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HIV Testing, Tuberculosis, and AIDS Stigma in Kampala, Uganda

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Introduction

In 1987, Jonathan Mann, then the director of the World Health Organization's Global Programme on AIDS, addressed the United Nations General Assembly and described three phases of the AIDS epidemic (Mann 1988). Now widely repeated, this characterization distinguishes between three separate but related processes. In the first phase the human immunodeficiency virus is spread through populations. The transmission of the virus in this phase is silent. Infection is unknown to people who have contracted the virus or their communities. Next comes the epidemic of AIDS itself. After a few years of dormant infection with HIV, people begin to fall sick as their bodies' immune systems fail and they are overwhelmed with opportunistic infections. This is a phase of pain, suffering, and death, and it is accompanied by a third epidemic. "This is the epidemic," Mann explained, "of economic, social, political, and cultural reaction and response to AIDS virus infection and to AIDS."

As HIV/AIDS moves through a community and a nation, it becomes far more than a medical disease. The costs of caring for people living with HIV are tremendous and far beyond the means of average people living in the most affected countries. And the impact on a nation's economy can be devastating, because it is young and middle-aged people, the core of a work force, who bear the greatest burden of disease. Entire societies are at risk, Mann claimed, "As anxiety and fear cause some to blame others, AIDS has unveiled the dimly disguised prejudices about race, religion, social class, sex and nationality." Stigma becomes a powerful barrier to prevention and treatment efforts and has many negative effects on the quality of life for people living with HIV/AIDS. A successful response to HIV/AIDS, he argues, must address all three phases of the epidemic—prevention efforts, including vaccine development, to stop transmission of HIV, improved care and access to care to help keep people already infected from getting sick, and research and interventions to minimize the social impacts of the disease.

Today this approach to combating HIV/AIDS has been institutionalized in global public health policies at every level. These recognize the barrier that HIV-related stigma presents to efforts to prevent transmission and provide care to people living with HIV. The UNAIDS 2006 Report on the Global AIDS Epidemic states:

> Ending the AIDS pandemic will depend largely on changing the social norms, attitudes and behaviors that contribute to its expansion. Action against AIDS-related stigma and discrimination must be supported by top leadership and at every level of society, and must address women's empowerment, homophobia, attitudes towards sex workers and injecting drug users, and social norms that affect sexual behaviour—including those that contribute to the low status and powerlessness of women and girls. (UNAIDS 2006a)

The stigma surrounding HIV and AIDS was first described in Western countries, where the predominance of viral transmission through homosexual sex and injection drug use led to discriminatory attitudes that grew from and reinforced prejudices against already marginalized groups. Early research and theoretical work focused on the interactions between sexuality, race, and stigma (Herek and Glunt 1988). Today, developing countries bear the greatest burden of the pandemic and the primary mode of transmission is heterosexual sex (UNAIDS 2006a). But around the world, caregivers, providers, researchers, and policy makers recognize that HIV-related stigma remains a barrier to prevention efforts, keeps HIV positive people from getting life-saving care, and is, in a way, a pathology itself with adverse effects on both the physical and mental health of people living with HIV.

The last ten years have seen an explosion of research into HIV stigma. Theoretical work from the behavioral sciences has attempted to explain the origins and psychological underpinnings of stigma. Descriptive studies have characterized the way that discrimination and denial manifest themselves in different communities, and others have evaluated interventions to reduce HIV stigma. Recently researchers have also documented the way that this stigma has begun interact with the stigma related to tuberculosis, one of the common opportunistic infections affecting people with HIV. Despite all this work, the third dimension of the HIV/AIDS pandemic remains incompletely understood, and without a clear understanding of stigma, interventions with the best intentions will not be completely successful in reversing either the toll of disease or the social disruption that the virus brings with it.

Theories of Stigma

The word stigma comes from a Greek word meaning "a mark," and by the seventeenth century took on the more metaphorical meaning of "a mark of disgrace." In medicine, a stigma is a visible sign that a person has a particular disease, but discussions of stigma today focus not on the mark or outward signs but on that characteristic which changes the way an individual or group is treated by the rest of society. Discussion of stigma in the social sciences generally begins with Erving Goffman's definition and description. In his 1963 book, *Stigma: Notes on the Management of a Spoiled Identity*, Goffman describes what it means to possess "an attribute that is deeply discrediting" (Goffman 1963). Stigma reaches well beyond the tattoos that marked slaves as property or the rashes that doctors use to identify disease. Instead the word stigma "is applied more to the disgrace itself than to the bodily evidence of it." This disgrace may be almost any trait in which an individual deviates from others' expectations or from societal norms. Among other attributes, stigma may be attached to a person's race, sexuality, occupation, disability, or disease. Any of these things can serve to make an individual "reduced in our minds from a whole and usual person to a tainted, discounted one."

One important point in Goffman's formulation of stigma is that, while it is a phenomenon focused around an attribute, what it really represents is an entire social arrangement. No trait is by itself immoral or deviant or stigmatizing. Instead, the norms and values of the rest of society—the stigmatizers or the in-group—define what behavior or appearance is expected from the others. This observation helps to explain how the extent to which an attribute is stigmatizing varies from one setting to the next. For example, being gay is far less "discrediting" in a relatively tolerant city like San Francisco than in a country, such as Uganda, where homosexuality is illegal. Alonzo and Reynolds extend this farther and take stigmatizing attitudes as signs of "culturally imbedded meanings." Any definition of deviance must be understood "in the context of a particular historic period and cultural context" (Alonzo and Reynolds 1995).

Although social stigma may be attached to nearly any personal attribute from race to occupation, disease is a common focus across cultures. Illness is a natural and universal part of life, but it does represent a deviation from a presumed state of optimal health, and disease is often accompanied by morbidity or disability that presents an obstacle to social interaction. The stigma that surrounds illness shares many of the basic qualities and functions of other kinds of prejudice. For example, a sick person, like any stigmatized individual, has lost some social value and may be excluded from full community membership. But avoiding diseased people also serves a psycho-protective function to the stigmatizers. In a process that Crocker and colleagues call "terror management," stigma provides "a worldview and meaning system that buffers one against existential anxiety" (Crocker, Major et al. 1988). Because people live with the knowledge that the universe is uncontrollable and that they will inevitably die, they construct cultural beliefs to buffer them from these truths. The same notion of terror management may account for the stigma towards people with what Goffman calls "abominations of the body." These are outward signs that remind us of our mortality—for example, pain, scars, or disability. Discriminatory attitudes help a stigmatizer to shield him or herself from his own fate by discrediting those who make sickness and death so obvious. Experimental findings suggest that people are more punitive towards those who violate cultural norms, when they are reminded of their own mortality (Rosenblatt, Greenberg et al. 1989). While this has implications for understanding stigma towards any disease condition, it may be particularly instructive in the context of HIV/AIDS, which is strongly associated with groups who are already stigmatized. The prejudice against, say, men who have sex with men or sex workers, is magnified if those groups become associated with a fatal disease.

Goffman began a tradition of identifying different sources of stigma. He described "abominations of the body," "blemishes of individual character," and "tribal stigmas" that are associated with familial lineages. Other authors have expanded this list to include other dimensions, which may trigger or exacerbate the stigmatization of specific attributes (Katz 1979). Alonzo and Reynolds merge several of these dimensions into a list of six characteristics that help to explain an illness's stigmatization (Alonzo and Reynolds 1995). First, an illness may be the focus of stigma, if it is associated with behaviors that are already stigmatized or deviant. The behavior in question may be marked as a cause of the disease, as is the case with sexual activity and sexually transmitted infections or cigarette smoking and lung cancer. Or, the deviant behavior may be seen as a result of disease, as is often the perception with mental illness. In either case, the association of an aberrant behavior with a disease can be enough to discredit people with the disease, whether or not the association is based on any true link. Susan Sontag documented numerous historical examples of spurious associations made between cancer and behaviors considered unhealthy, including eating too much, working too much, repressing emotions, or feeling too much grief or anxiety (Sontag 1990). In addition, the stigmatization of a specific disease may even extend to people who have not done the supposedly deviant behaviors. This is seen in the discrimination against those who contracted HIV through blood transfusions and people who live stable lives despite a diagnosis of mental illness (Herek and Glunt 1988; Stuart 2006).

The judgment that a behavior is deviant—and the associated stigma—becomes even stronger when there is a religious sanction against it. This is the case in the many churches and mosques around that world that have condemned HIV/AIDS as an immoral disease because of its association with illicit sex (Rankin, Brennan et al. 2005). Even when an illness is not explicitly associated with morally prohibited behavior, it may be the target of stigma that is authorized by religious institutions. And the weight of religious disapproval invariably increases the stigma surrounding disease. The Bible's treatment of leprosy is one example of this, but throughout history many diseases—from epilepsy to HIV/AIDS—have been viewed as plagues invested with religious meaning (Devine, Plant et al. 1999; Baskind and Birbeck 2005).

Another factor that can help determine whether and to what extent a disease is associated with stigma is its association with individual responsibility. Even if the behavior associated with an illness is not, by itself, a deviant act, there is a tendency for greater disapproval if blame can be attached to it. This may account for differential treatment of smokers and non-smokers who develop lung cancer (Sontag 1990).

Diseases that are perceived to be very contagious tend to be stigmatized more than non-infectious diseases. This may manifest itself as a rational avoidance of people likely to transmit disease, such as those with active tuberculosis (TB), but in other cases the perception of the risk of infection greatly exceeds any real risk of disease transmission. This can be seen in the tremendous stigma associated with both HIV and leprosy, two diseases that cannot be transmitted through casual contact.

The outward manifestations of a disease also play a role in determining how they are stigmatized in the public imagination. An illness associated with obvious outward signs, such as skin lesions or hair loss, tends to be associated with greater stigma. This may be partly explained by people's instinct to distance themselves from those who may present a risk of infection or an aesthetic aversion to physical blemishes. The stigma associated with visibly obvious disease may also be related to the way in which those signs remind the stigmatizer of his or her own mortality. Indeed, it is not only the outwards signs of a disease but the nature of the death associated with it that helps to determine the strength of the stigma towards it. While there are few deaths that are actually seen as desirable, there are deaths that are particularly distasteful and difficult. Diseases associated with long periods of deterioration and a painful death are the targets of greater stigma (Alonzo and Reynolds 1995). Some diseases are especially stigmatized if they are considered by the general public to be incurable. This was true in the early years of the HIV/AIDS epidemic, when the only course of disease progression was towards greater morbidity, disability, and inevitably death (Herek 1999). Even for diseases for which treatments are available, the perception of incurability is enough to create a fear of the disease and those it affects. Herek notes that, because highly active antiretroviral regimens do not work for all people with HIV and are not available to all those who need them, "AIDS will probably continue to be perceived as a fatal disease by most of the U.S. public for the foreseeable future." Even tuberculosis, considered a curable disease in much of the world, is highly stigmatized by people who are unaware of do not understand the available treatments. In a survey of TB-related stigma in

Ethiopia, more than one-third of those who reported that they were afraid of the disease said this because they believed it to be incurable (Gelaw, Genebo et al. 2001). The authors concluded that this was among the "most important factors contributing to the fear, social isolation and resultant stigmatization of those afflicted by the disease in the capital and other regions of the country."

The final dimension of disease that contributes to its stigmatization in Alonzo and Reynold's list is the extent to which it is "understood by the lay community and viewed negatively by health care providers." While a good understanding of the causes and effects of a disease do not guarantee that it will remain free of stigma, it is much easier for people to stigmatize a disease about which their knowledge is incomplete. This is true of diseases like cancer whose etiologies are multi-factorial and poorly understood, and it is especially true of emerging diseases that are still mysterious to medical science, such as HIV in the 1980s or the severe acute respiratory syndrome (SARS) that appeared in 2003 (Mak, Mo et al. 2006).

While the biologic characteristics of a disease like HIV/AIDS—sexual transmission, a mysterious origin, and visible morbidity—help to understand why it is particularly stigmatized, a model from Link and Phelan explains the social process by which the fear and concern about a disease are translated into discrimination against affected individuals (Link and Phelan 2006). They describe five overlapping components, which combine to create a stigma. The first of these steps is simply the identification and labeling of difference. Next, cultural beliefs attach undesirable characteristics to labeled individuals, stereotyping them. In the third component, the in-group creates some separation from the stigmatized Other, and in the fourth, there is discrimination and loss of social status. Finally, a fifth component is necessary, the exercise of power. Without the access to social, economic, or political power, stigmatizers cannot enact any of the other steps towards the stigmatization of others.

A sociological model as simple as Link and Phelan's has several advantages for both the conceptualization of stigma and the practical work of ameliorating its effects. First, it emphasizes the underlying social principles and structures that create a social stigma. Rather than focusing on the characteristics of any single disease, the authors recognize the complexity of social relations that lead to discrimination. This allows for a new, broader definition of stigma, such as Reidpath and Chan's description of stigma as "the whole gamut of social processes (including cognitive processes) that exclude people (or, more generally, classes of people) from community membership" (Reidpath, Chan et al. 2005). Guided by this conception of stigma as an expression of underlying beliefs and values, research and interventions into disease-related discrimination broaden their focus from the lived experience of the affected individuals to include the social, economic, and political environments in which stigma is enacted. Theoretical and empirical work from the social sciences explicates some of the diverse forces at work in each of Link and Phelan's five components.

Identifying and labeling differences

While there are countless differences among humans, few become socially relevant enough to become stigmatized. Skin color and intelligence are relatively easy to observe and tend to be important in many social situations. Medical conditions are not always as obvious, and there is considerable variation in the social consequences of ill health. Psychological theories based on evolution offer some explanation for how humans identify differences in health and how much significance is given to them. Kurzban and Leary describe a collection of cognitive adaptations that people use to identify those who may bear a risk to the survival of others (Kurzban and Leary 2001)[1]. Among these is the capacity for avoiding infection. Humans, following this theory, have developed detection systems that help them avoid contact with those who are infected with parasites that are likely to infect them. There are many examples from animal communities of the ways that uninfected individuals avoid and exclude those with obvious signs of infectious disease (Clayton 1990). Some of these examples are so simple that their application to human behavior is obvious. There is nothing remarkable about the ability to recognize or avoid an animal or person infected with rabies. If there is a strong survival advantage to avoiding infection, then it is reasonable to expect modern humans to have developed cognitive and behavioral tools to

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[1] Any attempt to explain modern social phenomena through evolution must demonstrate that those human traits and behaviors provide a reproductive advantage over people who do not possess those characteristics. Because there is little evidence available from the history of human evolution, Kurzban and Leary rely on observations from non-human animals to support their own theories of the origin of social stigma. While their argument, expanded by Reidpath and Chan among others (Reidpath, Chan et al. 2005), does offer a logical framework for understanding stigma and discrimination as rooted in the human survival instinct, it is unlikely that it will ever amount to anything more than a speculative theory. Plausible as it is, the theory falls prey to hazards common to other efforts in evolutionary psychology. Among these is a tendency to over-simplify direct connections between modern social phenomena, reproduction, and survival. Also, while evidence from zoology may be appealing, we can only extrapolate this evidence to human society very carefully.

do so. Kurzban and Leary suggest three qualities expected from these "parasite detection systems." The first is that humans should be able to detect and avoid signs of pathogens. Our aesthetic preferences may be an example of such a mechanism. Humans tend to avoid obvious signs of infection such as rashes and scars, and we tend to be attracted to signs of health such as symmetry (Grammer and Thornhill 1994). A second prediction that follows from Kurzban and Leary's argument is that humans should tend to avoid close contact and the exchange of bodily fluids with those who have outward signs of infection.

More subtle is the prediction from evolutionary psychology that humans' systems for detecting and avoiding infection will be biased towards "false positives." There is a wide variability in the effects that pathogenic organisms can have on their hosts, from a mild cough to gangrenous lesions, and there is a wide variability in the appearance of individuals, whether they are infected or not. That means that many healthy people will appear sick and some who appear sick will really be healthy. The cost of misjudging the former—avoiding exchange and friendship with healthy people—is low compared with the disability or death risked in contact with sick people. As a result, humans may have hypervigilant detection systems that lead them to stigmatize and discriminate against people who demonstrate even a suggestion of illness. For example, if people with a non-contagious disease exhibit symptoms suggestive of a parasitic infection, the false positive detection of risk could lead to fear and avoidance of these people. The strength of humans' evolved facility for evading disease may explain irrational stigmas such as avoidance of people with cancer or discrimination against people with HIV that is far out of proportion to the real risk of infection.

In addition to individual cognitive labeling systems, there are cultural naming and organizational schemes that identify people or groups which deviate from societal expectations. This is ubiquitous in the lay language that people use to describe the Other, but medical science and epidemiology also play a role in labeling difference and grouping people. Naming a disease and all its parts is essential to the practice of medicine. Epidemiology, too, is based on the identification of risk groups and tallying of associations. Indeed, HIV disease itself was only identified, when doctors began linking unusual pneumonias in a cluster of gay men in Los Angeles (Centers for Disease Control and Prevention 1981). Because the medical sciences bear so much power and authority, though, labeling a syndrome or a risk group carries extra weight and importance. Categorizing people by risk has been a core strategy in HIV prevention and case finding, but the practice also has the effect of stigmatizing those who are most in need. This is what Carol S. Goldin calls the "risk group problem" in her paper on the public health impact of HIV-related stigma (Goldin 1994). Although the notion of risk began as an identification of risky behaviors, associated with viral transmission, "the concept has been broadened in the public press so that *all* persons within a group are considered, because of association with that group, to be contaminated and dangerous." In the United States, men who have sex with men and injection drug users were among those who were stigmatized in this way by the both healthcare providers and the general public (Devine, Plant et al. 1999). In sub-Saharan Africa, it was migrant workers and sex workers who were further alienated by the logic of risk group membership. In her 1994, paper Goldin suggests that the fear of being identified with a stigmatized group may lead some people to avoid testing or care. Measuring the size of this hypothesized effect has been difficult, but a study of HIV positive women in Australia does find evidence of the way physicians have misused the notion of risk group to make assumptions about patients' HIV status (Lawless, Kippax et al. 1996). Women reported that their doctors delayed or dismissed the need for HIV testing if they were white, middle-class heterosexuals. And when some women requested HIV tests, they were subjected to suspicious questioning about drug use and sex work.

Stereotyping

Link and Phelan describe stereotyping as the process of associating labeled people or groups with undesirable characteristics. This may follow naturally from the labeling process described above, if his or her labeled difference makes an individual less socially valuable. Kurzban and Leary offer an evolutionary explanation for stigma that explains how humans might use it to maximize the fairness of social exchanges (Kurzban and Leary 2001). In order to increase the chance of trading resources with a trustworthy partner and avoid the risk of dealing with those likely to renege on an agreement, humans developed heuristics to help identify cheaters and exclude them from social transactions. Because complete knowledge of trading partners is impossible, humans have evolved cognitive tools to help predict which people are likely to be unreliable. One such tool is the exclusion or avoidance of those with unpredictable goals and behaviors. This might explain, Kurzban and Leary suggest, the stigma against people with mental illnesses that make them deviate from social norms. Further, anyone who subscribes to unfamiliar customs, religion, or behavior, could be seen as less predictable and therefore a poor choice for partner in social exchange. Another cue that someone might have little to offer in a trade is that they currently have no resources to offer. While this may be a trivial explanation for the exclusion of poor people from social exchange, it can be expanded to describe also the stigma against people whose age or illness reduces their ability to participate in exchanges. Similarly, those who lack valuable personal connections or social capital would be excluded through this mechanism.

In addition to improving the chances of success in a dyadic exchange, social stigma may arise from an evolutionary drive to enter into coalitions that improve individuals' access to resources (Tooby and Cosmides 1988). A similar psychology explains the choice of trading partners and group members. Humans tend to enter into coalitions with others who are predictable, able to contribute, and follow the agreements of the group. Some stigma arises from the efforts to exclude those considered unsuitable to join the group, but further discrimination comes from the groups' efforts to exploit outsiders or members of subordinate groups. This conclusion is supported by research that shows that when people consider themselves members of groups they tend to be more discriminating, competitive, and violent towards members of other groups (Schopler, Insko et al. 1993).

The evolutionary explanation of stereotyping attempts to explain it in terms of the survival advantage that social exclusion and avoidance provides to people who discriminate against others who are poor social exchange partners, but there are also powerful cultural values at work when people are excluded from full membership in their communities. Stereotyping is not simply attaching negative characteristics to a group. Goffman described it as a reflection of underlying inequalities, but Parker and Aggleton go further and theorize that social stigma is also a way to legitimize existing power structures (Parker and Aggleton 2003). This is an especially important distinction in the case of HIV/AIDS, which arrived superimposed on established social inequalities. As Alan Novick observed, "over 95% of persons with AIDS in the United States belong to social groups whose fundamental human rights had been truncated long before HIV had appeared—gay men, injection drug users, African-Americans, Hispanics, and sex workers. All of these people had been isolated, ostracized, or constrained by law and/or tradition from occupying full citizenship" (Novick 1997). While the marginalization of these groups probably contributed to their increased risk, their discrimination was compounded when they became publicly identified with HIV/AIDS. Indeed, national telephone surveys in 1996 and 1997 found that AIDS was "strongly linked to homosexuality in the minds of most Americans" and this perception was the strongest in those with the most hostile attitudes towards homosexuals (Herek and Capitanio 1999). A complete understanding of the stereotyping process, Parker and Aggleton write, "requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings." This perspective has practical implications for further research or interventions designed to reduce the stigma related to HIV or any other attribute. Questioning the role of stigma or attempting to alter it forces an examination of societies' hierarchies and inequalities. An investigation of stigma, following Parker and Aggleton, necessarily implicates all of a society's cultural values and institutions. In research related to HIV stigma, which focuses largely on developing countries, AIDS must be understood in the context of global capitalism that is characterized by the growing polarization between rich and poor, with women being especially affected by poverty. Also, the power of HIV-related stigma is linked to increasingly important politics of identity that define both groups that hold power and those at the margins. HIV, then, is only one attribute among many others—including gender, poverty, and civil empowerment—that define the hierarchies of social exclusion. Recognizing these complications to stigma makes further research exquisitely complicated, because it requires an approach broad enough to capture all of a culture's inequalities. The individualistic approach that is traditional in biomedical research, Parker and Aggleton suggest, may be less appropriate than one based in "community mobilization and social transformation."

Separation

Following labeling and stereotyping, the separation stage in Link and Phelan's model establishes a clear in-group, the stigmatizers, and an out-group, the stigmatized. This is the stage when the negative associations of a stigma are entrenched and become part of the identity of the Other. In their chapter on social stigma, Jennifer Crocker and colleagues explain some of the psychological functions that this separation may serve. On the individual level, stigma works to enhance the self-esteem of the stigmatizer. Recognizing "a downward comparison target" allows one to feel superior and improve his or her own self-image (Crocker, Major et al. 1988). At the group level, the same phenomenon helps to explain how derogating an out-group can help another group to maintain a collective identity. This explains why some groups make such efforts to distinguish themselves from others with whom they are in competition, but in-group bias has been found even when there is no direct benefit to the individual or the group (Vanbeselaere 1993). This finding suggests that stigmatizing may help to build collective self-esteem irrespective of any practical advantage that the group might hope to gain.

Another function of stigma operates at both the individual and group level. Discriminatory views and prejudices serve to justify the inequalities that exist in all societies. In social dominance theory, societies create ideologies that help people to feel that they deserve their privilege and that legitimate the systems that disproportionately benefit some people more than others (Crocker, Major et al. 1988). Pratto and colleagues suggest an example of such a myth that may be useful on an individual level (Pratto, Sidanius et al. 1994). The myth of meritocracy in the United States says that people get ahead, gain money and social status, through their own hard-work and acumen. Accepting this notion allows people to associate poverty with a lack of merit. In this view, poor individuals become discredited and, therefore, less deserving. Collective groups use the same system-justifying ideas to justify and maintain their power. Racism, one of the most widespread forms of stigma, has been used as a tool to explain and perpetuate white privilege in the United States. In this example, discrediting and derogatory character attributes are associated with an unrelated trait, skin color, in order to validate the privileges of the majority and excuse the inequities faced by people of color.

