strongly suggests that by giving poor people more pragmatic support to manage household members living with HIV and AIDS, both stigmatizing actions and experiences are likely to decrease.

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Notes

1. The research was funded by USAID, with additional support from the CORE initiative, GlaxoSmithKline's Positive Action programme, DFID, and SIDA.

2. In both urban sites and Mbabala township, people had to pay for water, and water was in short supply.

3. *Ka Pamela,* a small bag of maize meal (usually half a kilogram); *chiwawa,* pumpkin leaves; and *impwa,* small wild yellow eggplants.

4. K 100 is equivalent to 5 cents.

5. This refers to a reported practice at the time of rich people living with HIV and AIDS going to South Africa for blood transfusions.

6. In Zambia, ARVs were not subsidized and available in the government health services until 2004.

7. Property grabbing is a customary practice of a husband's family taking goods from his widow. It was made illegal in Zambia in the late 1980s.

8. Stephen Lewis calls the combination of hunger and HIV the "the most ferocious assault on women ever" (Lewis 2003).

9. See "Experiences of Stigma" for a more detailed discussion of blame.

10. As mentioned in the description of the study sites, the rural fieldwork was conducted during a period of food scarcity, which exacerbated household stress.

11. People may want to die or be buried in the village, close to their ancestors.

12. The farming season starts in October, with clearing the fields, and runs through May, when the fields are harvested. Vegetable gardens and gathering and selling wild fruits are often dry season farming activities, but not so labor intensive.

13. Cliggett (2005) and Moore and Vaughan (1994) write about how old people and young children are often neglected during the farming months and left without adequate food and water in the house while people work in the fields.

References

Alonzo, A. A., and N. R. Reynolds. 1995. Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory, *Social Science and Medicine* 41 (3): 303–315.

Barnett, T., and A. Whiteside. 2002. *AIDS in the 21st century: Disease and globalisation.* New York: Palgrave, Macmillan.

Bharat, S. 1999. *HIV/AIDS related discrimination, stigmatisation and denial in India—a study in Mumbai and Bangalore.* Mumbai, India: Unit for Family Studies, Tat Institute of Social Sciences.

Bond, V. 1998. *Household capacity and "coping up" in rural Zambia: Dealing with AIDS, other illness and adversity in Chiawa.* Doctorate thesis, University of Hull.

———. 2002. The dimensions and wider context of HIV/AIDS stigma and resulting discrimination in southern Africa. In *One step further—Responses to HIV/AIDS,* ed. A. Sisask. *Sidastudies* 7: 29–53.

Bond, V., L. Chilikwela, S. Clay, T. Kafuma, L. Nyblade, and N. Bettega. 2003. "*Kanyaka*": "The Lights is On": Understanding HIV and AIDS related stigma in urban and rural Zambia. Report, Lusaka, KCTT and ZAMBART Project, www.icrw.org.

Castro, A., and P. Farmer. 2005. Understanding and addressing AIDS-related stigma: From anthropological theory to clinical practice in Haiti. *American Journal of Public Health* 95: 53–59.

CBOH, 1999, HIV/AIDS in Zambia, background projections, impacts and interventions, Ministry of Health, September.

Clay, S., V. Bond, and L. Nyblade. 2003. *We can tell them: AIDS doesn't come through being together.* Children's experience of HIV and AIDS related stigma in Zambia 2002–2003, Report, KCTT, ICRW, and ZAMBART.

Cliggett, L. 2005. *Grains from grass, aging, gender and famine in rural Africa.* Ithaca, N.Y.: Cornell University.

CSO (Central Statistics Office Zambia). 2003. Demographic and Health Survey 2001–2002. Lusaka: CSO.

Deacon, H., I. Stephney, and S. Prosalendis. 2005. *Understanding HIV/AIDS stigma: A theoretical and methodological analysis.* Human Sciences Research Council Research Monograph. Cape Town: HSRC Press.

Gilmore, N., and M. A. Somerville. 1994. Stigmatization, scapegoating and discrimination in sexually transmitted diseases: overcoming "them" and "us." *Social Science and Medicine* 39 (9): 1339–1358.

Goffman, E. 1963. *Stigma: Notes on the management of a spoiled identity.* New York: Simon & Schuster.

Herek, G., and Glunt, E. 1988. An epidemic of stigma: Public reaction to AIDS. *American Psychologist* 43 (11): 886–891.

Kelly, P., R. A. Feldman, P. Ndubani, K. S. Baboo, I. Timaeus, M. J. G. Farthing, and S. Wallman. 1998. High adult mortality in Lusaka [research letter]. *Lancet* 351: 883.

Lewis, S. 2003. *Keynote Lecture, UN Special Envoy for HIV in Africa, WHO 3 by 5 Initiative.* www.whoint/3by5/partners/Slewis/en/index3.html.

Link, B., and J. Phelan. 2001. *On stigma and its public health implications, stigma and global health: Developing a research agenda.* Washington, D.C.: National Institutes of Health.

LCS (Living Conditions Survey). 1998. *Living Conditions Survey.* Central Statistics Office, Zambia.

Moore, H., and M. Vaughan. 1994. *Cutting down trees: Gender, nutrition, and agricultural change in northern province of Zambia, 1890–1990.* Portsmouth, N.H.: Heineman.

Nyblade, L., R. Pande, S. Mathur, K. MacQuarrie, R. Kidd, H. Banteyerga, A. Kidanu, G. Kilonzo, J. Mbwambo, and V. Bond. 2003. *Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia.* Washington, D.C.: ICRW Publication with CHANGE-AED, MHRC, MUCHS, ZAMBART, and KCTT.

Ogden, J., and L. Nyblade. 2005. *Common at its core: HIV-related stigma across contexts.* Washington, D.C.: ICRW and CHANGE.

Parker, R., and P. Aggleton. 2003. HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science Medicine* 57: 13–24.

Sartorius, N. 2004. *Report of the Workshop on Health Related Stigma and Discrimination.* The Royal Tropical Institute, 29 Nov–2 Dec 2004, http://www.dgroups.org/groups/Stigmaconsortium.

Scrambler, G., 2004. *Report of the Workshop on Health Related Stigma and Discrimination.* The Royal Tropical Institute, 29 Nov–2 Dec 2004, http://www.dgroups.org/groups/Stigmaconsortium.

Scudder, T. 1983. Economic downturn and community unravelling: The Gwembe Tonga revisted. *Culture and Agriculture* 18 (Winter): 16–19.

UNAIDS. 2002. *Report on the global HIV/AIDS epidemic July.* Geneva: UNAIDS.

UNICEF. 1999. *Joint USAID/UNICEF/SIDA study fund project, orphans and vulnerable children: A situational analysis, Zambia 1999.* Lusaka: GRZ.

Wallman, S. 1988. Sex and death: The AIDS crisis in social and cultural context. *Journal of AIDS* 1: 571–578.

World Bank. 2002. *Poverty reduction strategy paper (PRSP) and joint assessment.* Zambia, Vol. 1, Report No. 24035.

Zambia Sexual Behaviour Survey. 2000. *Zambia Sexual Behaviour Survey.* CSO, USAID, MEASURE Evaluation, Zambia.