When it comes to HIV-related stigma, dividing the infected or at-risk from the rest of the population has consequences for both groups. First, people who are already infected with HIV are blamed, because their disease is taken to be a result of their own deviant behavior. Blame is one of the clearest and most conspicuous manifestations of HIV-related stigma (Herek and Glunt 1988; Herek and Capitanio 1999). Uninfected individuals are then "presented as innocents, threatened not by their own risk behaviors but by guilty, blameworthy others" (Devine, Plant et al. 1999). Even AIDS education materials contribute to this distinction by emphasizing an us-versus-them theme (Croteau and Morgan 1989). One result of this distinction is that people who do not belong to one of the stigmatized "risk groups" may discount their own risk because they see HIV as a problem of the Other (Goldin 1994).

Status loss and discrimination

When people have been labeled, set apart, and connected to undesirable characteristics, there is a rationale for the in-group to devalue them and restrict their participation in the community. This component represents the most obvious forms of enacted stigma from neglect and avoidance to overt violence, but there is a wide range of such manifestations that includes many more insidious examples as well. In the case of HIV-related stigma, gossip and embarrassment are among the ways people are treated differently. More obvious examples of the status loss associated with stigmatization, though, include neglect or ostracism by family members. At the community level, stigmatized people may be avoided or excluded from social institutions, such as churches. People living with HIV/AIDS may lose their current jobs or housing or find it difficult to find new employment. And in healthcare settings, they may be denied care, given lower quality care, or have their privacy violated because of their HIV status (Rankin, Brennan et al. 2005; Lunga, Angami et al. 2007).

Because HIV-related stigma touches nearly every aspect of social interaction and also affects the psychological well-being of people with HIV, their families, and caregivers, it leads to discrimination that violates their human rights. Kohi and colleagues reviewed the narratives of people living with HIV/AIDS (PLWHA) and nurses for examples of stigma that contravene specific elements of the Universal Declarations of Human Rights and the African Charter on Human and Peoples' Rights (Kohi, Makoae et al. 2006). The latter document, adopted in 1981, has been ratified by 53 African states, including five countries studied in the African-University of California, San Francisco, Stigma Study. Subjects in that qualitative study mentioned many examples of people with HIV being denied medical care that is available to others in their community, in violation of provisions that mandate equal access to public services (United Nations General Assembly 1948; African Union 1981). Nurses in the study described stories of the denial of care in hospitals and also of family members who refused to take care of their loved ones with HIV. "Inhuman and degrading" treatment is also prohibited by the human rights documents, but 54 incidents of verbal and physical abuse were reported in focus groups. Others mentioned the deprivation of food, opportunities to produce food, and credit, despite provisions for an adequate standard of living, even in sickness. The right to work is also guaranteed, but many participants reported that people with HIV were dismissed from their jobs—even while healthy—when employers learned their serostatus. Privacy is also protected by the Universal Declaration of Human Rights (although not by the African Union's Human Rights Charter), but breaches of confidentiality and unwanted disclosure of serostatus are frequent experiences of people living with HIV. The most common human rights violation, though, in the Stigma Study was rejection. Both human rights documents recognize the dignity of human beings and aim to protect them from threats to life and security, but HIV-related stigma in Africa commonly leads to family and societal rejection, isolation, and expulsion from home or communal facilities.

Stigma's effects on health

Stigma can have drastic effects on the social fabric, from disrupting personal relationships to the human rights violations described above, but there are also direct consequences to the health of stigmatized individuals. Several mechanisms may operate simultaneously. First, there are the psychological stresses of belonging to a stigmatized group (Link, Struening et al. 1997). Also, the fear of discrimination and mistreatment may cause some people to avoid healthcare services. Many groups have been observed to delay care because of the stigmatization they face throughout society, including immigrants and injection drug users (Ford, Wirawan et al. 2004; Nadeem, Lange et al. 2007). And people with stigmatized diseases may avoid seeking care that could cure them or improve their quality of life, rather than face being identified as sick. Studies of tuberculosis patients in the Gambia, Vietnam, and Nicaragua have found that TB-related stigma may dissuade or delay some patients from using healthcare services (Long, Johansson et al. 2001; Katamba, Neuhauser et al. 2005; Macq, Solis et al. 2005), and stigma is a commonly cited reason for people not to seek HIV antibody testing (Chesney and Smith 1999). Once stigmatized people do enter healthcare services, they may continue to be discriminated against by providers who either deny care or provide lower quality care. Differential provision of services may be based on stigmatization of groups for any number of reasons. In the United States, disparities in healthcare based on race and ethnicity are well documented. Patients' behaviors may also affect the way they are treated by providers. For example, in a 1992 survey 41% of medical residents in three developed countries indicated that "If given a choice, I would not take care of any injecting drug users" (Scambler and Hopkins 1990). Additionally, an individual's disease may, by itself, lead to mistreatment by healthcare providers (Busza 2001; Monico, Tanga et al. 2001).

While the studies described above focused on the manifestations and extent of HIV-related stigma among the general public, others have looked specifically at the ways that this stigma affects the psyche of people living with HIV. Holzemer and colleagues identified four domains of internalized stigma, the "thoughts and behaviours stemming from the person's own negative perceptions about themselves based on their HIV status" (Holzemer, Uys et al. 2007). These sub-categories included a negative self-evaluation, social withdrawal, self-exclusion because of the fear of discrimination, and fear of disclosures. Other studies have shown the impact of these internalized forms of stigma on the mental health and health-related behaviors of people living with HIV/AIDS (PLWHA). Crandall and Coleman's 1992 survey of HIV positive people in ten states found that those who reported the most stigma also experienced the most anxiety, depression, and alienation (Crandall and Coleman 1992). Although it was not clear whether the stigma had caused negative affect or vice versa, both factors were associated with a loss of social support and a disruption in social relationships. A qualitative study of the experiences of Australian women living with HIV found that they experienced discrimination from their healthcare providers (Lawless, Kippax et al. 1996). This took the form of refusals of care, assumptions that the women were sex workers or injection drug users, and even coercion to have abortions or sterilization procedures. Regardless of the mode of HIV transmission, these women were seen as having "departed from the socially prescribed behaviour worthy of 'good women,'" and they described the ways in which they internalized others' assumptions and experienced an "enormous burden of self-blame, guilt, and sense of responsibility" (p. 1375).

A more recent study of the experiences of HIV positive men and women in Cape Town, South Africa found that more than 40% had experienced discrimination since testing positive (Simbayi, Kalichman et al. 2007). These experiences were correlated with internalized stigma, reflected in negative self-perceptions, self-abasement, self-blame, and concealment of HIV status from others. In turn, internalized stigma was correlated with substance use, depression, and poor social support. These findings were consistent with a study of PLWHA in the United States that found higher levels of internalized stigma to be associated with anxiety and hopelessness, in addition to depression (Lee, Kochman et al. 2002). This has implications for the provision of antiretroviral therapy, because depression is associated with lower treatment adherence, particularly in those with low health literacy (Kalichman, Ramachandran et al. 1999).

Ethnographic research from another community in South Africa found that stigma kept HIV positive people from disclosing their serostatus to others, because of a feared loss of social status (Mills 2006). Some people with HIV refused to attend clinics or allow visits by home-based care-givers, for fear of being identified as HIV positive. Others went to great lengths to conceal their serostatus, attending distant clinics, hiding pill bottles, or crushing their antiretroviral medicines to a fine powder. Another South African study found a 14.8% prevalence of post-traumatic stress disorder (PTSD) among patients recently diagnosed with HIV infection (Olley, Zeier et al. 2005). In some cases, the index trauma was intimate partner violence or sexual assault, but for 36% the knowledge of the diagnosis of HIV/AIDS was the traumatic trigger of PTSD.

Stigma and public health

The health consequences of stigma extend beyond the psychological stresses and discrimination faced by individuals who are discriminated against. There are some situations, in which an entire population suffers on account of the stigmatization of one group. Reidpath et al. cite the United States, where "stigmatizing attitudes by White Americans towards African Americans appears to result in White Americans disinvesting from general social infrastructure" (Reidpath, Chan et al. 2005). In addition, diseases that are stigmatized or associated with stigmatized groups are treated differently in public policy and public health programming (Herek and Glunt 1988). In the 1980s, physicians reported that stigma kept them from recording AIDS as a cause of death on death certificates or reporting cases to surveillance systems (King 1986). As HIV/AIDS became associated with homosexuality in the public discourse (Herek and Capitanio 1999), policy debates about prevention programs became increasingly imbued with moralistic tones that led to further stigmatization of people living with HIV. Congressman William Dannemeyer argued for the reinstatement of sodomy laws (Dannemeyer 1989), and the Senate twice approved a legislative amendment from Senator Jesse Helms, prohibiting federal funding of AIDS education "material or activities that promote, encourage or condone homosexuality" (Associated Press 1987). In 1996, the U.S. Congress mandated the discharge from the armed services of HIV positive military personnel, regardless of their health and abilities to perform their duties (Shenon 1996). Such expressions of stigma in public policy marginalize people living with HIV and make it harder for them to get the support and healthcare that they deserve, but these actions also have a consequence for the greater public. Legislators and public figures have a disproportionate power to "control the framing or defining of an issue" (Devine, Plant et al. 1999). Prohibition of effective and proven prevention efforts or disapproval of a group at risk changes the tone of public discourse. Rather than being driven by medical science, the discussion is colored by tones of discrimination and moral judgment. This changes the terms of debate for the majority—the un-stigmatized population—and affects the support they are willing to lend to public health efforts aimed at groups, who their leaders condemn. Castro and Farmer make an even broader argument that structural violence—the sum of large scale forces such as racism, sexism, political violence, poverty, and other social inequalities—not only determines the extent of HIV-related stigma and restricts stigmatized people's access to HIV prevention and treatment but also predisposes them to HIV infection in the first place (Castro and Farmer 2005).

The trajectory of HIV-related stigma

HIV/AIDS has the biological and epidemiological characteristics to become exceptionally stigmatized. As discussed above, the transmission of HIV is associated with taboo behaviors—sex and drug abuse—and is most prevalent in groups that are already stigmatized—men who have sex with men, commercial sex workers, drug users, and migrants. Around the world, people with HIV/AIDS are blamed for their disease and condemned as deviant (Rankin, Brennan et al. 2005). As their immune systems fail, people with HIV disease are attacked by mysterious and disfiguring opportunistic infections for which there are few treatments. These characteristics have been enough to cause fear and denial of HIV/AIDS in both infected and uninfected people, but Alonzo and Reynolds describe a natural history of HIV stigma in which emotions and understanding of the disease evolve over time (Alonzo and Reynolds 1995). HIV-related stigma is not a static phenomenon, but a series of stages that begins before an individual becomes infected and develops along with the course of health and illness. The trajectory that Alonzo and Reynolds depict begins with a stage of pre-stigma, the "at-risk" phase. People in this stage are not known, by themselves or others, to be infected with HIV, but they know that they are at risk. They live with the awareness that some of their behaviors or their identification with some group makes them susceptible. People living in the "at-risk" phase are cognizant not only of the possibility of that they are or will become infected with HIV but also of the consequences of HIV infection. These consequences include not only the threat to health and well-being that AIDS represents but the social repercussions that accompany it. This is a stage of pre-stigmatic fear, where individuals are discredited solely by their membership in an at-risk group and fearful of " moving into the stigmatized category." Individuals may manage their fear in many different ways, but among the most common is the strategy of denial (Muyinda, Seeley et al. 1997; Monico, Tanga et al. 2001). In this stage of pre-stigma, individuals may diminish their perceived risk by discounting "relevant educational material" or adopting a "sense of invulnerability" (Alonzo and Reynolds 1995). Others may deny their risk by thinking about HIV in categorical terms. For example, a promiscuous heterosexual may reduce his or her perception of risk by imagining that only circumscribed groups—homosexuals or drug users—become infected with HIV (Weitz 1989). Another way of denying the risk of HIV infection and delaying the next phase of stigma is to avoid HIV testing. While HIV antibody tests are accurate and offer important knowledge to both infected and non-infected individuals, a positive test represents an irreversible passage from membership in a group that is merely "at-risk" to one that is clearly stigmatized. For some people, Brashers and colleagues suggest, avoiding the certainty of an HIV test may be "preferred to reducing uncertainty because eliminating uncertainty also can eliminate hope" (Brashers, Neidig et al. 1998).

Once an individual does have a positive HIV test, he or she must face a new stage of stigma, confronting a new social identity. People newly diagnosed with HIV infection are challenged by the biologic realities of living with the virus, and they simultaneously become members of a stigmatized group, people living with HIV. A typical stress response to a new HIV diagnosis may be "characterized by disbelief, numbness and denial, followed by anger, acute turmoil, disruptive anxiety and depressive symptoms" (Alonzo and Reynolds 1995). Along with coping with a new health concern, people in the diagnosis phase of HIV-related stigma must manage their social status by engaging in what Goffman named "information management" (Goffman 1963). This is the process of deciding how, when, and to whom to reveal a stigmatized identity. For people living with HIV, this process includes balancing the need for social, financial, and medical support with "fear of rejection, avoidance of pity, the wish to spare loved ones emotional pain and concerns about discrimination" (Alonzo and Reynolds 1995). In some cases, an HIV positive diagnosis becomes the impetus for revealing a previously concealed stigmatized identity. Gay men, sex workers, or drug users, whose friends, families, employers, or healthcare providers were unaware of these identities, must decide carefully how to the manage the process of disclosing their "double stigma." For many this is a difficult and stressful challenge (Herek and Capitanio 1999).

The third stage of HIV stigma, in Alonzo and Reynolds's trajectory, is the latent phase, but it is the symptoms of disease and not stigma itself that is latent. In this phase, people living with HIV are otherwise healthy and, because they do not show signs of illness, they are able to conceal their infection or choose to reveal it. Concealing one's HIV status may preserve social relationships and protect self-esteem, but it brings some of its own burdens. People living with HIV report that it can be emotionally exhausting to "remember who has been told and who has not, what was told to whom." In addition, people who keep their diagnoses secret deprive themselves of the opportunity for social support from people who would not stigmatize them. They may avoid doing things that could be beneficial, like seeking appropriate healthcare, joining support groups, or practicing safe sex, because these would signal their HIV status to others. Of course, many people in the latent stages of HIV infection choose the risks of disclosure over the challenges of concealment. This exposes them to enacted stigma in all its forms of rejection, denial, and discrimination, but also allows them to prepare for stages of the disease that are harder to keep secret.

The fourth and final stage of HIV stigma comes with the manifestations of AIDS, a weakened immune system, opportunistic infections, symptoms, and, for some, more intensive medical care. While the advent of highly active antiretroviral therapy has allowed some patients with HIV to return to an asymptomatic phase after severe immunosuppression, without treatment the course of AIDS is unrelenting. One social consequence of this is that the signs and symptoms of the illness (and the associated therapies) become more and more difficult to hide. Even when HIV remains concealed as the ultimate cause, people must adopt a new identity as patients. This means that they depend on caregivers and healthcare providers in new ways. The stigma of this stage may be intensified as the disease becomes obvious to outsiders and symptoms decrease the opportunities that people with HIV have for social interaction. For some patients, the outward manifestations of AIDS help others to understand the condition and provide opportunities for support and expressions of sympathy (Alonzo and Reynolds 1995). But for others, the onset of symptoms means that they can no longer work and fill a productive role in their households. Reports from Uganda suggest that stigmatization within a home increases as the HIV positive person becomes a net burden on the family's resources (Monico, Tanga et al. 2001).

Assessing HIV-related stigma

Alonzo and Reynolds's theoretical trajectory of HIV stigma was based on early research into the experiences of people with HIV and their caregivers. Most of this literature was based on qualitative studies or case reports, but the last ten years have seen an explosion of empirical studies into stigma, both the perspectives of people living with HIV and those of the general public. In Western countries, where HIV/AIDS is strongly associated with gay men and injection drug users, many studies focused on the interactions of HIV-related stigma with prior prejudices. With growing efforts to combat HIV in the developing world, though, research looked to how stigma creates a barrier to prevention and treatment programs, even in places where heterosexual contact is the primary mode of transmission. While some authors have investigated HIV-related stigma as an instrumental variable, others focus on the phenomenon of stigma itself, documenting its extent and manifestations.

HIV-related stigma in the United States

Gregory Herek has been a leader in the study of HIV-related stigma in the United States. As early as 1988 he described the social consequences that accompany HIV/AIDS as an "epidemic" (Herek and Glunt 1988). Herek documented cases of discrimination and harassment of individuals living with HIV and public statements such as Christopher

Monckton's proposal that all people with HIV be "permanently" isolated and William F. Buckley's that they be tattooed. Herek also described how misunderstandings about the transmission of this newly discovered virus led to increased fear of HIV and the ways that prevention programs were hampered by prejudices towards gay men, drug users, and people of color. Beginning in 1991, he conducted a series of nationwide surveys of knowledge and attitudes towards HIV. These random digit dialing (RDD) surveys sampled hundreds of households in 1991, 1996 to 1997, and 1998 to 1999 (Herek, Capitanio et al. 2002). Measures of HIV knowledge focused on respondents' beliefs about HIV transmission, such as whether the virus can be spread by kissing on the cheek, using public toilets, or donating blood. Stigma was measured with a summary score that counted responses to nine questions concerning support for coercive AIDS-related policies (such as quarantine and mandatory testing), negative feelings (anger, fear, and disgust), attributions of responsibility and blame for people living with AIDS, and intentions to avoid contact with people with AIDS. Results of the three successive surveys showed that while AIDS-related stigma decreased in the United States throughout the 1990s, some negative feelings and misconceptions remained. "One fifth of those surveyed still feared PWAs and one sixth expressed disgust or supported public naming of PWAs." One important predictor of such stigmatizing views was incorrect beliefs about HIV transmission. While most respondents had a correct understanding of how the virus is transmitted, misconceptions of how it is not transmitted were prevalent. The authors concluded that the AIDS-related stigma they detected in 1998 to 1999 could be further reduced by HIV education programs that countered misconceptions about transmission.

These studies of HIV-related stigma in the United States showed how HIV knowledge determined people's attitudes and avoidant practices, but they also demonstrated that homophobia was an important driver of stigma. More than half of respondents in the 1996 to 1997 sample answered that the first group that came to mind, when they heard the word "AIDS" was homosexuals or bisexuals (Herek and Capitanio 1999). Those who associated AIDS with homosexuality also tended to have more negative feelings towards gay men. Further questions probed how attributions of responsibility and feelings of sympathy and anger varied, depending on the source of someone's infection; blood transfusion, sex with one partner, sex with many partners, or sharing needles. Gay and bisexual men who contract HIV sexually were held to be the most blameworthy and elicited the most feelings of anger and least feeling of sympathy.

Further complicating this depiction of HIV-related stigma and sexual prejudice are differences in the attitudes of black and white Americans towards people living with HIV. The 1996 to 1997 RDD survey found that respondents' feelings towards injection drug users (IDUs) were significantly more negative than feelings towards gay men (Capitanio and Herek 1999). Among Blacks, these negative attitudes were associated with greater AIDS stigma, but among Whites, stigma was more strongly predicted by negative attitudes towards gay men. This difference is, in part, related to differences in transmission patterns between black and white Americans with HIV. Injection drug use accounts for a greater proportion of AIDS cases among black men (29%, in 1998) than white men (11%) (Capitanio and Herek 1999), which may account for why feelings toward IDUs explain more stigma in the African American community. This interpretation is complicated, however, by the problem of homophobia in African American churches. Focus groups with clergy in the New York City area found that the stigma toward drug addicts and homosexuals was central to African American churches' inaction on AIDS issues (Fullilove and Fullilove 1999). Around 70% of African Americans report church membership, and "the churches play a major role in shaping attitudes, even for those who are not members." There is a tradition in these churches of a so-called "open closet" that tolerates the participation of gay church members, especially in musical components, while also subjecting them to the strongest condemnation. This denunciation of homosexuality has often been transferred to some churches' approach to the HIV/AIDS epidemic and the way they facilitate HIV-related stigma. One man explained in a focus group of middle-income gay men, "...but the problem is that since many Black churches are generally conservative theologically, AIDS does feed into some traditional notions about disease and the connection between disease and punishment" (p. 1118).

HIV-related stigma in developing countries

Research on HIV-related stigma outside of Western countries has a shorter history but has received increased attention in the last decade, as international donors emphasize interventions to improve the quality of life of PLWHA. In countries with a generalized HIV/AIDS epidemic—prevalence consistently greater than 1% in pregnant women (UNAIDS and WHO 2003)—the main mode of transmission tends to be heterosexual intercourse. Stigma is less associated with homosexuality and drug use, but HIV/AIDS is still connected to taboo behaviors—promiscuity and commercial sex work—in much of the public discourse.

The AIDS Support Organization (TASO) is a community-based organization founded in Uganda in 1986 to provide care and support to people with AIDS and their families. In 1997, TASO joined with UNAIDS to conduct interviews and focus groups to document the forms of AIDS-related discrimination, stigmatization, and denial in an urban center and a rural community in Uganda (Monico, Tanga et al. 2001). Subjects in this study included people living with AIDS and their families, HIV counselors and medical personnel, legal professionals, community and religious leaders, and workers in non-governmental organizations. They described manifestations of stigma extending to all parts of community life. While the qualitative methods do not provide a clear picture of the magnitude of HIV-related stigma, the examples provided by TASO in this study are consistent with experiences of people living with HIV across sub-Saharan Africa (Rankin, Brennan et al. 2005), and a direct comparison of TASO's findings with a parallel study in India found similar manifestations of stigma there (Aggleton 2000). Within families, people with AIDS were ostracized or neglected. Women, especially, were blamed for having brought disease into their homes, and following the deaths of their husbands were denied inheritance. Community-based stigma and discrimination typically took the form of isolation and avoidance of people living with HIV. Gossip was another form of stigma seen as especially damaging. Some subjects described avoiding healthcare or support services rather than face the gossip of their neighbors, which often takes a salacious tone, because most HIV infections are sexually transmitted. Non-governmental organizations denied directly discriminating against people living with HIV, but representatives of a women's credit group admitted that they withheld loans from "low-income earners" or women who were "going down, deteriorating." The extent of HIV-related discrimination by healthcare workers was unclear. Conditions seemed to have improved along with better HIV/AIDS training of medical staff, but some people with AIDS were still worried about a loss of confidentiality, whether through unwanted disclosure by providers or through association with well-known AIDS NGOs. Subjects reported that some companies required HIV tests of prospective employees and "respondents felt it difficult to be open about their serostatus at work."

Churches and mosques were named as a source of support, especially for women with HIV, but others found them to be a source of blame, judgment, and assumptions of promiscuity.

Measuring HIV-related stigma

Collecting accounts of HIV-related stigma is an important initial step, but as researchers and providers attempt to quantify the role of stigma in transmission of the virus and as a barrier in prevention and treatment programs, it is increasingly important to be able to measure stigma and its various dimensions. This is a challenging task, because stigma is a social phenomenon with a highly variable definition. In Goffman's description it is essentially a bilateral interaction between "normals" and the "discredited," but more modern conceptions implicate entire power structures as causes and representations of stigma, making it much more complicated to measure. Also, the instruments used to measure HIV-related stigma must be targeted to their intended subjects. The non-stigmatized population—individuals presumed to be HIV negative—are probed for their beliefs and attitudes about people with HIV, but HIV positive individuals may be asked a very different set of questions, because they may have more direct experiences with stigmatization. These questions may ask about stigma that is either felt or enacted. Letamo provides a description for this common distinction: "Felt stigma refers to real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute, disease (such as HIV), or association with a particular group. Enacted stigma… refers to the real experience of discrimination" (Letamo 2003). The latter type of stigma includes events that are easier to observe, report, and document, such as violence, loss of a job, or isolation. But perceptions of HIV-related stigma may be no less damaging if they prevent people from taking HIV tests, seeking healthcare, or adhering to medication regimens. Liu has even suggested that felt stigma may actually reduce the opportunities for enacted stigma (Liu, Hu et al. 2006). If the perception or fear of stigma keeps individuals from disclosing their serostatus or leads them to withdraw from socially, they may not expose themselves to public discrimination. In any event, Nyblade's review of quantitative assessments of HIV stigma found few studies that measured actual experiences of stigma. More often they asked PLWHA about their fears of what would happen if others knew about their status or their expectations of how supportive others would be (Nyblade 2006).

Much of the work to document HIV-related stigma has relied on qualitative studies that allow subjects to provide their own examples and ideas of what defines discrimination. For example, focus groups by Kohi and colleagues began with the broad questions, "How do people you know refer to people living with HIV and AIDS?" and "Can you share an example of stigma or discrimination directed toward a person living with HIV and AIDS, their family members, or nurses who care for them?" (Kohi, Makoae et al. 2006). In some parts of the world, though, 'stigma' is not a familiar term. Bond describes a focus group composed of rural Zambians. They did not understand the English word 'stigma,' and "there was not any strictly equivalent term in Shona. The researcher therefore had to explain that the research was looking at the negative terms, reactions and fears towards people suspected to have HIV/AIDS" (Bond, Chase et al. 2002).

The design of quantitative surveys in the non-stigmatized population varies as researchers focus on stigma alone or examine its relationships with other variables. Herek's longitudinal studies of HIV-related stigma in the United States are examples of the former. Questions in these surveys deal with subjects' support for coercive policies and their negative feelings towards people with HIV. While these responses were analyzed alongside respondents' knowledge about HIV transmission and some demographic characteristics, they were not correlated with any behaviors or health-related variables. In contrast, Liu examined HIV-related stigma as a risk factor for sexually transmitted diseases among Chinese migrant workers (Liu, Li, Stanton, Liu et al. 2005). In this study stigma was assessed through responses on a four-point Likert scale to seven stigmatizing statements. These statements included expressions of both overt discrimination ("HIV infected people should be ostracized by their spouse and family members") and positive feelings towards PWHA ("HIV-infected people should have the same rights to education and employment as others"). Although the internal reliability of these questions was only moderate (Cronbach's alpha = 0.60), the authors created a stigma index by averaging each individual's responses. This summary score was then used to show that migrants with STDs held more stigmatizing beliefs than those without. In a separate study, the same group of researchers was able to show that Chinese migrant workers with more stigmatizing attitudes were less likely to take preventive measures such as using condoms frequently and testing for HIV (Liu, Li, Stanton, Fang et al. 2005).

Reviewing assessments of HIV stigma in the general population, Nyblade found that they tended to focus on one of two broad dimensions (Nyblade 2006). The first group of studies assessed subjects' willingness to interact with PLWHA and their support for coercive measures, such as quarantine and mandatory reporting of status. Few studies "made explicit the underlying cause for the social distancing behavior," but there is a common assumption that social distancing and support for isolating public policies represent instrumental stigma. Instrumental stigma is the domain of stigma associated with avoiding HIV infection. Herek explains that "it reflects the fear and apprehension likely to be associated with any transmissible and deadly illness" (Herek 1999). It is contrasted with symbolic stigma, which focuses on the social meaning of HIV/AIDS. This is the stigma investigated in studies that assess subjects' attitudes and values. These evaluate the extent of blame, shame, guilt, and negative or punitive reactions towards PLWHA.

Nyblade concludes her review by pointing out several gaps in the literature on HIV stigma measurement. First, there is the problem of refining the instruments that have been used in studies in the general population. Many studies have documented that people avoid casual contact with PLWHA. This is assumed to indicate that their knowledge of HIV transmission is inadequate, but there may be other symbolic reasons to avoid PLWHA that are not captured by such surveys. On the other hand, a willingness to interact with PLWHA cannot be assumed to indicate a lack of stigma. Subjects may be willing to, say, buy food from or provide medical care to an HIV positive person but still gossip or socially neglect the patient in other ways. Another problem with existing measures of HIV stigma is that they are not very good at measuring the layering of stigma. Because HIV-related stigma is often directed towards groups that are already stigmatized—men who have sex with men, commercial sex workers, injection drug users, or women—it is difficult to quantify the relative contributions of HIV and other pre-existing prejudices. While this distinction may have little importance to a stigmatized PLWHA, interventions to reduce the stigma will work best when the underlying causes are understood. The final gap in the literature concerning HIV-related stigma that Nyblade mentions is a lack of comprehensive measures. Many surveys of stigma measure only one or two domains of stigma, but effective interventions require a more complete picture of its manifestations and the attitudes that cause it. Most studies also lack a comprehensive sample of the population. They tend to survey small homogenous populations, and most of the research has been conducted in developed countries, although they account for only a fraction of the disease burden. Nyblade also notes that the studies with larger samples asked relatively few, often ambiguous questions, while those with more detailed questionnaires were the smallest.

Stigma and HIV testing

Measuring stigma can illuminate the challenges faced by PLWHA or help to understand their social status, but a more functional understanding of stigma looks at how it interacts with the provision of healthcare. This is a particularly important area of research, because it may identify psychosocial barriers to prevention and treatment. A better understanding of the causes of stigma may lead to educational interventions, and a better understanding of its impact may lead to structural interventions that improve access to services for those most affected. Because voluntary counseling and testing is the first step to HIV care and offers a chance for infected people to learn about the disease and make informed decisions, many studies have focused on the psychosocial barriers to VCT.

In a theoretical paper from 1994, Goldin examined cultural beliefs in both the West and sub-Saharan African societies that lead to the stigmatization of PLWHA. She suggested, "The threat of loss of job or home because of discovery may lead to avoidance of diagnostic blood tests, and may deter medical care" (Goldin 1994). Goldin offered no evidence that this was actually happening, but since then a growing body of literature has documented the impact of stigma on the uptake of VCT services. Chesney and Smith reviewed evidence from the United States that showed that concerns about stigma are associated with delays in HIV testing (Chesney and Smith 1999). In a sample of 828 gay and bisexual men who had never had an HIV test, two-thirds endorsed statements such as "I'm afraid the test results would be used against me" and "I'm afraid how the test would affect my relationships" (Stall, Hoff et al. 1996). Other studies showed that men preferred anonymous testing and would avoid HIV testing that would lead to their names being reported to health authorities and that they feared discrimination if others learned that they had been tested (Kegeles, Coates et al. 1989; Weitz 1989). In Zambia, focus group discussions among healthcare providers and local leaders in both a rural and an urban community identified the fear of stigmatization as a barrier to the HIV testing of pregnant women (Bond, Chase et al. 2002). There were few perceived incentives to undergoing HIV testing, while disincentives included the fears of losing a husband, the death of the baby and mother, isolation, disgrace, blame, depression, and suicide. Similar fears were cited in a study of intravenous heroin users in Bali (Ford, Wirawan et al. 2004). Forty percent of subjects named stigmatization as a reason for avoiding HIV testing. When they were asked what they expected to happen if they received a positive test, they mentioned the breakup of sexual relationships or marriages, discrimination by employers, neglect, and physical abuse. In a Ugandan study, just the risk of being seen at a testing site was enough to dissuade participants from testing (Wolff, Nyanzi et al. 2005). Focus group participants explained that only people who had doubts about their serostatus would attend a testing center, and only people who are promiscuous or have promiscuous partners would worry about their statuses. People seen entering or leaving a testing center would become the subject of rumors and be presumed to be HIV positive.

Others have focused on the sequelae of HIV testing and the question of disclosure that follows a positive test. Holzemer and colleagues describe how an HIV diagnosis can act as a trigger for stigmatization (Holzemer, Uys et al. 2007). Internal stigma may be the first manifestation as an individual blames him or herself, withdraws socially, or becomes depressed. The patient must also consider how, when, and to whom to disclose a positive test result, which may expose him or her to the entire gamut of discrimination. Liu has suggested that in more collectivist, non-Western cultures the act of disclosure is particularly fraught (Liu, Hu et al. 2006). Because of the emphasis on familial responsibilities, patients may want to protect their families from shame or from the obligation to provide care. These claims are based on observations from Asia, and it is unclear to what extent they are relevant to sub-Saharan African cultures, but for many reasons disclosure in both regions remains low. Pregnant women were generally willing to take HIV tests at prenatal clinics in rural Uganda, but in focus groups they reported serious concerns about informing their husbands of positive results. "The consensus was that men would universally condemn their wives for 'bringing the disease into the home,' even if the woman was faithful and the husband knew himself to be promiscuous" (Pool, Nyanzi et al. 2001). Women feared separation, which would mean being thrown out of the home and losing their only form of financial support. A large study in Kinshasa found that only 37% of HIV infected women in prenatal care had informed their partners (Temmerman, Moses et al. 1990). When the same researchers implemented prenatal HIV testing in Nairobi, they counseled women to disclose their statuses to their partners, which resulted in violence towards nearly 6% of the women (Temmerman, Ndinya-Achola et al. 1995). In a more recent study in South Africa, only 22% of recently diagnosed patients had disclosed their HIV statuses, and 46% had no knowledge of their partner's status (Olley, Seedat et al. 2004). In this study, those who had not disclosed their status were more likely to be men and have high risk behaviors such as drinking alcohol heavily before sex, not using condoms, and having multiple partners.

Tuberculosis-related stigma

Tuberculosis is a widely stigmatized disease, but, compared to HIV, the discrimination has received much less attention from researchers and policymakers (Bond and Nyblade

2006). TB shares many of the characteristics that make HIV/AIDS so susceptible to stigmatization. It is fatal and often associated with a long painful death, marked by visible symptoms such as cough and weight loss. The major difference, in terms of stigmatization, is that the transmission of TB is not through sex but through aerosolized particles. This might be expected to reduce the shame and blame associated with contracting the disease, but, in fact, TB's transmission is poorly understood by laypeople especially in many of the highest prevalence regions. Like HIV, in some places people with TB are assumed to be sexually deviant and responsible for their disease (Long, Johansson et al. 2001; Eastwood and Hill 2004). Knowledge of the airborne transmission of *M. tuberculosis*, however, does not eliminate stigma. When people understand the risk that patients with TB disease pose, they avoid and isolate them (Liefooghe, Baliddawa et al. 1997; Macq, Solis et al. 2005).

Macq, Solis, and Martinez reviewed studies from around the world that attempted to assess the stigma related to TB and found several major themes (Macq, Solis et al. 2006). First, TB stigma is almost always investigated using qualitative methods. As with HIV, both perceived and enacted stigma associated with TB have been assessed, but TB stigma is usually studied in the context of TB control programs. The emphasis has been on the extent to which stigma delays diagnosis or limits patients' adherence to anti-TB treatment rather than stigma's effects on quality of life. Macq and colleagues found that a major determinant of TB stigma is incorrect beliefs about the transmission of the causative organism. This may account for shame in settings where the disease is assumed to be sexually transmitted. But others have found that an exaggerated fear of contagion causes unnecessary avoidance and isolation of people with TB. Subjects in Zambia, for example, reported fears of contact or proximity with any bodily fluids of TB patients, including feces, urine, and blood (Bond and Nyblade 2006). Even fears about airborne transmission extended well beyond the two weeks following initiation of treatment, when TB patients are no longer infectious to others. Finally, research on TB-related stigma often investigates its relationship to other potentially stigmatizing characteristics, such as gender, poverty, and HIV co-infection.

Two studies from East Africa are typical of much of the research on TB-related stigma. In Uganda, 56% of a sample of TB patients reported that people with TB are stigmatized in their communities, and 40% said they would not want to be near a person with TB (Kiwuwa, Charles et al. 2005). Still, when these responses were analyzed together with data on delays in diagnosis, there was no evidence that perceptions of TB stigma were associated with delays. Similarly, a survey of people being evaluated for TB in Ethiopia found that 61% believed that TB patients were not accepted in their communities (Cambanis, Yassin et al. 2005). In this case, those who saw TB as stigmatizing did seem to be more likely to delay presenting for TB evaluation, but the effect was not statistically significant and factors such as the cost or time needed for transport were more important determinants of delayed diagnoses.

A study from The Gambia used qualitative methods to develop a more detailed description of TB stigma (Eastwood and Hill 2004). Interviews with health workers and TB patients were analyzed with attention to the difference in attitudes between men and women. The authors concluded that negative perceptions of TB patients were common, and that theses had a greater impact on the women in the community. Women were more likely to seek care from traditional healers and pharmacies, because these facilities offered some degree of confidentiality. This greater need for privacy led women to delay their TB diagnosis more than men. When their illness was disclosed, patients faced avoidance, shame, and gossip with attributions of poverty, dirtiness, and prostitution. These kinds of stigma were more likely to bother women, who also reported more instances of stigmatization.

Focus group discussions in Vietnam yielded similar results (Long, Johansson et al. 2001). Focus groups were held in four different districts and included both TB patients and non-TB patients. Again, isolation was a major manifestation of TB stigma. Family members refused to share cups and other eating utensils with people with TB, and friends avoided greeting or being near them, even after they had completed treatment. These social consequences were especially difficult concerns for women. Men were more likely to worry about the economic consequences of TB. Because the cost of treating TB can be significant (even when the drugs are free) and patients cannot work when they are very sick, TB was believed to increase families' poverty. Because they are often the sole income earners in their households, this burden fell especially hard on men.

Interviews and focus groups in Nicaragua revealed similar findings, but in this study the inclusion of family members and health personnel illuminated patterns of care-giving for people with TB (Macq, Solis et al. 2005). As in other countries, friends and neighbors avoided contact or sharing eating utensils with TB patients, but there were also accounts of support and care, especially by family members. Mistreatment and negative attitudes towards people with TB by healthcare workers were documented, but the authors also identified some of the structural factors, such as the isolation of TB patients in low quality wards for up to two months, that reinforce the message that they are highly contagious and should be avoided. The authors suggested educational and organizational interventions to promote power-sharing between health personnel and TB patients and their families, who tend to come from lower socioeconomic classes. This could give TB patients a voice in decisions about their own healthcare.

Nicaragua and Vietnam are relatively low HIV prevalence countries, where TB is not strongly associated with HIV. But in countries where HIV is more common, TB is one of the most important opportunistic infections and a leading killer of people with HIV. In South Africa, for example, 60% of TB patients are also infected with HIV (Daftary, Padayatchi et al. 2007). The close biological relationship between the two diseases has changed the TB-related stigma in some regions. As many recent studies have observed, the stigma associated with HIV has begun to affect people with TB, regardless of their serostatus. In focus group discussions in Kenya, community members and hospitalized TB patients described many of the familiar characteristics of TB-related stigma (Liefooghe, Baliddawa et al. 1997). It is viewed as a dangerous disease, because it is both difficult to cure and socially disruptive. In one local language, Kikuyu, the word for TB actually refers to the consequences of isolation for people with the disease. Patients are isolated even from their families, and women are particularly worried about the disclosure of their diagnoses. A newer finding, though, is that participants found it difficult to distinguish tuberculosis from HIV/AIDS, because the signs and symptoms can be indistinguishable. One subject explained, "The relation between these diseases is that a person starts losing weight and then his skin starts drying up."

Such findings are increasingly common in the literature about TB-related stigma. For example, in in-depth interviews with African patients attending a TB clinic in London, respondents explained that symptoms such as weight loss and cough had led to increased stigmatization of TB, because of their association with HIV (Nnoaham, Pool et al. 2006). Many patients felt isolated or mistreated and more than half denied that they had tuberculosis, but they described relatively few instances of enacted stigma. Still, they faced assumptions from medical personnel and others that they were HIV positive. Some mentioned that they had declined HIV tests because they feared the stigmatization that might result.

A study from Thailand investigated more explicitly the relationship between HIV and TB stigmas (Ngamvithayapong, Winkvist et al. 2000). In focus group discussions, health workers, people with TB, PLWHA, and community members described the treatment of people with TB. They had many misconceptions about the way that TB is transmitted, and these led to unnecessary isolation of TB patients. Participants explained, though, that HIV/AIDS was more stigmatized than TB, because it "was associated with immoral behaviors." PLWHA face disgust and social shame that is not directed at those with TB. The stigma related to HIV/AIDS was felt to last longer, because TB stigma usually improved when patients stopped coughing. Also, the stigma of HIV could extend to spouses in a way that TB-related stigma did not. Even healthy partners of people known to have HIV/AIDS were excluded from social functions. Because symptoms, such as weight loss, fever, and cough, are so strongly associated with HIV/AIDS, most people with TB were assumed to have HIV/AIDS. Although the disclosure of a TB diagnosis increased discrimination for HIV positive patients, some HIV negative patients were relieved to be able to tell family and neighbors that they had TB rather than HIV. Others were too afraid of HIV stigma to present for evaluation of their symptoms. Some HIV positive participants reported that the stresses of HIV/AIDS made it difficult for them to adhere to their TB treatments.

As people in high HIV prevalence countries have watched their relatives and neighbors fall sick with tuberculosis, they have learned to associate the two diseases in new ways, and a new phenomenon of HIV-TB stigma has emerged. This entity combines elements of the stigma associated with both diseases and creates new challenges for some of the sickest people. Interviews and focus group discussions in Zambia found that people there have come to distinguish between traditional TB and the "TB of today," HIV-related TB (Bond and Nyblade 2006). While the old TB was associated with smoking or drinking alcohol, the new TB "is more often associated with hanging out in bars and in towns, and, with sexual transgressions." With these new associations come shame and blame that were not formerly attached to people with TB. To many, a diagnosis of TB has come to indicate HIV infection, too. When they see signs of TB, they observe that patient closely for other signs of HIV or simply assume that he or she is seropositive. The authors conclude that these associations have heightened TB stigma and may present a barrier to TB control programs as patients are deterred from seeking care. Daftary, Padayatchi, and Padilla made many of the same observations when they interviewed hospitalized TB patients in South Africa (Daftary, Padayatchi et al. 2007). While all of their subjects had eventually presented to a TB ward, many continued to avoid HIV clinics and decline HIV testing. Some reported being embarrassed to be seen at an HIV clinic, and others complained that the timing of voluntary counseling and testing was poor. They did not want to face the stress of an HIV test while they were dealing with the emotional and clinical burden of TB treatment. In addition, patients found it easier to disclose their TB diagnosis but feared abandonment or the break-up of relationships if they had to disclose an HIV diagnosis. One mediating factor, the authors report, was that the availability of antiretroviral therapy made these TB patients more likely to have an HIV test and more likely to disclose their result if they were found to be seropositive.

Study of HIV voluntary counseling and testing in patients at risk for tuberculosis

Setting

Uganda is a nation of 28.8 million people in East Africa (United Nations 2006). Ruled as a protectorate by the United Kingdom beginning in 1894, it gained its independence in 1962.

Since then, Uganda has faced periods of intense violence with the dictatorial regimes of Idi Amin and Milton Obote. The 20-year rebellion by the Lord's Resistance Army has further destabilized the population in the country's northern districts, but since the election in 1986 of President Yoweri Museveni much of Uganda has found stability and modest economic growth. This relative peace has allowed Ugandans, especially in the south, to exploit the land's natural resources, including deposits of copper and cobalt. More than 80% of working Ugandans are employed in agriculture; coffee, tea, cotton, and tobacco are major agricultural products.

Despite debt relief from donor nations and recent increases in export markets, around 35% of Ugandans live in poverty and inflation is a perennial problem. Communication and transportation infrastructure is poorly developed, especially in areas destabilized by violence. Uganda hosts more than 200,000 refugees from conflicts in Sudan, Democratic Republic of Congo, and Rwanda. In addition, around 1.5 million Ugandans have been internally displaced by the Lord's Resistance Army (Central Intelligence Agency 2007).

Like the rest of sub-Saharan Africa, Uganda faces an overwhelming HIV/AIDS crisis, but it is hardly the only health problem. With just eight physicians, 55 nurses, and 70 hospital beds per 100,000 people, Uganda's healthcare system is poorly prepared to deal with the infectious diseases that account for so much of the nation's morbidity and mortality. The World Health Organization reports that 44.8% of Ugandan children under five years of age have stunted growth, and the probability of dying under age five is 13.6%. Between one-quarter and one-half of these deaths are attributable to malaria, making it the single largest killer (World Health Organization African Region 2004; WHO Statistical Information System 2007). The incidence and prevalence of tuberculosis are also high, 158 and 559 per

100,000 people, respectively. Other major health problems include schistosomiasis, trypanosomiasis, and leishmaniasis.

The first cases of AIDS in Uganda were identified in 1982 in the Rakai district on the shores of Lake Victoria in southwestern Uganda (see Figure 1). The government responded relatively quickly and established the National Committee for the Prevention of AIDS in 1985 (Garbus and Marseille 2003), but by 1986 HIV had reached every part of the country, where it was accompanied by epidemics of opportunistic infections, including increases in tuberculosis case rates (Ministry of Health and ORC Macro 2006). HIV sentinel surveillance began with testing of women attending antenatal clinics in Kamapala in 1985, while the national government's prevention efforts focused on blood safety, prevention of HIV transmission in healthcare settings, and education. Over the next few years the surveillance expanded to other sites across the country, mainly in urban areas. HIV testing in sentinel clinics showed sharp increases in incidence throughout the 1980s and 1990s. By 1992, the prevalence of HIV among women attending antenatal clinics across Uganda was 18%. In some urban areas it was over 30%, reflecting a pattern of increased prevalence in cities that continues today.

President Museveni's government adopted the Multisectorial Approach to the Control of AIDS in 1992. Under this policy, a new body, the Uganda AIDS Commission controls the national response to HIV/AIDS across many different ministries, including surveillance, research, education, prevention, and treatment programs. An explicit goal of the Uganda AIDS Commission is to mitigate the socioeconomic impact of AIDS. While political and religious leaders were initially slow to promote the use of condoms, they eventually pioneered the "ABC approach to HIV prevention: abstinence/delay of sexual debut, being faithful/partner reduction ('zero grazing"), and condom use with nonregular partners"

(Garbus and Marseille 2003). Although it is difficult to parse the relative contribution of each component of the ABC plan, HIV incidence and prevalence did fall in Uganda during the 1990s. By 2000, the HIV prevalence at antenatal clinics nationwide was 6.1% and around 10% at the highest prevalence urban clinics. The greatest and most consistent declines in HIV prevalence have been seen in the youngest age groups and in urban areas. Rural areas are not monitored as closely as cities, but the data indicate that HIV prevalence in those areas has remained stable or declined modestly.

The best and most recent data about the HIV/AIDS epidemic comes from the Uganda HIV/AIDS Sero-Behavioural Survey (UHSBS), which sampled 10,437 households across the country from August 2004 to January 2005 (Ministry of Health and ORC Macro 2006). More than 18,500 people were tested for HIV and other sexually transmitted infections. They also completed questionnaires about HIV/AIDS knowledge, attitudes, and risk behaviors. The prevalence of HIV infection among Ugandans aged 15-59 years was 6.3%. Women were more likely to be infected (7.3%), and this difference was even more pronounced in urban areas. In Kampala, 11.8% of women in the survey tested positive, while only 4.5% of men did. The overall prevalence in Kampala was 8.5%. The UHSBS adds, "As in other countries in sub-Saharan Africa, Uganda's HIV/AIDS epidemic is predominantly spread through heterosexual contact." This claim is reasonable, especially given the high numbers of HIV-infected women, but data on homosexual transmission of HIV in Uganda are suspect, because gay sex is highly taboo in Uganda and punishable with lifetime imprisonment (Human Rights Watch 2007). As a result, homosexuality is likely to be under-reported in behavioral surveys. Vertical transmission of HIV from mother-to-child accounts for about 15% of new infections (Garbus and Marseille 2003).

There are many explanations for the decline in HIV infection rates in Uganda, and because the issue is so closely linked to sex there has been a highly charged debate about which is correct. Some religious leaders and policy makers—both inside and outside Uganda—have championed the abstinence component of ABC (Parikh 2007). There are modest data to support the claim that delay of sexual debut has contributed to a decline in HIV prevalence. Successive national behavioral surveys have found that the number of women aged 15-19 who have never had sex increased "from 38 percent in 1995 to 48 percent in 2000-01 and to 54 percent in 2004-05" (Ministry of Health and ORC Macro 2006). Over the same period, the median age at first sex among young women, aged 20-24, increased slightly from 16.7 to 17.1 years, but young men reported a lower median age at first sex. There is similarly contradictory evidence regarding the B-strategy, "be faithful." Between the 2001-01 survey and 2004-05, the proportion of women reporting having more than one partner in the preceding 12 months increased from two to four percent, while the proportion of men reporting multiple partners increased from 25 to 29 percent. Condom use does seem to have increased in Uganda in the last few years, but it remains uncommon. Among sexually active adults, 9.1% of women and 16.1% of men report using a condom at most recent sex (Ministry of Health and ORC Macro 2006).

Study aims

The Ugandan government's strong and sustained commitment to combating the HIV/AIDS epidemic, along with relative stability in southern districts, has made it an excellent place to conduct medical research. Since 1994, Case Western Reserve University has operated a site of the Tuberculosis Research Unit at Mulago Hospital in Kampala. Funded by the National Institute of Allergy and Infectious Diseases, this international collaboration has conducted research on the epidemiology, immunology, and microbiology, of *Mycobacterium tuberculosis* infection. In Uganda, tuberculosis in people living with HIV has been the subject of several recent studies. A similar partnership in malaria research between the University of California, San Francisco, and Makerere University in Kampala began in 1998. This research collaboration focuses on evaluating antimalarial therapy, but includes malaria surveillance, investigation of malaria in children infected with HIV, and most recently operations research regarding HIV and TB coinfection.

Uganda's success in reducing the prevalence of HIV infection makes it a unique setting for research. While there is still significant morbidity and mortality related to HIV, there is also relatively broad coverage of prevention messages. The UHSBS found that more that 63% of women and 72% of men knew that both monogamy with an HIV uninfected faithful partner and consistent condom use could reduce their chances of contracting HIV. In Kampala and other urban areas, even more people displayed correct knowledge about HIV transmission and the ways to prevent it. For example, more than half of respondents in Kampala knew that the risk of mother to child transmission of HIV could be reduced by taking drugs during pregnancy and not breast feeding. (In rural areas, less than a third of respondents correctly identified these methods for the prevention of mother to child transmission.) The presence of international health organizations in Kampala has helped to expand both the reach of prevention messages and the availability of treatment for HIV infection. Uganda is a focus for the roll out of antiretroviral therapy in Africa. Around 56% of HIV infected adults in Uganda receive antiretroviral therapy (UNAIDS 2006b). The figure for the rest of Africa is closer to 17%.

Voluntary counseling and testing (VCT) for HIV, following a standardized protocol promoted by the US Centers for Disease Control and Prevention, provides an opportunity for individuals and couples to learn about HIV transmission, assess their level of risk, and make a plan to reduce risk behavior (Centers for Disease Control and Prevention 2001). Early trials of HIV VCT in developing countries showed that is was a cost effective way to reduce risk behavior, especially when couples received counseling together or when one partner was HIV positive (Sweat, Gregorich et al. 2000). And Ekanem and Gbadegesin point out, "The family also stands to benefit when an infection is discovered early enough to permit advanced planning for the financial security of the survivors. Benefits to the community flows [sic] especially when people with HIV feel safe enough to be open about their infection and become involved in the fight against the epidemic" (Ekanem and Gbadegesin 2004). In addition to changing behavior, VCT also provides an opportunity to link those who test positive to appropriate healthcare and social support. In the early days of the epidemic, medical care for people living with HIV in poor countries was limited to prophylaxis for opportunistic infections, if it was available at all. In Uganda, though, local organizations such as The AIDS Support Organization began providing education and resources for "Living Positively with AIDS" (The AIDS Support Organization 2003). This included strategies for improving diet, exercise, sleep, and other health-related behaviors. TASO and similar organizations also provide individual and family counseling to help people living with HIV combat stigma and prepare for "living positively and dying with dignity." Increasingly, HIV VCT is not just a way for an individual to learn his or her serostatus but a gateway to life-saving medical care. The last few years have seen a dramatic increase in the availability of antiretroviral therapy in the developing world. In 2001, 240,000 people in low- and middle-income countries were receiving antiretroviral therapy. By 2005, that number had reached 1.3 million (UNAIDS 2006a), and it continues to grow as countries scale up their treatment programs and donor funding increases, especially from the Global Fund to Fight AIDS, Tuberculosis and Malaria, and the President's Emergency Plan for AIDS Relief.

Despite the benefits of voluntary counseling and testing, its uptake in Uganda remains low. Of individuals of reproductive age—between 15 and 49 years—surveyed in the 2004-05 UHSBS, just 11.9% reported having previously been tested for HIV and receiving the results (Ministry of Health and ORC Macro 2006). This represented an increase in testing by women of reproductive age (regardless of whether they received results), from 8 percent in the 2000-01 survey to 15% in 2004-05. During the same time period, the proportion of men aged 15-49 who had ever tested remained constant. Although rates of ever testing were much higher in Kampala—36.6% of women and 26.3% of men—this may be a less important figure than the proportion of people who have tested recently. Men and women in Kampala had the highest rates of high-risk sex—that is, "with a nonmarital, noncohabiting partner in the 12 months preceding the survey"—in the country. In a community where nearly one in ten adults is HIV positive, such high-risk behavior suggests a need for repeat testing, but while 46.3% of respondents in Kampala who had had sex reported high-risk sex in the last 12 months, just 9.0% had had an HIV test in the same time period.

The Uganda HIV Sero-Behavioural Survey asked subjects who had never had an HIV test, why not. The most common response, from almost half of men and almost a third of women, was that they did not believe themselves to be at risk. Another 20% of men and women said that they had not tested because they did know where to go, and more than 15% said it was too expensive to have an HIV test. Another common response from those who had never tested was that they did not want to know if they had the virus. Among men who had never had an HIV test, 9.4% gave this as a reason, and even more women (15.8%)

said that they did not want to know (Ministry of Health and ORC Macro 2006). The survey did not probe these responses further, but it is likely that the fear of the social consequences of being marked as HIV positive play at least some role in these individuals' decisions, as has been reported in both the United States and Uganda (Muyinda, Seeley et al. 1997; Chesney and Smith 1999).

Given the high numbers of people at risk, there is a pressing need for new strategies to increase the rates of HIV testing and to respond to the reasons people give for not testing. The study of HIV voluntary counseling and testing in patients at risk for tuberculosis (TB-VCT, Principal investigator – Dr. Edwin Charlebois) is an intervention trial designed to increase the uptake of HIV voluntary counseling and testing among a high-risk population and address barriers to testing such as those mentioned by participants in the UHSBS. It investigates a protocol for the testing of patients presenting for evaluation of TB and their families. Although there are strong biological links between the HIV and TB epidemics, the public health response to the two diseases has largely been separate. It is widely known that the prevalence of HIV among TB patients is very high (Raviglione, Harries et al. 1997), and data from Botswana suggest that HIV prevalence may also be elevated among patients under evaluation for TB (Lockman, Hone et al. 2003; Talbot, Hone et al. 2003). Still, HIV testing of TB patients is not routine in Uganda, where an estimated 30% of new TB cases are in people infected with HIV (World Health Organization 2007). In Kampala, where the incidence of TB is 9.2 cases per thousand people per year (Guwatudde, Zalwango et al. 2003), testing in this population offers an excellent opportunity for HIV case finding. A successful protocol for HIV testing of people presenting for the evaluation of TB should be acceptable to patients, efficient at identifying HIV infected people, inexpensive, and easy to implement at TB clinics, even those with few technological resources.

The TB-VCT study uses several strategies to overcome logistical barriers to HIV testing and make it more acceptable to patients. Because so many Ugandans mention their low risk as a reason for not testing, targeting people who are already sick may be a way to identify people who recognize their risk. A study of mobile-VCT in Zimbabwe found that having symptoms of possible HIV-related disease was an important reason for people to choose to have a test. "Testers described opportunistic infections and weight loss as reasons for testing" (Morin, Khumalo-Sakutukwa et al. 2006), suggesting that symptoms may trigger consideration of HIV risk in people who previously did not believe they needed to have an HIV test, and consistent with findings from the pilot study that preceded the TB-VCT trial at the Mulago Hospital TB clinic. In that study, both TB patients and those who received a non-TB diagnosis had come to the clinic because of symptoms, including cough, weight loss, night sweats, fever, difficulty breathing, and diarrhea. Of the 565 subjects in this study "36% reported concern that the symptoms prompting their visit to the Mulago TB clinic were actually due to HIV infection"(Srikantiah, Lin et al. 2007).

In the UHSBS, reasons for never having had an HIV test included not knowing where to get one, the cost of the test, and the distance to testing centers. Offering HIV VCT to patients presenting to a TB clinic meets all of these challenges. Patients do not need to know about dedicated HIV testing sites or travel long distances to find them, because they can receive testing and counseling while they wait at the TB clinic. Using rapid enzyme immunoassay (EIA) tests for HIV reduces the cost of testing—free to patients—and allows for test results to be received at the same visit, eliminating the need for a return visit. Several studies have already shown rapid EIAs to have high sensitivity and specificity (Stetler, Granade et al. 1997; Kassler, Alwano-Edyegu et al. 1998; Bhore, Sastry et al. 2003), and data from Malawi suggest high rates of acceptance for same day HIV testing in TB clinics (Zachariah, Spielmann et al. 2003). The TB-VCT study will determine the uptake of HIV VCT and, through questionnaires administered to both testers and non-testers, evaluate what barriers to HIV testing remain when VCT is very convenient.

A second component of the TB-VCT study involves the recruitment of family and household members of TB clinic evaluation subjects. Preliminary data suggest that HIV prevalence may be elevated among the household contacts of HIV-TB co-infected patients (Christopher C. Whalen, personal communication). Following the counseling, specimen collection, and the return of HIV test results, test-counselors will inform the participant of the option to participate in a randomized trial of two strategies for providing HIV testing to family and household members. Consenting subjects will be assigned to either refer their family and household members to come to the TB clinic for free HIV VCT, or they will arrange a time for study workers to visit their homes to offer testing and counseling there. The pilot study found that most subjects (86%) were "very willing" to refer their family members for HIV VCT. Although there was a preference for clinic-based VCT over home-based VCT, even the latter was acceptable to 67% of subjects (Srikantiah, Lin et al. 2007). Studies in the United States have shown that patients are often willing to refer partners for HIV testing, but it remains unclear how many partners actually use these referrals and there have been few such studies in Africa (Passin, Kim et al. 2006). The TB-VCT study will determine the uptake of both clinic- and home-based VCT and the prevalence of HIV infection among family and household members of TB evaluation patients. In a longitudinal component of the TB-VCT study, staff will follow-up HIV positive subjects to observe what proportion keep referral appointments to medical care and social support, and receive antiretroviral treatment or opportunistic infection prophylaxis. Subjects will be visited at 1, 3, 6, 9, and 12 months to evaluate the effectiveness of TB clinic- and home-based VCT at linking HIV infected people to medical care and social support.

The TB-VCT study was approved by institutional review boards at the University of California, Berkeley, and the University of California, San Francisco. In Uganda, both the Joint Clinical Research Centre and the Uganda National Council for Science and Technology approved the study.

Stigma survey methods

In the pilot study that preceded the main TB-VCT study, 85% of TB suspects accepted HIV testing, a high rate in any setting. As the study continues, though, one of the major questions is what barriers to HIV testing remain after the logistical barriers have been removed. Prior research has suggested that the stigma surrounding HIV and TB prevents or delays some patients' entrance into care (Chesney and Smith 1999; Bond and Nyblade 2006). If this is true, then some of the TB evaluation patients who refused HIV testing may be among the most vulnerable to stigma. It is especially important to understand the concerns and fears that keep them from testing and find ways to diagnose HIV infection in this population and link them to care. Two survey instruments attempt to assess psychological barriers to care. One instrument specifically assesses the perceived risk of domestic violence in subjects with an intimate partner. The second instrument, the subject of this thesis, attempts to measure the more amorphous concept of HIV- and TB-related stigma and the perceived relationship between the two diseases.

Instrument development

The stigma survey began with seven questions that probe subjects' understanding of the biology of HIV and TB co-infection. Respondents are asked whether they Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree with statements such as "People who have HIV are more likely to get sick with TB than other people" and "People who say they are sick with TB really have HIV." The next three statements assess subjects' feelings about HIV testing, after which a section of the instrument adapted from a questionnaire used in India (Steward, Ramakrishna et al. 2006) assesses the stigma and discrimination that HIV positive individuals perceive and directly experience. Because the subjects in the TB-VCT study verbally answer the questions of the stigma survey between blood sample collection and receiving their HIV test results, most do not know yet know their serostatus and presumably few have been victims of HIV-related discrimination. Therefore, the questions were adapted to ask about the perceived levels of stigma in patients' communities. Thirty-six questions began with the phrase "In your community, how many…" Possible responses are No One (0), Very Few People (1), Some People (2), and Most People (3). Half of these questions ask about perceptions of HIV-related stigma in the community. These questions are repeated verbatim with TB substituted for HIV. A random number table determines whether subjects are asked the HIV or TB questions first. Three staff members individually translated the instrument into Luganda, the major language in Kampala, and resolved translation differences as a committee. This translation was back translated by a professional into English, which the committee reviewed for discrepancies with the original. A small number of corrections were made where necessary. To test the translation and practice administering the survey it was given to several TB clinic employees.

The TB-VCT study began using this instrument on August 10, 2006. It is available to subjects in either English or Luganda. Through December 1, 2006, 115 subjects had enrolled and completed the stigma survey. These responses were analyzed using Stata, version 9.2 (StataCorp, College Station, Texas) to find redundant questions or those with low variation in responses in order to shorten the survey and reduce the burden on both the test-counselors, who administer it, and the sick patients, who face several long questionnaires during their HIV counseling and testing session. One question was dropped from the initial seven questions about HIV-TB co-infection because it was considered unlikely to provide any new information. Two questions about HIV testing showed little variation in response. More than 90% of respondents agreed or strongly agreed with the statements "Getting tested for HIV helps people feel better," and "Getting tested for HIV helps keep people from getting sick." The high proportions of positive responses means that these questions are unlikely to be useful for predicting whether subjects' will choose to have an HIV test or will keep referral appointments. Still, it is interesting to find good feelings towards HIV testing to be so prevalent in a population with comparatively low rates of prior testing (50%). These questions were left in the revised version in part because they are the only supportive and encouraging statements in a long questionnaire about discrimination and mistreatment.

Analysis of the next sections of the stigma survey focused on the 18 questions about HIV-related stigma because HIV testing (and not TB-care seeking) is the primary outcome of the stigma study. Three of the eighteen questions asked about manifestations of HIV-related stigma in healthcare settings. Although earlier studies reported these as important examples of discrimination in Uganda (Aggleton 2000; Monico, Tanga et al. 2001), few people reported either mistreatment or unwanted serostatus disclosure by healthcare workers. These questions were dropped from the revised version, but the question "In your community, how many people are refused medical care or denied hospital services because of their HIV?" had greater variation of responses and was kept. Two more questions designed to detect a difference in stigma towards men and women with HIV infection were dropped, because most participants did not respond differently to questions about the shame associated with an HIV positive son or daughter. Responses to the question "In your community, how many people are afraid to be around a person with HIV?" were correlated with responses to two other questions. That question was determined to be redundant and dropped from the revised survey. Another question was dropped because it was difficult to interpret the meaning of the responses to it: "In your community, how many people think people with HIV are not as good as everyone else?" Durin translation meetings, study staff raised concern about this question, used previously in Indian studies, because they felt it was too ambiguous. "Not as good in what way?" they asked. Including this question in a factor analysis of the first 115 observations showed that it loaded weakly (0.4247) onto a factor that was not internally reliable. Excluding the "not as good" questions made all four final factors internally reliable (Cronbach's alpha>0.80) and easier to interpret. Because of the combination of translation and analytic difficulties, this question was dropped from the revised instrument.

The remaining twelve HIV-related stigma questions formed a questionnaire that was reliable; its results can be reproduced. The design of the TB-VCT study does not repeat testing of the stigma instrument, which could give a measure of the survey's stability—although this would assume (improbably) that stigma was a concept that remained constant throughout time. It is also impractical to compare the results of the stigma instrument to an alternate assessment of perceived stigma, because of the time and attention that administering two surveys would require from sick study subjects. Instead, the instrument's reliability was determined by using Cronbach's alpha, a measure of internal reliability. Cronbach's alpha is an average of all the pair-wise correlations of individual items in the instrument, weighted by the number of items (Yu 2001). If the mean correlation of items remains the same, Cronbach's alpha will be greater for an instrument with more items. Values for Cronbach's alpha range from zero to one, with higher values indicating greater internal reliability. There is no defined value that determines whether or not a survey instrument is sufficiently reliable, but a score greater than 0.70 is generally taken to indicate that all the items on a questionnaire ask about the same underlying concept. After six redundant and ambiguous questions had been excluded from the HIV stigma survey, the twelve remaining questions had a Cronbach's alpha of 0.881, high enough to conclude that there is a relatively high degree of consistency among the questions. The final version of the stigma survey is in Appendix 1.

While such a high Cronbach's alpha suggests that the instrument is testing a single construct—presumably stigma—it does not preclude the possibility that there are subsets of questions that together measure a dimension of the larger concept. Indeed, factor analysis of the final twelve HIV-related stigma questions suggests that there are sets of questions that group together. Factor analysis attempts to find latent factors that best account for the variance in a data set. Each variable can then be represented as a linear combination of just a few factors (plus a constant that is unique to that variable). If questions (variables) are related to the same latent factor, their variance will largely be explained by the same linear vector in multidimensional space (Afifi and Clark 1990). Four different factors emerge from the twelve HIV-related stigma questions and separate the questions into different dimensions of stigma. A calculation of Cronbach's alpha for each subgroup of questions gives a measure of their consistencies. The first of these subgroups contains five questions that all ask about the personal blame associated with being infected with HIV. They inquire about community beliefs that people with HIV deserve their disease, are paying for their sins, or should feel guilty. Cronbach's alpha for this subset of questions is 0.852, indicating that all five questions relate to personal blame. One surprising result of this analysis is that questions about insisting "that a person with HIV move out of the house" and thinking "that a person with HIV is disgusting" seem to be measuring personal blame much more than they test the stigma associated with avoiding proximity to PLWHA.

This latter concept defines the second subgroup, which contains just two questions. These two highly correlated questions ask how many mothers in the community would not want someone with HIV to hold their babies or feed their children. Cronbach's alpha for these two questions is 0.885. Although these questions seem to probe the instrumental fear of acquiring HIV infection through casual contact, a definitive interpretation of the underlying dimension of stigma is difficult. The questions both refer to children. They may be observing a heightened vigilance regarding the transmission of HIV to children or they may be indicating the social censure of people who are associated with "immoral behavior." A third explanation is that people who associate with PLWHA are running the risk that others will assume they are also HIV positive, exposing themselves to discrimination. Nyblade has explored this challenge of measuring the social distancing of PLWHA and also notes the ambiguity inherent in questions about feeding or sharing food (Nyblade 2006). The language of the stigma survey asks about feeding children, but it does not specify whether the food has been prepared by a PLWHA, if utensils will be shared, or if the PLWHA will share the meal with the children. Because eating together is a culturally symbolic act, there is the possibility that the refusal to allow PLWHA to feed children is a way to express a social reprimand of some taboo behavior. Still, the high correlation between the two questions about children and their separation from the more symbolic factors of blame and shame suggest that they are from a distinct group, probing instrumental stigma.

A third group of questions inquires about the social shame or community retribution associated with HIV infection. Shame and blame are two very similar concepts, but the important difference between the two factors probed with this survey is that the blame questions focus on personal responsibility, while the shame questions represent socially mediated responses to HIV. The social shame questions, for example, ask about avoiding "visiting the homes of people with HIV" and thinking "that HIV-infected people have brought shame on their families." Cronbach's alpha for the four social shame questions is 0.811. Just one question makes up the final group; this is the question "In your community, how many people are refused medical care or denied hospital services because of their HIV?" After dropping two other questions about stigma in healthcare settings, this remaining one was distinct from all the other questions in the survey. Still, it is an important concept to probe among people deciding whether or not to have an HIV test. Cronbach's alpha is not calculated for this final dimension of HIV-related stigma, the denial of healthcare, because it is composed of a single question.

To allow direct comparisons, six questions were eliminated from the series about tuberculosis-related stigma, corresponding to the HIV-related questions that were dropped. Cronbach's alpha for the remaining twelve tuberculosis questions was 0.828, but alpha was not calculated for the tuberculosis stigma subscores, because factor analysis showed that the tuberculosis questions grouped differently from the HIV-related stigma questions. This may mean that different latent concepts—dimensions of stigma—explain the variance in the answers to the tuberculosis questions. Alternatively, the different factor loadings could indicate that some of the same questions, when asked about TB, suggest a different dimension of stigma than when asked about HIV. For example, the question "In your community, how many people avoid visiting the homes of people with HIV?" was associated with other issues of social shaming. When the same question was asked about people with TB, though, factor analysis showed that it was associated with questions about avoiding infection. This is consistent with early indications that subjects in the TB-VCT study perceive the stigma associated with tuberculosis to be driven by its risk of transmission through casual contact, while the stigma associated with HIV infections is more related to shame and taboo behaviors. The full data set will allow a more complete investigation of the discrepancies in factor loadings.

Responses to the stigma survey will be used to answer three distinct questions about stigma and HIV testing. First, what demographic characteristics determine levels of perceived stigma among TB evaluation patients? The literature suggests some possible predictors of increased stigma. One relatively consistent finding is that women perceive more HIV- and TB-related stigma (Long, Johansson et al. 2001; Monico, Tanga et al. 2001; Eastwood and Hill 2004; Sandelowski, Lambe et al. 2004; Rankin, Brennan et al. 2005). Multivariate analysis of data from the questionnaire will examine the associations between subjects' perceived stigma and variables, such as gender, age, education, income, marital status, religion, sexual history, HIV testing history, and tuberculosis diagnosis.

Second, do perceptions of stigma predict subjects' healthcare decisions? Possible outcomes predicted by a perception of high levels of stigma may include participants' willingness to take an HIV test, utilize HIV services, and disclose HIV status.

Finally, the stigma surveys will investigate the similarities and differences between HIV- and TB-related stigmas. Are high levels of perceived stigma associated with the same demographic predictors? Do the same underlying concerns drive higher levels of perceived HIV- and TB-related stigma? Responses to corresponding questions will allow a quantitative comparison of different types of avoidance and discrimination of people with HIV or TB.

These analyses, though, has several limitations. The first is a sampling problem. Eligible patients are invited by clinicians in the TB clinic and further screened by HIV test counselors. Through April 20, 2007, 72% of eligible subjects have chosen to have HIV tests. Many of the non-testers have completed the stigma questionnaire. If their choices to not test were influenced by stigma, then the data should reflect this, but many of the non-testers are individuals who have tested HIV positive previously or tested negative recently (Srikantiah, Lin et al. 2007). This means that the sample of patients who complete the stigma questionnaire is skewed towards those who feel comfortable with an HIV test—and theoretically perceive less discrimination towards people living with HIV. The study collects no data about the patients who decline to participate (at least 8.5% of those invited). It is reasonable to assume that stigma plays a role in some of their decisions.

A second limit of the stigma instrument is that it asks simplistic and relatively concrete questions about a complicated social phenomenon. It may indeed capture specific fears, such as being forced to leave the family home, but more subtle concerns like gossip and self-esteem are harder to measure. A related issue is the problem of interpretation. For example, more than 29% of subjects to date have agreed or strongly agreed with the statement, "People who say they are sick with TB really have HIV." These data demonstrate a strong relationship between the two diseases, but, without more information, we can only speculate about subjects' reasoning or the associations they perceive.

Finally, there is the challenge of validation. Because there is no gold standard or even agreed-upon definition, it is hard to know if any questionnaire actually measures stigma. More information is needed to compare to the results of the stigma survey. As Van Brakel explains in his review on the measurement of health-related stigma, "A stigma scale and other interview-based instruments would assess *reported* attitudes and practices, which are not necessarily an accurate reflection of the real situation. They therefore should be complemented and validated with the help of qualitative methods, such as key informant interviews, focus group discussions and in-depth interviews with people affected" (Van Brakel 2006). Nyblade explains that instruments for measuring HIV-related stigma that ask respondents about behavior towards PLWHA do not help understand what motivates community discrimination (Nyblade 2006). For example, one question in the TB-VCT stigma survey asks respondents, "In your community, how many people are uncomfortable around someone with HIV?" A Likert scale response may quantify some form of stigma, but without more information it is unclear whether this question is probing the instrumental stigma of avoiding HIV infection or the symbolic stigma of being uncomfortable around a socially discredited person.

Qualitative study methods

The stigma survey provides just a first layer of data about community attitudes in Kampala. In the TB-VCT study, one additional source of information is subjects' behaviors. An instrument that can predict choices—having an HIV test, disclosing the result, or entering HIV care—can be said to have some validity, even if it cannot be said with certainty to be measuring HIV-related stigma. The addition of qualitative interviews with key informants brings one more source of information about subjects and their decisions. These data help to address the limitations described above. Test counselors and providers have front-line contact with all patients and may be able to speculate about the role that stigma plays in some subjects' decisions to not have an HIV test. They may offer new interpretations of the quantitative findings or provide examples of HIV- and TB-related stigma that are not captured in the short questionnaire. And they may help to validate the questionnaire by providing another perspective on a complicated social phenomenon.

In addition to the quantitative data collection described above, 16 open-ended interviews were conducted with key informants at the Mulago Hospital TB Clinic. These included the HIV test counselors and technicians on the staff of the TB-VCT study and the related Tuberculosis Research Unit. In addition, the clinic's nurses and physicians, who are involved in the care but not the counseling and testing of people with HIV and tuberculosis, were invited to participate. Staff of the TB-VCT study were the first subjects in the qualitative study. They suggested other questions to be pursued and referred other subjects who they thought would be especially insightful about issues of stigma. All subjects were 18 years or older and fluent English speakers. Subjects were verbally invited to participate (individually and during staff meetings). They were not compensated.

Participants first completed a short written questionnaire that asked for non-identifying demographic information and about personal experiences with HIV/AIDS. Following the completion of this questionnaire, interviews were conducted in English and lasted up to one hour. Questions were open-ended but directed by an interview guide (see Appendix 2), which probed for stories of stigma and clarifications of findings from the quantitative instrument. Responses in earlier interviews suggested additional questions and topics to be explored in later interviews.

Interviews were audio-recorded and transcribed by a local typist. Analysis of the transcripts was conducted in California. First, the transcripts were edited by the interviewer to fill in gaps left by the typist and to clarify punctuation. Then, they were coded using HyperRESEARCH 2.8 software (ResearchWare, Randolph, Massachusetts). The goal of coding was to elaborate and expand on the findings of the quantitative component, following Knoblauch's description of a focused ethnography, which does not aim to "reconstruct the cultural stock of knowledge… It only aims at certain elements of (partly embodied) knowledge relevant to the activity on which the study focuses" (Knoblauch 2005). Transcripts were reviewed for common themes and explanations, which were compared and contrasted with findings from the ongoing analysis of quantitative data as well as theoretical explanations of stigma from the literature. This process was iterative. The first interviews were recoded as additional themes were suggested by later interviews and following consultation with advisers and the Joint Medical Program's Qualitative Methods Working Group.

As with the quantitative analysis, the aims of the quantitative portion of the study were to investigate what people or groups are most affected by stigma, how stigma affects TB clinic patients' healthcare decisions, and how HIV- and TB-related stigma are similar and different. Although the small sample size and open-ended methods make the quantitative results less generalizable than the stigma survey, they provide more information about the processes and mechanisms at work in the discrimination of PLWHA. Where do people in Kampala get information about TB and HIV? How does this change their attitudes? What fears and hopes do patients bring to HIV counseling and testing? And what interventions do providers believe can decrease stigma and increase the number of people taking HIV tests?

Quantitative stigma survey results

Recruitment for the current phase of the TB-VCT study began on August 10, 2006, and continued until January 10, 2007. The analysis described in this portion of the results will be applied to a larger sample as additional subjects are recruited. A total of 149 patients were recruited. Significant portions of data were missing for one subject, who was excluded from the analysis, leaving 148 participants. Complete data are recorded for most of the remaining subjects, although there are infrequent scattered missing data points. There are at least 145 observations for nearly all variables, including all the stigma questions.

The sample was 60% female (Table 1). Most subjects were younger than 40 years old, with 69 (47%) under age 30. Forty-three of the 148 subjects had never been married. Of the 105 who had been married, 58 (55%) reported being in monogamous unions, but 34 (32%) were separated or divorced. The remaining subjects were in polygamous unions or widowed. Nearly two-thirds (62%) of subjects reported earning less than 50,000 Ugandan Shillings (~30 USD) in the month before enrollment; many had earned no money. Seventy-nine subjects had no more than primary education, and 69 had some secondary education, but only 16 of these had any additional technical or university training. Roman Catholics and Anglicans each made up about one-third of the sample. Another 20% were Muslim, and 9% described themselves as Born Again.

Forty-six percent of subjects agreed or strongly agreed with the statement "People in my community are embarrassed to be seen coming out of an HIV testing clinic" (Table 2). Despite this claim of embarrassment, more than half of the subjects reported having had an HIV test before enrolling in the TB-VCT study. This is much higher than the 12% of Ugandans, who reported having ever had an HIV test in the UHSBS and even higher than the 34% reported for Kampala. As in the nationwide survey, female TB-VCT subjects were more likely to have undergone testing in the past then male subjects (p=0.015).

Twenty-eight subjects (19%) reported a history of a positive HIV test. Seventeen of these subjects underwent repeat testing when they enrolled in the VCT study. The most common reason given for having another HIV test was that subjects wanted referral letters to access HIV care or antiretroviral therapy or to confirm the results of their prior tests. All seventeen of these subjects' HIV tests in the TB-VCT study were positive.

A total of 116 (78%) of the 148 participants accepted an HIV test at the TB clinic, and 99 of the 120 subjects (83%), who did not know themselves to already be seropositive. In response to closed-ended questions about why subjects chose to test at the TB clinic, nearly every subject cited the convenience and the availability of same-day results (Table 2). Also, 83% of subjects said that they were influenced to test because it was free. Forty-three subjects said they were worried that their symptoms were due to HIV, and forty-one were concerned that they might have both HIV and tuberculosis. There was considerable overlap between these groups (34 subjects), but they were not identical. Only 9% of subjects reported accepting an HIV test because of a doctor's recommendation.

There were few significant demographic differences between subjects who accepted an HIV test and those who did not (Table 3), but those who earned more than 50,000 UShs in the last month were less likely to test than those who earned less, 69% compared to 84% (p=0.037). Also, those who had tested in the past were less likely to accept an HIV test. Just 69% of these subjects tested, compared to 89% of those who had never tested (p=0.005).

Forty (34%) of the 116 testers were HIV positive, and one had an indeterminate result (Table 4). Women in the study were more likely to be HIV positive than men, but the difference was not statistically significant. There were, however, significant differences in other demographic characteristics between HIV infected and uninfected subjects. Subjects older than the median age of 31 were more likely to be HIV positive ($p=0.002$). Those who had been married were more likely to be HIV seropositive than those who had never been married ($p=0.006$). Nearly half of subjects, who earned more than 50,000 Ugandan Shillings in the last month were HIV positive, compared to just 27% of those who earned less ($p=0.034$). Finally, many subjects who reported that they considered themselves to be at risk for contracting HIV were HIV-infected. Fifty-nine percent of these subjects were HIV positive, compared to just 19% of those who did not answer that they considered themselves at risk ($p <0.0005$).

Table 5 shows the means, medians, standard deviations, and Cronbach's alpha of the summary scores for HIV stigma as measured by the twelve-question instrument. The earlier factor analysis suggested four different domains of stigma; Instrumental Stigma, Blame, Shame, and Denial of Healthcare. For each respondent, a summary score was created in each domain by averaging the relevant questions. Because Blame and Shame are such closely related concepts, a combined score was created to include both concepts. This score, Symbolic Stigma, is the mean of all Blame and Shame questions. Total Stigma is the average of all twelve responses. Each of the summary scores ranged from 0 to 3. Six subjects had a Total Stigma score of 0, answering "No One" to each of the twelve survey questions. Similarly, two subjects answered "Most People" to all HIV stigma questions. These subjects' responses cannot be totally discounted, and they are not extreme outliers. Still, it seems possible that these subjects did not consider their responses very carefully, because they were sick and tired, because they were eager to finish the long questionnaires, or because they did not understand the questions. Excluding these subjects from the summary scores does not substantially change any of the measures (Table 5). Means increased slightly, medians did not change, and standard deviations and Cronbach's alpha each decreased a fraction. The range of scores for Avoidance, Shame, Blame, Symbolic Stigma, and Denial of Healthcare remained 0 to 3. The range for Total Stigma, when outliers were excluded, was 0.83 to 2.92. All 147 observations are used in the following analyses.

The highest scores, indicating the greatest amount of perceived HIV stigma, were for Instrumental Stigma (mean=1.83), and the lowest were for Denial of Healthcare (1.19). Shame scores (1.50) were significantly higher (p=0.0036) than Blame scores (1.31). For each of the summary scores, Cronbach's alpha was greater than 0.79, indicating a higher degree of internal reliability. Alpha for the combined twelve questions was 0.89.

Predictors of HIV stigma

Bivariate analysis examined whether demographic characteristics were associated with the stigma summary scores. Because these data are not normally distributed, the non-parametric Wilcoxon-Mann-Whitney test was used to test whether the distribution of stigma scores was the same for both levels of binary variables. For variables with more than two levels, the Kruskal-Wallis test was used. Both methods revealed similar results, but for clarity's sake only the results of the Wilcoxon-Mann-Whitney tests are shown here with multilevel variables condensed into dichotomous variables. Statistically significant results are summarized in Table 6. Although some of the results have only marginal significance ($0.05<p<0.10$), they are shown here because these variables were further examined in the multivariate model discussed below.

No demographic characteristics were significantly associated with perceived denial of healthcare. The association between having had a prior negative HIV test and the belief that people infected with HIV "are refused medical care or denied hospital services" was of borderline statistical significance (p=0.0804).

There were no significant differences in perceived stigma by income, number of sex partners, rate of condom use, tuberculosis diagnosis, or education level, with one exception. Subjects who described their highest level of education as "Technical or diploma training" did report significantly less perceived stigma than those in other education groups. This was true for the Blame, Symbolic Stigma, and Total Stigma scores. However, there were only eight subjects in this group, and they tended to be male, older, married, non-Muslim, and have no history of HIV testing. These confounding factors probably explain any associations between technical training and perceived stigma, as these characteristics proved to be predictors of lower stigma scores.

Several strong associations stand out in the bivariate analyses. First, although Instrumental Stigma was the domain with the highest scores for perceived stigma, there were few strong demographic predictors of this factor. Having a prior negative HIV test—a strong predictor of other stigma domains—was only weakly predictive of a high Instrumental Stigma score (p=0.0690). Muslim subjects did report significantly greater stigma in the Instrumental Stigma domain (p=0.0106), but, in general, scores on these questions were high regardless of individual characteristics.

Another important finding from the bivariate analysis is that women reported more perceived stigma then men. This was especially true in the Blame dimension, which assesses the personal responsibility associated with HIV infection. Also, younger people reported more stigma than older people. In this case, higher perceived social Shame stood out as particularly associated with younger age. One other demographic characteristic associated with age is marital status. As expected, those who had never been married had higher stigma scores than those who had been married.

Finally, one of the strongest predictors of higher perceived stigma was having had an HIV test at some time prior to enrolling in the TB-VCT study. In particular, having had a negative HIV test was strongly associated with higher scores in every domain except for social Shame.

Multivariate analysis of stigma surveys

Tables 7-12 present the results of the multivariate analysis of the stigma surveys. In Tables 7-11, variables are added one at a time to a linear regression model with robust standard errors for each of the stigma domains (Hamilton 1991). The first column of each table shows the coefficient and p-value for each variable when it is the only one included in the model. The next column shows the coefficients for a model that considers only the relationships between gender and Muslim religion and subjects' stigma scores. These are the first variables included in the regression because, as stable characteristics, they are not affected by the other, time-dependent, variables. The next variable, age, may lie on the causal pathway between either sex or religion, so these variables are potential confounders. Age's effect on the previous coefficients is demonstrated in the third column of each table. The coefficients for the next variables—being unmarried, having had an HIV test before enrollment, and having had a prior negative test—are added in turn. Each variable's coefficients are bolded in the columns that show the effect of adding them to the previous model. This allows an examination of how they may have affected the relationship between the other variables and the different domains of HIV stigma.

A glance at Tables 7-11 shows that there are few statistically significant coefficients, suggesting that much of the variation from one model to the next may not indicate an important relationship between the variables. Still, some interesting themes emerge from these models that illuminate the associations found in the bivariate analyses. One important finding is that while having had an HIV test prior to enrollment in the TB-VCT study was associated with increased perceptions of stigma, the more important variable is whether or not the subject tested HIV negative. Having had a prior HIV test, by itself, was not sufficient to predict significantly higher levels of perceived stigma. Instead, having had a prior negative HIV test is the important predictor of higher stigma scores.

The coefficients for the model of predictors of Instrumental HIV Stigma are shown in Table 7. In this model, being Muslim is by far the most important variable. It has the highest coefficient and is the only variable that remains statistically significant when the effects of all variables are considered. The relationship between being Muslim and perceiving high levels of Instrumental Stigma is confounded by gender, because Muslim subjects were more likely to be women than non-Muslim subjects, but both of these characteristics seem to increase perceptions of Instrumental Stigma. In this domain, though, being Muslim is the more important predictor. In contrast, being Muslim does not have a significant effect on perceptions of Blame, as shown by the low coefficients for this variable in Table 8. In the model for Blame, being female has the highest coefficient and the strongest association with high levels of perceived stigma.

Two variables that are predictably associated are age and marital status. Eighty-six percent of subjects under the median age of 31 were unmarried, but only 39% of subjects older than 31 were unmarried. While both being young and being unmarried were associated with higher levels of perceived stigma in the bivariate analysis, the multivariate models reveal the relative contribution of these two related characteristics. In the domains of Instrumental Stigma, Blame, and Symbolic Stigma, being unmarried was more closely associated with higher levels of perceived stigma than was being young. In fact, when marital status was considered, the effect of age on these stigma scores, including Total Stigma, was negligible. The lone exception to this is seen in Table 9, which shows the models for predictors of Shame. For this domain, being young and being unmarried were similarly (but not significantly) associated with increased perceptions of stigma.

Table 12 shows the models that result from the backward regression for predictors of each domain of stigma. All variables are initially included in a robust regression model and then removed in a stepwise process until only coefficients with p-values below 0.10 remain. This technique would be useful for creating models to predict patients' stigma scores, which was not a goal of this study. The models in Table 12 do not illuminate anything new about the potential causal associations that create a high perception of stigma in subjects, but they do suggest what some of the most significant empirically adjusted associations are. One interesting result that emerges from these backward regression models is the division between the domains of Shame and Blame. While the factor analysis of the first 115 observations indicated that these were distinct concepts, influencing the levels of perceived stigma, it is difficult to understand the qualitative difference between the two groups of questions. The backward regression models for Blame and Shame, though, show that they are associated with different predictor variables. While increased perception of Blame is most clearly associated with being female, unmarried, and having had an HIV test, Shame is most clearly associated with being Muslim and younger than 31 years-old.

Stigma as a predictor of HIV testing

As the TB-VCT study continues to enroll subjects, their stigma scores will be compared to their willingness to refer household members for testing, whether or not they have disclosed their HIV infection, whether they have kept HIV-related medical appointments, and whether they are taking medications. At this time, the only outcomes that can be compared to the stigma scores are subjects' decisions to have an HIV test at the TB clinic. If stigma does indeed influence this decision, then participants who chose not to test, would be expected to have higher stigma scores. This is the pattern seen, as demonstrated in Table 13. None of the differences is statistically significant when compared using the Wilcoxon-Mann-Whitney test, but the mean of non-testers' responses is higher than that of testers' on all but two HIV and two TB questions. Twenty-eight of the subjects had previously tested HIV positive. Some of these patients chose to have another HIV test to confirm their results or to get a referral for HIV, and their decisions were presumably not influenced by stigma, because all had tested previously. When the scores of the 28 subjects who had previously tested HIV positive are excluded, the differences between testers and non-testers are more pronounced but still do are not statistically significant. Based on this finding, the effect of stigma on subjects' testing decisions does not appear large, although the number of subjects enrolled thus far and the number who refuse HIV testing is still low.

Qualitative findings

Subject characteristics

Qualitative interviews were conducted at Mulago Hospital in Kampala between July 13 and July 27. Sixteen subjects were recruited from the staff of the TB-VCT study, the TB

Clinic, and the related TB Research Unit. Their responses to the preliminary questionnaire are in Table 14. Among the 16 staff were six HIV test counselors, three home visitors, three doctors, two laboratory technologists, one nurse, and one pharmacy technician. Subjects ranged in age from 30 to 58 (median=39). Most subjects described themselves as Roman Catholic or Protestant, and reported weekly church attendance. They had spent from 5 to 24 years working with PLWHA. All subjects reported having lost family members or friends to HIV/AIDS, with the exception of one counselor who did not answer the question. Also, 14 subjects reported currently having family or friends living with HIV/AIDS.

Early experiences

Subjects described how they first learned about HIV/AIDS. Older interviewees were already working in healthcare when the disease first appeared in Uganda. At that time it was universally fatal and very mysterious. One counselor described hearing about the disease from a nurse, who said, "'It makes you slim slowly, slowly until you die… You wait. One day you will see people getting smaller and smaller. Those are the people.'" (HIV counselor, age 50). Younger respondents had had less exposure to the disease, but they had observed it in their friends and families.

> At that time, it was not a very, I guess, talked about thing, but then people were dying. That is all you would hear. Not so much about the disease, but somebody's parent died. Then the mother dies the next term, or, you know, a child within a space of a year or two years looses both parents (Medical officer, 31).

Even early on, AIDS was understood to be a different kind of illness, and there was shame attached to it. One physician explained, "Oh, it was a taboo. If fact, if anybody had a patient, who was suffering from that kind of AIDS—what they call slim, because someone was wasting away—you would just keep quiet. Even if he died, they would just bury secretly, and it was an outcast" (Medical officer, 48). Many subjects described early rumors about the origin of the diseases. These tended to blame people from Tanzania or witchcraft for the disease:

> There was a story in the eastern side. One driver was robbed. He had a very expensive watch, so one of the culprits, they thought, he had similar signs of slim or HIV. So people around thought the owner of the watch bewitched the man. And there was a war between Uganda and Tanzania, when Idi Amin invaded their place, so some valuables were looted. So what our people thought that maybe the owners, the Tanzanians, have bewitched our people (Pharmacy Technician, 52).
>
> I first heard about HIV/AIDS when I was in primary six. That was in 1986, from one of the pupils, who was narrating a story of how the father died, but she related it with witchcraft from Tanzania... By then, I had no knowledge about it. Actually, I took it as so. I thought it was witchcraft, because the pupil was saying that "this is a disease, when they bewitch you grow as thin as a pen." So, we took it at that. I thought it was witchcraft, but when I went for my training, actually when I was in secondary, we started hearing, one of our fellow students fell sick due to HIV/AIDS, and it was really clear that this is not witchcraft, but it was a sexually transmitted disease. That is how we took it. We feared it so much in school. As people who related with that girl, we feared her so much (Research counselor, 34).
>
> As this counselor explains, further education helped to dispel many of the early misconceptions about disease transmission, but the notion of witchcraft has not completely disappeared. Several subjects described patients who continue to attribute their illness to curses or other supernatural forces. One discussed how this affects the test counseling process:
>
> You talk all about testing and everything, but while you are ending, these people just burst into tears, crying, 'No, no. This was just... we were just bewitched. Do not tell us about that. Me, I have never believed to have HIV. No, no, no. Don't even give me your medicine.' They throw away (Counselor, 37).

Regardless of the explanations for HIV/AIDS, all subject reported serious discrimination against people who fell sick in the early years of the epidemic. Usually this took the form of ostracism and neglect by families. In the most serious examples, patients were completely abandoned. As one counselor explained:

> Sincerely, it was really a tragedy, because really you are also in the same critical condition and people throw you out. You would just understand that

> it is very terrible and you are no longer liked by any society… They would come dump them in the ward. Off they go. They give you a telephone number that when this person dies, just call on us. We shall pick the body. And during those days we had very serious complications in the wards, because I also work in the wards. There were so many complications. Patients could come very emaciated. The women had genital sores, very bad sores. You can imagine, by that time we did not have ARVs, no objection of having Septrin [trimethoprim and sulfamethoxazole]. Patients used to have very bad signs that these people could not allow to stay with such a patient in the house, and remember, these patients are renting. Even landlords could not allow people to stay on their houses with such very sick patients (Counselor, 37).

Even patients who were allowed to remain with their families faced discrimination in the homes. One interviewee told of patients being sent to out-buildings or structures specially built so that PLWHA would not die in the main house. A more common form of discrimination related to sharing eating utensils at meal times. One subject remembered, "The plates were put separate. What made me get scared, because it had just started, the owner of the home, after the patient died, all the cups and plates were broken and thrown into a pit latrine. So it scared. Even the clothes were burnt" (Pharmacy Technician, 52).

Much of the discrimination associated with HIV/AIDS in those early days was focused on fears disease's mortality and the painful deaths that patients faced, but even early on there were also moralistic overtones to the stigma. The connection with witchcraft reinforced the belief that people with HIV were cursed or disgraced in some way. Because HIV was known to be sexually transmitted, the disgrace was often associated with sexual transgression. A home visitor mentioned that this was part of the message that he heard in school. He said, "According to the way they were telling us that everybody who has HIV should be having affairs, which are—like prostitute—like people who are having extramarital relationships" (Health visitor, 32). One counselor explained it plainly, "But at that point, I look at people, who had it, as people who were misbehaving" (Research counselor, 34). Because many of the first cases of HIV/AIDS were among truck drivers or people who lived along major trucking routes, especially around Masaka in the southwest (see Figure 1), these groups became marked as promiscuous, whether they were sick or not.

The abandonment, neglect, and avoidance of people with HIV/AIDS are not limited to the past. Physicians and healthcare workers who primarily work with tuberculosis patients reported little enacted stigma occurring today, but HIV test counselors have more time to spend with patients. They hear more intimate stories and establish a rapport that allows patients to be more open about their experiences. A lab technician who is closely involved in the HIV testing process and the care of people with TB recounted several stories of people with HIV and TB co-infection being abandoned by their families. One young woman was admitted to the TB ward with a baby, who was also sick. Her husband left them in the hospital and refused to provide any more assistance. Even after the baby died, he denied his relationship until nurses on the ward carried the baby to his home with assistance from the local council leaders. Another young girl, who was admitted with HIV and TB co-infection, was denied assistance by her mother. The technologist described what happened when the father was informed:

> He came with somebody and said: "This girl is my daughter, but she is no longer my daughter. I am going to give her money. This is the person who is going to look after her." ...So, he handed over the girl to the nurses and to this lady, gave them assistance and said "Even when she cures, do not call me again. I have given them what is enough for them. I will be paying this lady for the work she is doing for her, but when she cures, I don't want her even in my home" (Lab technologist, 34).

Changes in HIV-related stigma

Despite troubling stories like these, interviewees agreed that the treatment of PLWHA has improved in recent years, although there are still instances of abandonment and isolation in the home. Sharing eating utensils is still problematic in some families, but in general there are fewer instances of the most egregious forms of discrimination. One doctor explained how the stigma has changed over time:

> The stigma is still there a lot. People still look at people differently. Where we have reached, I think, people will not stop you from boarding a taxi, if they think you have. Pretty much everybody knows the basics about how it is transmitted, but again people will look at you, and they are wondering. They think they know what you have. So, I think, the treating people differently is not like it was in the old days where people would leave someone to die alone, and relatives run away, and someone is sick and bedridden and is in the home alone and can't get someone to bring them to hospital, because everybody is worried about transmission. I think that is pretty much reduced, but it's a more distanced kind of stigma. You may not directly say something to somebody, but you are thinking it and probably are looking at them differently. You may not be able to control it, but you are (Medical officer, 31).

This description of a shift from overt discrimination to a more subtle suspicion and distancing is consistent with the change in enacted stigma that many subjects described. Also, many subjects agreed that improved knowledge about disease transmission was central to the shift to better treatment for PLWHA. Much of this knowledge has come through large-scale education campaigns.

> In fact it is our government through the Ministry of Health, they have done sensitization in almost every corner of Uganda. Even non-governmental organizations have also contributed to that. So at least almost every Ugandan knows about the disease and how you can acquire the disease, and it looks like people are more positive these days than it used to be (Home visitor, 54).

Most subjects agreed that outreach efforts and mass media had played a major role in educating the public and that this knowledge has helped to alleviate social stigma. But the experience of seeing people with AIDS get better was also an important motivator of changes in attitudes. The same home visitor explained, "people we treat go down the community and say, 'You see I have been treated for this, and you see I am okay.' They are not afraid anymore, many of them" (Home visitor, 54). This kind of personal interaction was frequently mentioned. Several subjects even noted that as patients attended health clinics and met there, they learned about each other's experiences and gained a better understanding of HIV/AIDS.

In all these discussions, though, the availability of treatment, especially antiretroviral therapy, was essential to changing the perceptions of PLWHA. Subjects explained that people in Kampala were not necessarily stigmatized for being HIV positive, because this was something they could keep secret. Instead, visible illness was the trigger for discrimination. Thus, HIV positive people who remain asymptomatic are often spared the isolation and gossip faced by others when they fall sick. A test counselor explained how this works:

> People used to fear the way people look, the appearance of someone with HIV, but because these days there is medicine, they say, 'I am not going do what? I am not going to develop diarrhea. I am not going to get rashes.' Because like in women when they get rashes, they know that they are what? They are gone. With medication they know that the rashes will not come, the diarrhea will not come, so they will look like any other person. So the stigma reduced (Counselor, 32).

As important as antiretroviral drugs are in helping patients regain their health and avoid stigmatization, they are also a burden. The drugs have considerable adverse effects and they must be taken everyday, which means that they can serve as stigmata themselves, marking a person as HIV positive.

> Stigma gets better, as people probably get better on treatment and live with the knowledge longer about the disease process and get more information, but it also impacts on how people take their treatment. Nobody wants to be seen by people, who do not know their disease status, popping pills all the time. (Medical officer, 31)

Subjects described men who keep their pill bottles at their offices in order to hide their HIV seropositivity from their wives. A lab technologist told of finding empty pill bottles thrown into shrubs along an abandoned stretch of road. He explained, "I think this person must have been taking the drugs secretly. He does not want either the wife or the household members or the friends around him to know. So once that person got space, where nobody was seeing, it was early in the morning, he decided to pour them" (Lab technologist, 34). Other interviewees reported that patients tell others they are taking medicine for cancer or even tuberculosis rather than admit that they are taking antiretroviral drugs.

The fact that some people in Kampala go to such lengths to hide their HIV positivity suggests that discrimination indeed continues. While this still may take the form of abandonment, neglect, loss of employment, and even violence, the most common descriptions of today's HIV-related stigma centered around avoidance and gossip. Interviewees explained that people in their communities associated many different symptoms with HIV/AIDS. They most often mentioned loss of weight, rashes, oral lesions, and coughing. Any of these could be enough to suggest to people that their neighbors are HIV positive. When this happens, explains a counselor, "They don't socialize much with them, especially when they really show the signs of the disease. But when the signs are not there, they socialize much with them. But once they see somebody is emaciated or coughing too much they don't socialize much with them" (Research counselor, 34). Several patients mentioned this kind of avoidance, even in people who have a clear understanding of how HIV is (and is not) transmitted. There seemed to be heightened vigilance to protect children from PLWHA:

> Much as people have known that HIV can't get you, when you touch somebody, who is infected, but some people still have it, because they will not want their children to go near that adult who has it. Yes, the adults will change a bit to show that they are not scared of the patient, because of the education we give, but they always refuse children to go near that person, something like that (Counselor, 30).

Another example of the extra lengths that people in Kampala go to in order to avoid exposing their children to HIV infection came when a test counselor described the attitudes of healthcare workers. No respondent was able to describe an instance of discrimination against HIV positive people in a healthcare setting in recent years, although some acknowledged that in the past PLWHA may have been denied care or otherwise stigmatized by providers. Still, it seems that at least some healthcare workers are not as tolerant in their own homes as they are in a professional setting.

> Actually even to the medical people, some of them I know in the hospital, they can never hire a house girl, who is HIV positive. Once they hire a house girl they have to first test them for HIV. Yes, they think, if they leave this person with their children, they may harm them and they get infected. Just living as adults, people don't take it as bad, but they always fear to entrust those people with their children (Research counselor, 34).

Gossip is another common manifestation of stigma. While gossip seems benign compared to other forms of discrimination, several respondents named gossip as a fear that kept people from having HIV tests, disclosing their results to others, or adhering to medication regimens. When a person's HIV infection becomes known or even just suspected, neighbors begin to speculate about his or her sex life. Some, according to one counselor, "refer HIV to prostitutes, because in the past those prostitutes were the most important infected people" (Counselor, 52). Gossip may not be limited to the patient:

> Oh! They gossip a lot! (*laughs*) So they start saying, "That boy has been messing around with so many girls. No wonder." That sort of talk… Some do not mind about others' business. They care about their business. Others are just so critical to, you know, like, even when you cook posho and some groundnuts, they talk. "Those people are..." Those people will talk and blame even the whole family (Nurse/midwife, 54).

This kind of gossip may be especially harmful to young adults, because it threatens their prospects for future romantic relationships, as one interviewee explained, "Maybe for if people are to go into a relationship. That's when people start saying, 'Be careful about so and so,' secretly, or keep warning people about that person. 'It may not be good' or 'Don't involve yourself too much with that person' in terms of sexual contact" (Lab technologist, 34).

Perceived and internalized stigma

All the respondents agreed that the combination of avoidance, gossip, and blame took a toll on the lives of PLWHA. Many mentioned the ways in which patients change their behavior after testing positive to avoid the attention of their friends and families. A lab technologist told of a patient who tried to convince the HIV testing team to falsify his result form. He wanted to hide his seropositivity from his main caregiver, his stepmother.

> Reasons were this woman would go and tell everyone that he is HIV positive. She will go on announcing, telling everyone, 'Now this has HIV,' things like that. Then we fear also, maybe this person may start judging that 'Uhh, it was your mistake,' because most of the people have grown up, when they know about HIV. And when they catch HIV, somehow their… Haaa, people say, 'You are careless. It is your problem,' things like that. And they tend to put the blame on you (Lab technologist, 34).

Correct knowledge concerning HIV transmission has improved the instrumental stigma that PLWHA face. Others no longer go to such lengths to avoid physical contact, but, as the quotation above demonstrates, correct knowledge has also made PLWHA more susceptible to being blamed for their own infections. They are now assumed to have known enough to be able avoid infection, increasing the responsibility that people bear when they do become infected. A test counselor described her experiences working with pregnant women in a clinic for the prevention of mother to child transmission:

> And others, they used to tell us, 'How am I going to be looked at in the community, if I am HIV positive? The moment that people learn that I am HIV positive, they are going to do what? To see me as someone who has done something wrong, who has committed what? A crime, because I am HIV positive.' Because they know the mode of transmission (Medical counselor, 32).

A physician agreed with this description of the way blame weighed on his HIV positive patients. They carried the responsibility both for becoming infected, themselves, and for bringing a stigma to their families. This doctor said, "She may tell you what she has gone through by the time she comes here, and you really feel sympathetic. They tell you a lot. They say, 'Now, now, you know, I have been abandoned. I have been looked at by my family people as somebody who has actually ashamed my original'" (Medical officer, 48). While churches were most often described as supportive and consoling in interviews, several subjects mentioned the way that the church and church officials could increase the shame the PLWHA feel. A test counselor, who described herself as Born Again, explained, "Actually with pastors it is even worse. They feel like if you don't keep to the word of God, you will end up getting into this. So the judgment passed around as they give out the word about HIV/AIDS is the one, which affects the people, when they get it" (Research counselor, 34).

These psychological effects were another common topic in interviews. Faced with the gossip and discrimination in their communities, PLWHA withdraw socially, only to become more depressed. This makes them further isolated and may also affect their physical health.

> You try to feed yourself well, but inadvertently, you know, you are losing weight, whether you like it or you go downhill, and then another thing is that you are not as happy as you used to be, and you have mood swings, you know, because inside you, you know what the problem is and now you start feeling, 'Why did I go to school? Why did I struggle? This and that. I have now HIV, and I believe I have it. What is the way forward for this life? This life is hopeless.' So somebody becomes more withdrawn. Somebody, who used to be outgoing, then he is withdrawn, and some people can start saying, 'This guy, these days, I do not know.' You know, this disease can cause even mental problem (Medical officer, 48).

One interviewee described how two of her relatives were so changed by learning that they were HIV positive that they left the country. "They don't feel like they are of much worth to the public anymore and they should withdraw from the public" (Research counselor, 34). In one of these cases, a woman "changed her character." She stopped speaking to other people, lost her job, and rarely left her house. She eventually found another job, but struggled at this one, because she had difficulty interacting with her co-workers. Finally, she found a way to leave the country; she "escaped." This story is particularly remarkable, because the workplace where this woman had so much difficulty interacting was an HIV/AIDS organization, where she, herself, was a client. Although her serostatus was known to at least some of her co-workers, these people were as supportive as anyone in the community. In this case, the stigma faced by this unfortunate woman came not from her family or neighbors but from her own internal shame. "I think she judged herself as not having been responsible enough for herself that she ended up getting the disease. So she condemned herself. That's why she ended up reacting that way" (Research counselor, 34).

Other subjects agreed that sometimes the fear of AIDS or its associated stigma is worse than the actual enacted discrimination that PLWHA face. Without good counseling, people learning that they are HIV positive assume the worst:

> You know, they think that when you know your status, people around you, [who] know, will change their attitude and even the surroundings. Everything will change in your life, so they just fear for that change, fear for change and then fear of taking drugs throughout life (Home visitor, 54).
>
> The mere knowing that I am HIV positive is enough to stigmatize me. You know, 'I just throw away everything. I think…' If you don't get a good counselor or anybody to counsel you, you just say, 'This is the end of the world. This is the end of me' (HIV Counselor, 50).
>
> People feel like that, because sometimes they will have seen how other people with HIV/AIDS were treated, so they carry all that to themselves. And then they begin to get depressed over the issue (Research counselor, 34).

Gender and stigma

Many subjects discussed the differences in the ways that men and women living with HIV/AIDS are treated. Some offered real examples of enacted stigma they had observed among their patients and communities. Others recounted the different fears that men and women have as they consider whether or not to have an HIV test. For most patients, an important factor in the decision to have a test is what they will do with the information if they turn out to be HIV positive. Who will they choose to tell and what consequences will they face as they share their serostatus with others? Two counselors explained that the burden on HIV positive women is particularly hard if a woman's husband predeceases her or if he is HIV negative.

> Ehhh, in the society men fetch a lot of favor from people than women. For example, if a man lost a wife, the community serves him so much and favor them so much and feel like, how are they going to stay? Who is going to take care of them? And they feel a man should marry early enough, but if a woman looses the husband, the treatment is different. For example, even due to HIV, the community and society feels like this person should always be there and live to serve the children, and should not really marry. So the treatment is different. Men fetch a lot of sympathy from the public than women (Research counselor, 34).

> I encouraged one who tested. I encouraged her to test. She took up a test. I encouraged her to bring the what? The partner to be tested in the men's access clinic. The husband came... It turned out to be a discordant couple. After being a discordant couple, the man decided to what? To disappear from the what? The woman. So the woman would come back and tell me, 'Musawo [doctor], you are the one, who encouraged me to come with my husband. Now my husband has what? Disappeared completely, and I am suffering with the what? With the children'" (Medical counselor, 32).

There were two kinds of explanations for why HIV positive women were stigmatized more than men. One was essentially economic, while the other depended on sociocultural understandings of women's roles in the family and the community. These issues are certainly related, but the way respondents described the fears of women can be separated into threats to material survival and threats to a social identity. Two counselors explained how women without another source of income feared abandonment by their husbands if they were discovered to be HIV positive.

> Yes, for women it is worse. Why? Because most women rely on their spouses economically, so they feel like if they ever share out it may lead to a lot in their lives. It may mean losing their relationships or losing their means of survival. So it is worse for women than men (Research counselor, 34).

> Many women would say, 'My husband will neglect me. Where will I ever get food?' (*Is that some thing you still see today?*) Very much. It is still going on. 'I can't tell my husband, because my husband is the one catering for me, paying for the rent bills, everything. I can't tell him, and after all he will say that I spread the disease to him. He will do what? He will throw me out.' It is still existing, because even up to now, our participants in some studies are still getting pregnant, and when you ask really those women, 'We told you really you have to use barrier method and at least some injectable, Depo, or pills for family planning. Why didn't you do this?' These people tell us, 'We cannot tell the husbands. First of all they are not aware that we have HIV. Secondly, we really fear to be thrown out' (Counselor, 37).

Of course, the economic dependence of women is a result of larger cultural structures that diminish women's opportunities for education, employment, ownership of property, and other rights. One consequence is that many women are not just economically dependent on their partners. Their entire identities are tied to their husbands and their families. Their decisions are not their own, and their shame is also shared with their families. Because many women's identities are so closely tied to their roles as wives, mothers, and caregivers, a sexually transmitted disease is especially problematic. It may suggest that a woman has violated the norms of marriage, even if she has been monogamous and was infected by her husband. And if a woman is no longer able to care for or bear healthy children, then she has less social value to her family. Two doctors described how these social forces converge on HIV positive women.

> In a marriage, I guess, if I test—and different for different people—particularly women, because the community—it is as if a woman is not defined until you have a man by your side—and then after you have that person by your side, it's like almost, depending on how dependent you are on this person, it's like almost every decision that you make is governed by the other person, or is directed by the other person, such that even though the opportunity may be given to you to have a test, how do you test without informing your husband, even though it is your life, and it is you who is sick. I mean, 'My husband will kill me, if he thought I did this.' It's like you are living, but with the permission of another person, or whatever you do is with the permission of another person that you cannot have this test until your husband permits you to do it. If you went ahead and did it on your own, then there are repercussions thereafter (Medical officer, 31).

> Yes, the way the society treats them differ, because like in some cultures, they believe that a man is entitled to have more than one wife. Now, if in the attempt to do so, he gets a problem like HIV, he is looked at as somebody, who has not offended so much, and he has not much fault to talk about, and he should be treated like, you know, should remain in society as acceptable and recognized as somebody, who is important, and the people don't tend to run away from him, unlike a female subject. If she fell sick of the problem, the people, and especially if the man is still healthy and going on well, she carries much, much, much blame from the society than it would have been for a man. That is the difference, and therefore the lady herself so is reduced to nothing, and you know many of these societies, cultures and whatever, they tend to say that a woman is a subject of a man. You know, he has to be looked at as the other big man and bow down and whatever, and she will always remain with that one man, so she looks at herself as carrying a very big blame, whereas it might not be her cause anyway, and you know, their security is the family. Their security is marriage. Their security is children, you know, that kind of a thing. So out of that, even where he came from, her relatives, her home, they tend to look at her as somebody who is an outcast, bad behaved woman, you know, that kind of a thing. Socially she is an outcast. So they carry a lot of blame on themselves. When you are female and get the problem, you feel so much reduced, and, you know, they look at their future as being the family and whatever, and, you know, because once you leave your home and get to the marriage, because of the attached dowry and whatever, you have been sent away. You know, you can't go anywhere, that kind of a thing. So culture has a big impact on how the female subject feels, when she gets a problem (Medical officer, 15).

Many subjects agreed that women faced more difficulties than men in HIV prevention, testing, and treatment, but some also noted that some men face distinct challenges, too. For men who define their masculinity by their romantic relationships, HIV poses a threat to their sex lives. One nurse explained simply, "I think, especially men think that it is not necessary to test, because if he knew he might miss some of his girlfriends" (Nurse/midwife, 46). A TB home visitor agreed with this description and added that such men would be less likely to disclose their HIV status, if they did test positive:

> And because in Uganda here very few men have only one woman, so you find that this one, if he ever mentions, the girlfriends will get to know and maybe he will be like a reject in society. And whereas if he comes, tests, and finds I am HIV positive, gets on the drugs, will continue those relationships without them knowing that he is already on drugs. And you know, there he won't fall sick, so nobody will really care, so they will just continue like they

> have been. So it is mainly the men, who do not want to admit they are HIV positive (Home visitor, 54).

Feelings about HIV testing

A central subject of all sixteen interviews were the attitudes and beliefs that Ugandans have regarding HIV testing. Subjects discussed the reasons that testing rates have increased in recent years and why some individuals still refuse tests. One of the first points that several respondents made is that there are important factors in patients' decisions not to test that have nothing to due with stigma. Among these are logistical barriers to testing, such as the cost, in time and money, to reach a testing site. Although free HIV testing is now widely available in Kampala, interviewees reported that many patients are unaware of this. Also, many erroneously believe that HIV test results still take a week to return. Some individuals prefer not to test if it requires a return visit to the clinic. Although many sites now offer same-day test results, the high demand for testing—and especially for test counseling—means that there are long lines to test in many places. This is especially true in places like the Mulago TB Clinic and the TB Research Unit, because patients are being investigated and counseled for other illnesses in addition to HIV.

Several subjects also pointed out that diagnostic testing is not a normal part of health maintenance for Ugandans. One doctor noted, "Even the medical testing is not traditionally a thing people... If you are well, you are well. You do not want to know what you do not have. Maybe that spills over into HIV" (Medical officer, 31). A nurse agreed with this assessment that many patients wait until they are ill before making the decision to have an HIV test. She suggested that this was particularly true for men: "Especially male, the males, when you tell them about this thing, they say, 'What is the use of testing? I am healthy.' You know, there is even that denial: 'I am okay. If I fall sick, I will go and test'" (Nurse, 54).

Subjects also mentioned some of the alternative treatments that patients pursue rather than present to a clinic where they believe they will be tested. Respondents described how some patients have strong suspicions that they are HIV positive, because they have been frequently ill or seen partners fall sick. Some of these individuals go to great lengths to avoid being tested and having their suspicions confirmed. They attend private clinics, even expensive ones, where they will not be tested for HIV but instead treated for bacterial infections or malaria. Others buy drugs—usually antibiotics or antimalarials—from local pharmacies. Some patients save some money by visiting traditional healers. These healers often charge much less than Western clinics and may not ask for payment until after a patient has improved. And they offer the advantage, to some, of not testing for HIV infection.

> I know there are some people, who have lost their spouses, but because they fear to come to hospital to test, they just start taking native medicine. You know, that one in the jerrycan. So they just start on that. You had rather not know that you are HIV positive but just take the drugs. You know, this one in the jerrycan, the local native medicine (Home visitor, 54).

Another alternative to Western medical care is prayer therapy. Subjects mentioned this being used by both people who suspect that they might be infected and those who have already tested positive. Some pastors, especially in Born Again churches, claim to be able to heal HIV. Individuals may choose to attend one of these churches, pray, and, often, donate money in exchange for prayers on their behalf. One subject even described a scam organized by a church to prove that it can cure people of HIV:

> That belief is there because many pastors have declared so, and people have been put even on TV, testifying with medical reports that this one, you see, was positive and this one is negative. And around Mulago we have one big church, and there is a pastor. When people, who are positive go there, they

> test positive. He declares healing onto them and sends them to a particular person somewhere in a clinic, who tests and gives them wrong results, which say they are now negative (Research counselor, 54).

This kind of fraud was not limited to religious groups. A doctor described centers that sell negative results as a way to comfort patients:

> You know, some people have deceived some people that actually they do HIV test, and they get money out of such people, and they always know that some people will feel very happy, if they are told that they are negative. So what they do, they get a lot of money from these guys and tell them the wrong, and actually they don't do the test, and they tell them, Okay. And he writes on the paper, it is 'non-reactive,' you know, that kind of language to just to please him. They go out, they think they don't have any problem, and they are happy, when actually they are going to go downhill, you know (Medical officer, 48).

It would be precipitous to assume from these comments that such practices are prevalent or more than isolated occurrences. Still, even a rumor of fraudulent HIV testing could be enough to give individuals pause when considering whether or not to have a test. Wavering patients might avoid a test rather than risk receiving false results. The doctor quoted above mentioned that some patients who are considering HIV testing delay it because they are uncertain where they can be assured the most reliable result.

Another concern of individuals choosing where to have an HIV test is confidentiality. Subjects were emphatic that there was little risk of their own patients' HIV test results being revealed without their permission, but some mentioned that the patients themselves worried about privacy, and made a point of choosing testing sites where they trusted providers to be discreet. Even when they trust healthcare workers, some patients worry that their status may become public if they are recognized by others while attending an HIV testing center. Several subjects concurred with this test counselor's description:

> They just associate it with HIV results basically. Most people think that if you go to test, chances are higher for them to be HIV positive than negative. So they fear that if they are seen moving out of the testing environment, they may associate them with having misbehaved" (Research counselor, 34).

Another subject noted that patients fear that their partners, in particular, will learn that they have been to have an HIV test.

While being seen by lay people at an HIV clinic may be embarrassing to some patients, subjects reported that few patients found the offer of a test embarrassing. Although in the early years of the epidemic there was greater stigma attached to HIV testing, today it is understand as a common test. Patients tend not to take the suggestion of a test by a doctor or counselor as an implication that they are promiscuous or sexually deviant. "In the past it used to be like that," one counselor said, "but these days people are well informed, so they do not mind, but we give them options, because these things are voluntary" (Counselor, 52).

The fear of testing came up in most interviews. In some cases, subjects could describe the post-test events that patients feared; shame, gossip, abandonment, violence. More often, though, the fear was nebulous. The knowledge of being HIV positive was described as a burden, even when there were no specific outcomes associated with it. A doctor told the story of a patient who had lost her husband and two children. She suspected that she was HIV positive, but went to great lengths to avoid testing. Rather than present to Mulago Hospital, where she would receive free care, she went to a private health center each time she experienced bouts of cough and fever. At this clinic, she knew that she would not be tested for HIV, even if it cost here hundreds of thousands of Shillings each time she was admitted. Finally, a healthcare worker there tricked her into going to Mulago's Infectious Disease Institute, where she finally agreed to HIV testing and confronted her serostatus. A counselor described a 23-year-old man with tuberculosis, who refused to consent to an HIV test. He told the staff that he would not have an HIV test until he was 30. Only then, he explained, would he have "fulfilled what he wanted" (Counselor, 52) and be able to face the knowledge of being infected with HIV. Many subjects had similar explanations of the fear of a positive HIV test.

> Because they fear to be told that they are positive. Some of them will say, if I am told I am going to live less, my life will not be the same. I will stop working for my family. I will see I am just wasting time. I will see a dying person within me, just hopeless, something like that (Counselor, 30).
>
> Fear is the most important, fear of knowing that they are HIV positive, and the other one says, 'If I know that I'm positive, all my plans will be shattered, because I won't have energy to pursue whatever I am planning to do in my life' (HIV counselor, 50).
>
> I think they fear what will happen next. You have HIV; what next? 'There is no cure for HIV. Well, I can be assisted but for a short time.' So somebody starts thinking. Some people believe that they would rather stay without knowing than knowing. They prefer not knowing the fact within them (Lab technologist, 34).

Some of the patients believe that the knowing their status will not help them, because they will not have access to or be able to afford treatment. Others believe that an HIV test will not help because they already assume themselves to be seropositive. "Some of them think that they are infected," a pharmacy technician explained, "Even if they go for the test or not, it is all the same" (Pharmacy technician, 52). One physician speculated that the HIV prevalence among TB patients who refuse an HIV test is much higher than that among those who accept the test. The former, he explained, came to the clinic suspecting themselves to be HIV positive, because they knew that they had been exposed. But they would rather not be burdened by having their suspicions confirmed.

A similar, but better articulated, fear of the HIV test is the belief that a positive test heralds a rapid death. A lab technologist told of a young friend, who believed he was HIV positive, but could not be convinced to have a test. She explained, "So now the boy says, if he tests—he has said, 'If I test now, I will not finish even a week. I will die.' If he tests and confirms that he is HIV positive, he will die" (Lab technologist, 34). Other subjects had similar descriptions of how strongly their patients associated a positive test with immediate death.

> These people at any time you tell them that they are positive, they think of death there and then. That is why in some instances, when we get participants to test, they will always say no. They will say no, I still have many plans. I wish to marry. I wish to have a newly wedded wife. I wish to have children, so why do you think about telling me about HIV. And when somebody has HIV, has to die automatically. That is why people now, some of them don't really want to test, because when you talk of HIV they think of death there and then (Counselor, 37).

Although there were many examples of the negative feelings that people in Kampala had towards HIV testing, subjects did describe some of the factors that made their patients more willing to have an HIV test. Among these is the misconception that testing is a method for preventing HIV/AIDS. Several respondents told of patients who repeatedly test for HIV but who make no changes in their sexual behavior.

> Some people feel that when they test, it can help them from getting infected from HIV, and these are the kind of people who keep on testing, testing, testing until when they find a well informed counselor, who will inform them that it is your behavior that is a problem. If you change your behavior and you live with this, you may not get the virus, otherwise if people do not know. Some of them think it is a measure of preventing them from getting HIV. Because I have ever had such a client. He was a secondary teacher, and he had had around sixteen times testing (Research counselor, 34).

While this counselor noted the kind of misconceptions and risk behaviors that may be perpetuated when patients have inadequate test counseling, subjects also described how high quality counseling can convince people not only to have HIV tests themselves but to encourage testing in others. Some patients may even present for HIV testing as a way of accessing counseling services. Several subjects mentioned the support that counselors provide for victims of sexual assault. In addition to offering a test that can dispel the uncertainty victims may have about their serostatus, the process offers a confidential setting and compassionate ear to share what for many has been a long-held secret. This comforting environment is important in overcoming the reluctance of some people to accept an HIV test, especially after enduring the long lines and curt treatment of doctors and nurses in a busy hospital, as this technologist explained:

> So by the time they are there, they tell you all how they have been moving that is already telling you how they have been stigmatized. Then you tell them don't worry. You will get all your treatment. Be free here. Talk everything. Then you will find them talking to the counselor and telling them so many other things, telling them how they feel, how other people have been treating them, and how they feel they will continue with their life. But now because they get the counseling, they move away when they are happy. They feel now they have got revival of their lives. They now get strength to even take their drugs. They get the strength to actually talk and cooperate with other people (Lab technologist, 34).

Such experiences are especially useful for encouraging couples' testing. Although subjects acknowledged that this was not very common, they explained how establishing a good relationship and providing clear information about HIV testing and AIDS can make it easier for patients to refer their partners. Several counselors explained that often the first partner may pretend not to have tested. Then, when he or she brings a partner the testing team draws blood from both partners to maintain the appearance that both have been tested on the same day. Although couples' testing may be rare in Uganda, other interviewees described the way that one person's positive testing experiences can influence other people to test. One doctor said:

> Yes, because, like now, what we have seen, if someone tests and gets the results, and the way they take care of her or him, it encourages him to go out and tell a friend or something to come as quickly as possible to come and get a test, because when you test there is a way out, and you will be happy, better than what you are, where you are (Medical officer, 48).

As the above quotation suggests, the quality of care is important in influencing people to have an HIV test. Many of subjects mentioned that HIV's incurability was often cited as reason not to test, but there was also wide agreement that the availability of antiretroviral treatment was a major factor in patients' testing decisions. A lab technologist explained, "Yes, it helps, because some of the questions people had was, 'Even if I test, there is nothing I am going to benefit.' But now they know, if you test, there is hope" (Lab technologist, 34).

As described above, concerns that their serostatus will not remain private seem to keep some individuals from testing, and just attending an HIV testing site may amount to disclosure for some people. This very fact, though, made HIV testing at the Tuberculosis Clinic more attractive. Several subjects mentioned that although tuberculosis is associated with HIV, there is less stigma connected to the TB clinic than to dedicated HIV centers, such as Mulago's Infectious Disease Institute (IDI).

> Most of the time and maybe that was just traditional; even though people think TB means HIV/AIDS, still I think it is more preferable to them to go to a TB facility rather than the IDI. If for example you are walking into the IDI, everybody who sees you just at the door will know just know your results without a doubt. So I think, yes, it is more acceptable to come to the TB clinic (Medical Officer, 31).
>
> It is rare to see a person walking to TASO to test for HIV. He would rather go to a clinic. So the stigma, at least for testing at the tuberculosis center, is not so much, because it is a new service, which we have just implemented, and it doesn't pin the patient of HIV, because he has come for other things, though he will get in these other services. That is why the acceptance rate is good (Counselor, 30).

In summary, stigma is just one of several barriers to HIV testing, but the fear of testing positive and having to disclose a positive test are significant considerations for many people in Kampala. Testing is not routine and there are concerns about the accuracy and confidentiality of HIV tests, but interviewees recognized some factors that make testing more comfortable for their patients. High quality test counseling provides important education about HIV and can reassure people who test positive that there is hope for them. One of the most important factors in providing hope to people considering an HIV test is the availability of antiretroviral medications. These have changed the outlook for many

PLWHA, who now offer a model of survival to people who previously associated HIV/AIDS with certain death.

HIV-TB Stigma

Each subject in the quantitative portion of the TB-VCT study responded to a set of questions investigating the relationship between HIV and tuberculosis before they answered the stigma questions. Results from these questions are summarized in Table 15. Three questions address the real biological relationship between the two diseases. Eighty percent of subjects agreed or strongly agreed with the true statement "People who have HIV are more likely to get sick with TB than other people." And only slightly fewer recognized that "People who are sick with TB are more likely to have HIV than people who do not" is also true. These responses suggest that subjects in the study recognize the close relationship between the two diseases and know that many people are affected by both.

When subjects were asked to respond to the statement "Most people who are sick with TB have HIV, also," 53% agreed or strongly agreed. Data from the same community have demonstrated that fewer than 40% of TB patients are infected with HIV (Srikantiah, Lin et al. 2007), but subjects' responses indicate that the perceived overlap between the diseases is greater than is, in fact, the case. It may reflect an assumption of HIV infection—with all its attendant stigma—in seronegative people who are sick with tuberculosis. Subjects were also asked to agree or disagree with the statement "People who say they are sick with TB really have HIV." Like the previous question agreement would reflect an exaggeration of the association between the two diseases. Additionally, agreement would imply heightened suspicion of anyone in the community who disclosed a diagnosis of TB. Most subjects disagreed, but 28% agreed or strongly agreed with the statement.

Quantitative comparison

Every question about HIV stigma was also asked with regard to TB-related discrimination. A random numbers table determined whether patients answered the set of HIV or TB questions first. Factor analysis showed that the TB stigma questions did not load on to the same dimensions of stigma that characterized the HIV questions. A direct comparison of those stigma domains is not possible, but some observations can be made by computing a Total TB stigma score, the mean of the responses to all TB questions. As for Total HIV Stigma, the Total TB scores ranged from 0 to 3, but only one subject had a score at each of those margins. The mean Total TB Stigma score was 1.61, the median was 1.67, and the standard deviation was 0.63. Cronbach's alpha for the twelve-question TB Stigma survey was 0.84. The Wilcoxon matched-pair signed-rank test indicated that scores for Total TB Stigma were significantly higher than for Total HIV stigma (1.61 vs. 1.44, p=0.0087).

More revealing, though, is that only one of the demographic variables that was associated with greater HIV stigma was predictive of TB stigma. Kruskal-Wallis and Wilcoxon-Mann-Whitney tests found no association between TB stigma and gender, age, marital status, income, education, religion, number of sex partners, condom use, or TB diagnosis. Only subjects' HIV testing history was predictive of TB stigma (Table 12). Subjects who had never had an HIV test or who knew themselves to be positive had similar TB stigma scores, but these were significantly lower than those of subjects who had tested negative for HIV in the past. These responses are summarized and compared with HIV stigma in Table 16.

While the domains of stigma developed from the HIV questions—Instrumental, Shame, and Blame—cannot be used to compare data from the TB survey, a pair-wise comparison of the two questionnaires is revealing. The Wilcoxon matched-pair signed-rank test was used to compare corresponding questions. To account for the twelve pair-wise comparisons used in this analysis the Bonferroni adjustment was used to determine a threshold level of significance (alpha) of 0.0042. Even with such a low alpha, some important trends emerged, as demonstrated in Table 17. The mean scores for four questions about proximity to a sick person are higher when asked about TB than when asked about HIV, suggesting that subjects recognize the dangers of transmission of the airborne bacilli that cause TB and that they understand this risk as greater than the risk of HIV transmission through casual contact. In contrast, the mean scores for three questions about the personal responsibility associated with disease are higher for HIV than for TB. This implies not only that subjects associate HIV with voluntary actions but also that there is blame attached to these actions. Only one question had similar mean scores when asked about HIV and TB: In your community, how many people think that people with HIV/TB have brought shame on their families?

Although subjects reported higher levels of perceived TB-related stigma than HIV-related stigma, it is unclear what this difference represents. All subjects in the TB-VCT study have a concern that they may have TB, while some know that they are infected with HIV. Still, the types of stigma that subjects reported differed significantly when they were asked about HIV or TB. Instrumental concerns were most important in determining TB-related stigma, but subjects recognized the symbolic meaning of HIV/AIDS and the shame and blame that can accompany it.

Qualitative comparisons

Many of the key informants who participated in the qualitative interviews worked primarily with patients with TB. All had experience with PLWHA, but some were trained as

TB health educators or as study staff at the Tuberculosis Research Unit. These subjects were able to describe the treatment of people with TB they have witnessed in their communities, as it is recounted to them in the clinic, and, in some cases, as they have seen in visits to the homes of their patients. Isolation and avoidance were named as common manifestations of TB-related stigma. One nurse who works on clinical TB studies described the challenge of trying to find patients and bring them back to the clinic for follow-up. When they tell their families in Kampala that they have TB, she explained, they are sent back to their villages. Other subjects describe the fear that friends and neighbors feel when they hear coughing. As with HIV, there is isolation in the household and families stop sharing eating utensils or eating together.

> TB still has some stigma, because it is an infectious disease. It can go through everyone in the family, so still it is treated with not so much of stigma, but stigma is there, because when people say that someone is coughing in the neighborhood, it could be TB. Yes, they start keeping a distance. They try to withdraw. They do not want to share any thing, like utensils and other things and whatever. They do not want to come in their homestead to talk and to chat. They say, 'That is TB. It is infectious. It can be very bad.' Everyone can go, and considering its treatment, 'It's a long treatment, and so many pills. No, no. Keep away' (Medical officer, 48).
>
> Of course, with tuberculosis the whole element is coughing. Patients who cough too much, most of the people around that patient they tend to get scared. Every time you cough everyone doesn't want to get close to you. So that's a big issue, and people know that once you cough in their faces or around them, they are going to get infected, so there is that fear. People still fear a lot, and it leads to isolation (Medical officer, 39).

After only two weeks of anti-tuberculosis treatment, patients present little risk of transmitting *M. tuberculosis* (Bond and Nyblade 2006), but respondents explained that the discrimination often lasted much longer, until a patient had finished the many months of therapy or even longer. With education from health workers, some families become more accepting of people with tuberculosis and recognize that there is little risk of transmission after patients have stopped coughing.

> Especially for the patients whom we see in the clinic. It keeps on changing, because we keep health educating the relatives, attending to the person, and we tell them this person is now taking drugs. They are checking the sputum every month. The bacilli, they are reducing. He is not so infectious, and you can get TB like this, like this, if you are to get it, you got long ago, before he started treatment. Do they kind of, they change the behavior, the attitude changes a bit, and by the time this patient finishes the treatment, it has already gone. It improves (Counselor, 30).

Although most subjects explained that coughing was the most common trigger of TB-related stigma, they also recognized that some coughing patients avoid or delay presenting to TB clinics because they fear the isolation that will result when they receive a diagnosis. A home visitor explained, "People will cough sometimes for months, and they are not showing up. They will go to the small drug shops, buy drugs, and they are not responding. And you see, they will keep there, because they fear to come to hospital to be diagnosed (Home visitor, 54)." Others interviewees explained that patients will continue to buy traditional herbal medicines even as their conditions deteriorate. By the time they present to the Mulago TB Clinic they may be quite sick.

The connection between TB and HIV was a major subject of all sixteen qualitative interviews. Subjects agreed that their patients knew how closely the diseases are related and that often they assumed the TB indicated HIV infection. One technologist explained, "Because now TB is much related to HIV. Most people, when somebody presents TB, the first thing, which comes to everybody's mind, is 'What is your serostatus? What is your HIV status?' (Lab technologist, 34)." It is not just health workers who make this association. Several HIV test counselors described TB patients who were incredulous to learn that they were HIV seronegative. Others told how patients declined HIV tests because they assumed that they were HIV positive.

> That's what we have been encouraging them in VCT/TB, because someone, the moment they know that they have TB, they know they are already gone. They already have what? Some used to tell me, "Do not test me for HIV. If

> I have TB, I know I am HIV positive." So, I always encourage them, "Please, you must have a test to know that you are HIV positive. You may think that you are HIV positive, when you have only what? TB, because the symptoms (Medical counselor, 32).

Community members, too, make the connection between HIV and tuberculosis. For many, a diagnosis of tuberculosis indicates not just HIV infection but an imminent death. A counselor explained the stigma that may result when neighbors see TB health workers visiting patients in their homes, "Because if people start coming home that you have TB, then all the neighbors, the village members, will know that that one is finished. He is having TB. What don't you know about TB? TB is a cardinal sign of HIV, so that one is finished (Counselor, 30)."

Information about the relationship between HIV and TB comes from many sources. Interviewees explained that people in Kampala receive many different messages about the two diseases. While all of these messages emphasized the strong connection between HIV and TB, they did not always convey complete information. For example, some radio programs stress the importance of HIV testing, as this technologist explained:

> Now in the radio stations, there are programs certain weekends, even weekdays, there are certain programs, which keep on telling people about TB, that if you know that you cough for more than three weeks please go and see any medical person to try to see why you are coughing like that. Sometimes the coughing might be associated with HIV, so please try and go and do the HIV testing (Lab technologist, 34).

The message commonly received by patients, though, is that all people with TB are infected with HIV. Others just assume this, having watched their friends and family members fall sick. One counselor said, "It is out of experience with most relatives they have had, nursed, maybe in the home. And these people coughed at some point, maybe were diagnosed with TB at some point and later would pass away. So they keep on saying, 'This person had HIV. Now TB also proceeded. Chances are high'" (Research counselor, 34). Other subjects noted that some healthcare providers in the community perpetuate the idea that TB always indicates HIV. They may be uninformed themselves or unable to communicate to patients a nuanced message that TB is often, but not necessarily, associated with HIV.

Although HIV and TB are strongly associated, the patients described by interviewees understand HIV to be the worse of the two diseases. For families who understand the modes of transmission, the physical isolation of TB patients may be more overt, but the incurability of HIV makes it more dangerous. One counselor described the reactions of TB patients who present for VCT:

> They used to say, 'Aaha! It is too much. I am not going to take what? I am not going to take HIV testing. Let me have my TB. If HIV is there, let it be there. At least TB has been there all the what? All the time.' This new illness the HIV/AIDS, so at least they used to say, 'I would rather be with TB than what? Than HIV, because I know HIV cannot be cured, but TB is what? Treated'" (Medical counselor, 32).

Another common reaction to facing both HIV and TB at the same time is to avoid HIV testing and the stresses that knowledge of HIV infection brings. Many interviewees described sick patients, struggling to cure their TB and unwilling to cope with a second diagnosis.

> Most of the people who I see in my practice, they come with tuberculosis, and the reason they give that why they don't test is they first handle the side of tuberculosis, because that is also a big problem that people think they can not be able to combine both of those issues at the same time. To me that is the most standing out problem in my practice (Medical officer, 39).

Other patients are glad to have a diagnosis of TB, because it allows them to avoid disclosing their HIV status. They are able to blame their symptoms on TB and can hide the fact that they are on antiretroviral treatment by claiming to be on a protracted anti-TB regimen.

> But sometimes they escape that by presenting with TB alone. That's the good thing. And people say, 'But you are coughing?' You know, when you discover TB, and you get HIV test, and you get positive, they may never tell their spouses their results of HIV, but they only tell them that 'You know what they have discovered? It's TB. All that I have been having, these

> fevers, wasting, skin, and whatever, this is TB.' So they go home. They never give the information that actually I tested positive for HIV, never or rarely, and sometimes it is after sometime when they say, you know after TB treatment, they go on to other treatments, like maybe the TB/HIV clinic. They continue with ARTs, so eventually in the house the spouse may ask her or he, 'But you are continuing to take these pills. Are you still treating TB beyond even one year?' They say, 'Yeah, you see, I was put on these pills, because they thought maybe I may be having something that is eating me up, maybe cancer. They are still trying to look at what is happening. They are doing me well. My skin is coming back to normal' (Medical Officer, 48).

The stigma related to HIV affects TB treatment in other ways. Just as some patients avoid VCT because they fear the discrimination they will face it they learn they are HIV positive, others avoid presenting for evaluation and treatment of TB, because they fear that their TB is a sign of HIV. Avoiding treatment is a way to avoid facing a new diagnosis. In another case, an HIV negative man was neglected, even as he became sicker and sicker with tuberculosis.

> There is another man. I do not know whether he died. He came in. He was too emaciated. He was a hawker, and when we looked at him, all of us were suspicious, but the story he was giving was sort of showing he was negative. Then when he tested, he was actually negative for HIV, and we were asking him why he had delayed to come and seek treatment for TB, and it was that isolation. When he started coughing, he had a lot of chest pain, was weak, and all people around thought he was positive, and they could not come to give him help (Research counselor, 34).

Other patients are so discouraged by their HIV diagnosis that they refuse TB treatment. For them, the incurability of HIV makes taking medications futile. A nurse described one of her patients, "He was a man with a wife. They came here. They had TB. The wife was treated, but the man resisted. 'What is the use of TB treatment, when I am going to die? After all, I have HIV.'" (Nurse/midwife, 46).

The TB-related stigma that subjects described in qualitative interviews could be even more isolating than HIV-related stigma. But it was usually transient, with the treatment of TB patients improving as their symptoms decreased. In contrast, HIV-related stigma was more lasting and more tied to social shame. Often, though, these two stigmas combined to isolate people, dissuade them from HIV testing, or make it harder for them to get medical care.

Discussion

Findings

The stigma portion of the TB-VCT study has already produced copious data about perceptions of the discrimination of PLWHA and attitudes surrounding HIV testing. As enrollment continues, more will surely be learned, but some major findings have already emerged.

In quantifying HIV-related stigma, the TB-VCT study was able both to compare the levels of perceived stigma in different domains and the characteristics that increase perceptions of stigma. Subjects reported greater perceived Instrumental Stigma than Symbolic Stigma (1.83 vs. 1.39, $p<0.00005$). This seems to suggest a heightened awareness of the risk of transmission, but, as discussed above, the two questions that contribute to Instrumental Stigma scores both refer to the proximity of children to PLWHA, which makes them problematic to interpret. Still, the fact that scores for Instrumental Stigma are high across demographic groups suggests that the fear of casual transmission of HIV—to children, at least—is prevalent in the community. This interpretation is complicated by the responses of the study's 29 Muslim subjects. They made up only 20% of subjects, but they reported significantly higher perceptions of Instrumental Stigma than non-Muslims. No Muslims were interviewed in the qualitative portion of the study, and interviewees were reluctant to speculate on the attitudes of religious groups other than their own.

Determinants of HIV-related stigma among Muslims in Kampala could be further investigated in another study.

In the domains of Symbolic Stigma—Blame and Shame—and Total Stigma there were other significant predictors of increased perceptions of stigma. Among these was being female. This finding is consistent with other studies of stigma (Pronyk, Kim et al. 2002; Rankin, Brennan et al. 2005) and is reflected in the policies of international organizations like UNAIDS that presume that the social burdens of HIV/AIDS fall disproportionately on women and girls (UNAIDS 2006a). In qualitative interviews, subjects were not unanimous in describing greater felt stigma among women or discrimination against HIV infected women. Some recognized the ways in which HIV/AIDS could present a challenge to masculinity as well. Still, the dominant theme with regard to gender and HIV-related stigma was that the low social status of women and their economic dependence on men made them especially vulnerable. While men are often assumed to have multiple sex partners, a suspicion of promiscuity is much more damaging to a woman's relationships and reputation. And when a woman falls sick with HIV/AIDS she is less valuable to her family and community. She may not receive the same support that a man could expect in the same situation. This finding of the TB-VCT study is well known to healthcare providers in countries around the world. It seems unlikely that education alone can alleviate the burden of HIV/AIDS on women. Instead, as Castro and Farmer suggest, changes in the disproportionate prevalence of HIV in women and the increased social burden that they face will only follow shifts that increase their socioeconomic status (Castro and Farmer 2005).

Two other characteristics that are associated with increased perceptions of HIV-related stigma are young age and being unmarried. Qualitative interview subjects explained the ways that HIV was an increased threat to young people. It is seen as a major obstacle to many of the goals that they have for their futures—getting an education, marrying, and having children. Believing HIV/AIDS to be such a threat may increase the perceptions that young people have of its negative consequences. As described above, marital status and age are predictably related, with older subjects much more likely to be married. Multivariate analysis, though, was able to distinguish the relative contributions of each of these to levels of perceived stigma. For the domains of Instrumental Stigma, Blame, and for Total Stigma, being unmarried had a stronger association with high levels of perceived stigma. This seems to indicate that being married somehow insulates subjects from many of the negative social consequences of living with HIV. The social support provided by marriage may be one explanation for this. In one domain, Shame, being young and unmarried had similar relationships to levels of perceived stigma. The quantitative data do not offer any explanations of why this dimension of stigma should be especially associated with young age, but several participants in qualitative interviews described the ways that HIV infection can disrupt family relationships. A counselor explained the decision a twelfth-grade student must make to disclose or conceal a positive HIV test to his or her parents.

> They think if I am in S6 and tell my parents that I am positive, all they will say, parents will just say, you are useless, you are going to die. No school fees. Let me pay for these ones who are not positive. Another thing, the parent will think negatively towards that child, because he will know this child, I have been wasting my school fees, and what you have been doing is going for other boys and other girls, instead of doing what I sent you to do. They have so much like, just leave him. Just leave him, because if I tell my parents, they will stop loving me, and they will think I am a spoilt child (Counselor, 30).

It is not obvious that the stigma described in this passage is more related to Shame than to Blame, but the stigma does seem to be associated with the responsibility that young people feel to their families. This sense of responsibility may mediate the increased shame that they associate with HIV infection.

The most surprising finding in the analysis of the predictors of HIV stigma is that subjects' prior testing history is associated with levels of perceived stigma. More than half of subjects had had an HIV test before enrolling in the TB-VCT study. These participants reported higher levels of perceived stigma, especially in the Symbolic domains. Multivariate analysis, though, showed that having an HIV test was not, by itself, strongly associated with a high stigma score. Instead, having a negative test before enrolling in the TB-VCT study predicted high levels of perceived stigma. Subjects who had tested positive reported similar levels of perceived stigma to those who had never tested (see Table 16). This finding seems to contradict data from a study in Cape Town, South Africa, where individuals who had not been tested for HIV held significantly greater HIV-related stigmas than those who had been tested (Kalichman and Simbayi 2003). That study, though, assessed how many stigmatizing attitudes subjects themselves held, while the TB-VCT study asks about the perceived prevalence of stigmatizing attitudes in subjects' communities. Also, while the South African study distinguished between those who had tested and those who had not, it did not report differences in stigma associated with HIV test results. To further complicate the question, subjects in the TB-VCT study who had tested HIV negative in the past also reported increased levels of perceived TB stigma. In fact, this was the only significant predictor of high perceived TB stigma.

Because the association between having a negative HIV test and a higher stigma score was not anticipated, it was not explored in qualitative interviews. The study has little information that can help explain this finding. Only guesses may be offered to explain why people who have tested HIV negative should perceive more HIV-related stigma than others. Individuals who present for HIV testing, usually do so with some concern about their serostatus. They may be worried about an exposure to HIV infection or have symptoms suggestive of an opportunistic infection, commonly associated with HIV/AIDS (such as tuberculosis). Testing negative for HIV, then, frees an individual from the uncertainty with which he or she approached the testing process. With the confidence that he or she is now HIV negative, it may be less psychologically damaging or frightening to imagine the negative social consequences associated with HIV infection. They may have a heightened awareness of these consequences, because they know that they are not vulnerable to them. This may even be a psychic defense mechanism that helps people who have tested HIV negative to accentuate the distance between themselves and PLWHA. Devine and colleagues explained how such a mechanism might work.

> When group boundaries are made salient, people search for intercategory differences that favor the group to which they belong or with which they identify. This competitive orientation leads to perceptual biases and discriminatory behavioral strategies, which function as an attempt to differentiate between the ingroup and outgroup in a manner favoring the ingroup. As a result, differences favoring the ingroup are exaggerated, whereas differences favoring the outgroup are minimized or ignored (Devine, Plant et al. 1999).

Another possible explanation for the increased stigma that subjects with prior negative HIV tests perceive is that some component of the post-test counseling they receive heightens their awareness of the negative social consequences of HIV infection. The message of post-test counseling for people who test HIV positive tends to be sympathetic and encouraging, with referrals to services and reassurances of support. For people who test HIV negative, the counseling emphasizes risk reduction strategies. It is possible, though, that some test-counselors, wittingly or not, scare their HIV negative clients in their attempt to help them remain uninfected. Even if the counselors only describe the medical consequences of HIV, the message received by their clients may also increase their awareness of the social costs of HIV.

Further research in this area should pay attention to the experiences of people testing HIV negative. What messages do they receive in post-test counseling? How do their relationships to PLWHA change after an HIV test?

One of the most important goals of the stigma study was to determine whether or not perceptions of HIV-related stigma were a barrier to HIV testing. The data indicate that the effect of stigma on testing decisions is small, if any. With 147 subjects, the study does not have the power to exclude a small effect of perceived stigma on the decision to have an HIV test. This finding, however, is consistent with a recent study of VCT in Zimbabwe, where subjects recognized the existence of HIV stigma but rarely named it as a reason for not testing (Morin, Khumalo-Sakutukwa et al. 2006). In that study, the most important reasons cited for having an HIV test were having been sick—especially having had a sexually transmitted or opportunistic infection—and weight loss. Many subjects in the TB-VCT study also noted that they were concerned that their symptoms were related to HIV infection. All had some concern that they might have TB, and most recognized that people with TB were more likely to be HIV infected. If perceptions of HIV-related stigma play any role in subjects' testing decisions, these appear to be less significant when patients face a condition that may be related to HIV. As enrollment in the TB-VCT study continues, it will be important to see if a significant association between stigma scores and testing decisions emerges or if it can be detected in a sub-group of subjects who may be especially affected by HIV-related stigma.

Limitations

Measuring stigma is a difficult endeavor. There is no gold standard and, as Nyblade has observed, it can be difficult to correlate reported beliefs with real world behaviors (Nyblade

2006). Even when enacted stigma is documented it is usually not possible to determine the real attitudes that may have caused it. In a qualitative interview, one physician explained the challenge of separating the effects of HIV stigma from all the other social and economic disparities that her patients face.

> She may tell me she is worried about what her husband will say about this test, but really what she means she is going to get a beating, and I will never know and a lot of the time do not get a feedback on all these things, and they may not be things that people talk about readily but that go on continuously for so many other reasons. The beating in the home may be for something, which you and I would consider totally trivial. And okay, you and I would consider it should never happen, but it happens for much smaller things than you thinking you have a right to go out and do an HIV test without telling me as the husband (Medical officer, 31).

The social status of PLWHA is determined by hundreds of complex relationships, many of which have nothing to do with HIV/AIDS. A twelve-question survey can only hope to assess a narrow cross section of attitudes at one point in time. This study has no data on the attitudes of patients before they arrive at the clinic or after they go home. In addition, the stigma questions used in the TB-VCT study ask explicitly about the attitudes of "people in your community." Responses, though, are understood to implicitly reflect the treatment of PLWHA that subjects have felt or observed themselves. A patient who knows he is HIV positive, though, probably considers such questions quite differently from one who tested HIV negative just weeks before presenting to the TB Clinic.

Like other surveys, this one is susceptible to a social acceptability bias. Questionnaires in this study are administered verbally, and some patients may try to respond with answers that they think study staff would prefer to hear. This bias may be intensified in the context of HIV testing, because the stigma questions are asked after subjects have gone through pre-test counseling. This intense interaction depends on the counselors' abilities to build a trusting relationship and provide health education to often-anxious clients. For those who choose to test, the questionnaires follow a blood draw for the rapid HIV tests. It is in this charged and uncertain environment that subjects are asked intimate and provocative questions by the same counselors who helped them choose to test and who will provide the HIV test results when the questionnaires have been completed. An additional obstacle to survey administration is the subjects' poor health. All participants in the TB-VCT study respond to its questionnaires in the midst being evaluated for tuberculosis. While all the patients are ambulatory, many are quite sick. Responding to a verbal survey with close-ended answers is unfamiliar to most subjects and a burden to many. Some may be eager to answer quickly and finish the counseling and testing process. Others may not be able to apply their full energies to considering the survey's questions.

In the face of all these challenges to the quantitative assessment of stigma, it will be difficult to claim that the TB-VCT study has made a completely valid measurement of perceived stigma in Kampala. Still, there are some reasons to believe that the questionnaires have measured some important component of the social effect of HIV/AIDS. Although the difference is not statistically significant, the observed difference between perceived stigma among testers and non-testers is consistent with findings from other studies of HIV testing and stigma (Chesney and Smith 1999; Bond, Chase et al. 2002). More important, though, is the validation that comes from the qualitative interviews with key informants, who work at the Tuberculosis Clinic. While the data from these interviews were more detailed and less likely to be generalizable than the quantitative data, triangulation across the sources of data presents a consistent picture of the determinants and manifestations of both HIV- and TB-related stigma in Kampala.

Other limitations to the TB-VCT study were related to the challenges of conducting a large trial in a developing country. Enrollment of subjects faced several delays and suspensions due to administrative problems. The management of the study moved from the Case Western run TB Research Unit to the Makerere University-UCSF Malaria Project. Among the difficulties this caused were lapses in the study's approval by both the Joint Clinical Research Centre and the Uganda National Council for Science and Technology and the need to suspend enrollment. Once enrollment was suspended, it took longer than expected to renew the institutional review boards' approvals. The TB-VCT study is expected to last several years, and it will eventually accrue a large sample size, but the enrollment has been slower than expected.

Uganda is recognized as a leader in sub-Saharan Africa in the prevention and treatment of HIV. And Kampala has, by far, the most resources to devote to these efforts. This makes it a unique and therefore unrepresentative setting for conducting HIV research and especially for studying HIV-related stigma. The population has relatively good access to HIV education and treatment for HIV/AIDS, including antiretroviral treatment. Both of these factors probably affect the treatment of PLWHA. These facts do not challenge the validity of the TB-VCT study's findings, but they do reduce their generalizability. Qualitative interviews suggest that correct knowledge of HIV transmission and the prospect of regaining health with antiretroviral therapy reduce the discrimination of PLWHA. And the latter also seems to play a role in increasing people's willingness to have an HIV test. It remains to be seen how TB clinic-based VCT will work in settings with less HIV education, fewer resources, and, perhaps, more HIV-related stigma.

Implications for future phases of the TB-VCT study

The testing protocols of the TB-VCT study are working well, as judged by the high rates of acceptance of testing and of HIV detection. Still, it is important to review procedures continually and to apply lessons learned so as to provide the highest quality services. In the qualitative interviews, subjects suggested some important considerations for operating procedures as the study moves into the phase that includes HIV testing of household members. The first of these involves the inclusion of children under age 18. Quantitative survey data suggest that younger people may be particularly sensitive to HIV stigma, and in the qualitative interviews subjects noted that young people are often torn between the pressure to disclose their HIV test results to their families and the shame they feel if they test positive. Testing an entire household then may become a particularly charged event. Parents who provide consent for their young children will probably want to know the test results, but TB-VCT counselors will have to be especially sensitive mediating the disclosure of positive tests by teenagers, especially when parents are HIV negative. These counselors already have experience assisting discordant partners disclose test results to each other, but family-based testing will require additional care and sensitivity to issues of shame.

Another issue that arose in the qualitative interviews was the time that it took individuals to come to terms with positive HIV tests and to become comfortable disclosing their results to partners and family members. Often, interviewees reported, patients begin treatment for tuberculosis and wait for symptoms to decrease. “Then with time,” a counselor explained, “when she gets used to idea of having been positive, they normally open up slowly, but they don’t do it abruptly” (Counselor, 30). Some patients wait until they have begun antiretroviral treatment to disclose their seropositivity to family members. Because the study protocol for testing depends on subjects referring their household members for VCT, it is important to allow them enough time to accept their own status and to raise the issue of testing with their families. For this reason the protocol for household testing was modified

to allow patients up to a month in which to refer their families for free voluntary counseling and testing.

Many subjects in qualitative interviews noted that women face especially difficult challenges in disclosing positive HIV tests to their partners, but counselors also described some of the techniques they use to make disclosure easier for their female clients. Among these was the process of retesting or pretending to retest HIV positive women when they bring they partners to the clinic for testing. This allows the women to pretend they have not previously tested and act as if they are receiving their results at the same time as their husbands. Tests results are still given confidentially, but counselors then assist couples as they disclose their results to each other. Because this has proven to be a useful method, both for convincing male partners to test and increasing rates of disclosure between partners, the study protocol has been modified to include simulating HIV testing when it is useful to create the illusion that all family members are learning their results at the same time.

Possible interventions to reduce stigma

In this study's qualitative interviews, all key informants were offered a chance to suggest future interventions that they thought could either reduce stigma or increase the uptake of HIV testing. The most common suggestion was additional education and sensitization programs in the community. Subjects had observed the ways that educational messages have changed Ugandans' understanding of HIV/AIDS and the treatment of PLWHA. Many of the home visitors and counselors had seen up-close how the information that they provided to patients and families diminished the stigma and discrimination of PLWHA. When it was pointed out, though, that significant HIV- and TB-related stigma persists, despite two decades of mass media and outreach efforts, many key informants suggested ways to increase the impact of educational interventions. Among these was utilizing peer educators to spread information about HIV and tuberculosis. While such strategies have been used by non-governmental organizations, such as TASO, for many years, interviewees noted that these efforts often missed some of the people at greatest risk, especially youth and school dropouts. Using these people as peer educators could not only provide employment opportunities, but also target a high-risk population. Some key informants mentioned additional sites they thought would be useful settings for educational interventions, such as work places and sporting events. One home visitor suggested bringing educational outreach to bars in order to reach the commercial sex workers who meet clients there. Several interviewees suggested ways to use existing community institutions to teach people about HIV and TB. If church groups and pastors were targeted, they could share the information with their congregations. Local councils were also mentioned as influential organizations that could help spread educational messages. Finally, there was agreement that knowledge and attitudes about HIV and TB were very different in Kampala compared to rural areas of Uganda, where there has been much less exposure to health education. Several interviewees mentioned the importance of extending all HIV interventions beyond the capital to reach "deep in the village."

Educational interventions are the most obvious ways to reduce HIV stigma, and in cases where discrimination is driven by misconceptions about HIV transmission, they are often effective. Today, though, correct understanding of HIV's modes of transmission is widespread, and many negative attitudes towards PLWHA seem to grow directly from people's knowledge that HIV is usually spread through sex. Because the stigma associated with TB is so much more driven by fears of infection, education about its transmission and treatment have a greater effect on the attitudes towards people with TB. In a review of 22 studies testing interventions to reduce HIV-related stigma, Brown and colleagues concluded that "information is not sufficient to change attitudes or effect behaviors toward those with HIV/AIDS" (Brown, Macintyre et al. 2003). In addition, they found that while some carefully designed interventions were able to report superficial changes in attitudes based on improved knowledge, there was little evidence in the literature about how to change deep fears in a way that persisted over the long term. Other interventions depend on promoting interaction between PLWHA and non-infected individuals. In Uganda, though, nearly every person has seen people struggle with HIV/AIDS, as demonstrated by the key informants in this study. Almost every participant reported both losing friends or relatives to the disease and having friends or relatives currently living with HIV/AIDS. This contact, though, is not enough to eliminate the discrimination against PLWHA.

Some subjects in the qualitative interviews suggested changes in clinical programs that could improve the quality of life for PLWHA. If these interventions did not directly reduce HIV-related stigma, they might at least make VCT more attractive to people who feared the negative consequences of a positive HIV test. The most common such suggestion was to increase the quality of and time devoted to health counseling of PLWHA. Many key informants—and not just the counselors—described the ways that careful test counseling could reassure and comfort PLWHA. They noted that in situations where patients were able to have a long-term relationship with counselors, as during the many months of tuberculosis treatment, a therapeutic relationship was built that often broadened beyond medical issues. Counselors became a resource for supporting patients in their relationships with their partners and helping alleviate some of the discrimination they experienced in the community. Key informants described several other ways that PLWHA could be supported in non-medical ways, including supplementing nutrition, offering to pay school fees for orphans, and even providing employment opportunities.

Changes to HIV testing programs were less commonly suggested, but several key informants offered suggestions about ways to make HIV testing more attractive to people in Kampala. One lab technologist recommended taking services directly into the community with mobile testing centers that could set up in busy commercial areas. A physician emphasized that testing should be offered in a way that is both confidential and accessible. He noted, "Usually the HIV centers are not the best, because they know everybody who goes there may be a client of that place, but [the TB Clinic] is more, it's more like an open space, not labeled for any trouble" (Medical officer, 48). Some subjects mentioned a new testing protocol that is already gaining popularity in Kampala. Routine counseling and testing (RCT) incorporates HIV testing more seamlessly into the rest of medical care, without the need for a dedicated counselor and specific consent. Ideally, such a procedure includes pre- and post-test counseling from the physician who ordered the test, but interviewees noted that the counseling component is often only cursory, especially when patients test HIV negative. While such a strategy might increase the numbers of people tested for HIV, it would not take full advantage of an important opportunity for HIV education.

Many subjects noted the ways that the availability of antiretroviral treatment had increased people's willingness to have HIV tests. This finding is consistent with other studies that have found that hope offered by new medications could outweigh the resistance that some people have to HIV testing (Ekanem and Gbadegesin 2004; Ford, Wirawan et al. 2004). When people test HIV positive, antiretroviral treatment can also reduce the stigma that they face in the community. With ARVs, patients regain weight and avoid many of the disfiguring opportunistic infections that can act as triggers for HIV-related stigma. Although providing treatment to all those who need it is expensive and can only be accomplished with the help of international donors, it has the potential to improve the lives of PLWHA in numerous ways. Still, the fact that some people feel the need to conceal their antiretroviral medications means that they alone are not sufficient to eliminate stigma completely. Research must continue to determine what other interventions—in education, programming, and policy—can best reduce the discrimination faced by PLWHA.

Tables and figures

Table 1 – Subject demographic characteristics

Subject Demographic Characteristics	n	(%)
Sex		
Female	89	(60)
Male	59	(40)
Age, years		
18 – 27	58	(39)
28 – 37	53	(36)
38 – 47	28	(19)
48 – 57	5	(3)
58 – 70	3	(2)
Marital Status		
Never married	43	(29)
Ever married	105	(71)
Monogamous union	58	(39)
Polygamous union	7	(5)
Separated or divorced	34	(23)
Widowed	6	(4)
Subjects' monthly income		
Less than 10,000 Ugandan Schillings (~6 USD)	51	(34)
10,000 – 100,000 UShs	61	(41)
More than 100,000	30	(20)
Don't know	6	(4)
Highest level of education		
None	15	(10)
Some primary school	64	(43)
Some secondary school	43	(29)
Completed A level	10	(7)
Technical or diploma training	8	(5)
University degree	8	(5)
Religion		
Roman Catholic	52	(35)
Anglican	49	(33)
Muslim	29	(20)
Born again	14	(9)
Other	4	(3)

Table 2 – HIV testing attitudes and practices

HIV Testing Attitudes and Practices		
	n/N	(%)
Agree/Strongly agree: People in my community are embarrassed to be seen coming out of an HIV testing clinic.	68/147	(46)
Consider self to be at risk for HIV infection	62/146	(42)
Excluding those with prior positive tests	36/119	(30)
Ever had an HIV test	78/148	(53)
Prior positive HIV test	28/78	(36)
Accept TB clinic VCT	116/148	(78)
Excluding those with prior positive tests	99/120	(83)
Reasons for testing (N=116)		
Doctor's recommendation	10/116	(9)
Test is free	96/116	(83)
TB clinic VCT is convenient	114/116	(98)
Results available the same day	115/116	(99)
Worried that symptoms prompting TB clinic visit are due to HIV	43/116	(37)
Concerned about having both HIV and TB	41/116	(35)

Table 3 – Characteristics of testers in TB clinic-based voluntary counseling and testing

Characteristics of TB-VCT Testers						
	Accept TB clinic VCT			**Accept TB clinic VCT (excluding those with prior positive tests)**		
	n/N	(%)	p value*	n/N	(%)	p value*
Monthly income						
≤50,000 UShs	74/88	(84)	0.037	64/74	(86)	0.132
>50,000 UShs	37/54	(69)		30/40	(75)	
Ever had an HIV test						
No	62/70	(89)	0.005	62/70	(89)	0.051
Yes	54/78	(69)		37/50	(74)	

*p values are for Fisher's exact test.

Table 4 – HIV test results

HIV Test Results*	**HIV seropositive** n/N (%)
All subjects	40/117 (34)
Sex	
Female	28/70 (40)
Male	12/45 (27)
Age, years	
18 – 30	13/61 (21) †
31 – 70	27/54 (50)
Education	
≤ Primary school	22/65 (34)
≥Secondary school	18/51 (35)
Marital status	
Never married	6/36 (17) †
Ever married	34/79 (43)
Monthly income	
≤50,000 UShs	20/73 (27) °
>50,000 UShs	18/37 (49)
Consider self to be at risk of HIV infection	
Yes	27/46 (59) †
No	3/34 (9)
Don't know	10/35 (29)

* One of 117 tests had an indeterminate result and is excluded from the exact tests in this table.

° Fisher's exact test p value < 0.05

† Fisher's exact test p value <0.01

Table 5 – HIV stigma survey results

HIV Stigma Survey Results									
		All responses (N=147)				**Outliers excluded* (N=139)**			
Stigma domain	Number of questions	Mean	Median	SD	α	Mean	Median	SD	α
Instrumental stigma	2	1.83	2.00	1.17	0.91	1.90	2.00	1.13	0.90
Blame	5	1.31	1.40	0.92	0.85	1.34	1.40	0.88	0.83
Shame	4	1.50	1.50	0.96	0.79	1.54	1.50	0.92	0.76
Symbolic Stigma (Blame and Shame)	9	1.39	1.44	0.86	0.89	1.43	1.44	0.82	0.87
Denial of Healthcare	1	1.19	1.00	1.17		1.22	1.00	1.15	
Total Stigma	12	1.45	1.50	0.79	0.89	1.49	1.50	0.73	0.86

* Six subjects who responded No One and two who responded Most People to all HIV stigma questions were excluded.

Table 6 – Predictors of HIV stigma

Predictors of HIV Stigma*

	Denial of Healthcare		Instrumental stigma		Blame		Shame		Symbolic stigma		Total Stigma	
	mean	p	mean	p	mean	p	mean	p	mean	p	mean	p
Sex												
Male					1.16	0.0213			1.26	0.0374	1.33	0.0382
Female					1.54				1.59		1.63	
Age												
18-30					1.43	0.0940	1.69	0.0276	1.54	0.0431	1.58	0.0503
31-70					1.19		1.31		1.24		1.32	
Marital Status												
Never married							1.74	0.0508	1.60	0.0783	1.64	0.0756
Ever married							1.40		1.31		1.37	
HIV testing history												
Never tested					1.11	0.0165			1.25	0.0581		
Tested					1.49				1.52			
Most recent result												
Positive or never tested	1.08	0.0804	1.71	0.0690	1.18	0.0153			1.28	0.0220	1.34	0.0177
Prior negative	1.43		2.10		1.59				1.64		1.70	
Religion												
Muslim			2.33	0.0180			1.81	0.0424			1.67	0.0877
Non-Muslim			1.71				1.42				1.40	

* P values are for Wilcoxon-Mann-Whitney tests. Only associations with $p<0.10$ shown.

Table 7 – Multivariate model for predictors of Instrumental Stigma

Multivariate model for predictors of Instrumental Stigma												
	Number of variables in model											
	I		II		III		IV		V		VI	
	β	p	β	p	β	p	β	p	β	p	β	p
Female	0.335	0.079	0.280	0.137	0.323	0.094	0.356	0.067	0.326	0.102	0.308	0.121
Muslim	0.616	0.002	**0.575**	**0.004**	0.555	0.006	0.543	0.007	0.547	0.006	0.554	0.006
< 31 years	0.065	0.739			**-0.036**	**0.856**	-0.136	0.532	-0.142	0.515	-0.179	0.408
Never married	0.203	0.323					**0.236**	**0.277**	0.277	0.209	0.240	0.285
Ever tested	0.186	0.339							**0.155**	**0.432**	-0.085	0.747
Prior negative	0.385	0.045									**0.394**	**0.121**

Table 8 – Multivariate model for predictors of Blame

Multivariate model for predictors of Blame

	Number of variables in model											
	I		II		III		IV		V		VI	
	β	p	β	p	β	p	β	p	β	p	β	p
Female	0.380	0.014	0.375	0.018	0.366	0.027	0.395	0.020	0.323	0.057	0.317	0.063
Muslim	0.108	0.541	**0.054**	**0.764**	0.031	0.861	0.020	0.910	0.031	0.858	0.033	0.849
< 31 years	0.242	0.115			**0.156**	**0.318**	0.067	0.697	0.051	0.768	0.038	0.829
Never married	0.240	0.156					**0.210**	**0.259**	0.308	0.097	0.295	0.110
Ever tested	0.386	0.010							**0.370**	**0.017**	0.287	0.182
Prior negative	0.414	0.010									**0.136**	**0.560**

Table 9 – Multivariate model for predicators of Shame

Multivariate model for predictors of Shame												
	Number of variables in model											
	I		II		III		IV		V		VI	
	β	p	β	p	β	p	β	p	β	p	β	p
Female	0.253	0.105	0.220	0.157	0.173	0.290	0.202	0.223	0.176	0.291	0.165	0.322
Muslim	0.389	0.046	**0.358**	**0.069**	0.328	0.091	0.317	0.108	0.321	0.102	0.325	0.099
< 31 years	0.376	0.018			**0.320**	**0.054**	0.230	0.235	0.224	0.252	0.202	0.311
Never married	0.344	0.033					**0.214**	**0.254**	0.250	0.206	0.227	0.246
Ever tested	0.131	0.413							**0.133**	**0.419**	-0.010	0.963
Prior negative	0.302	0.057									**0.235**	**0.287**

Table 10 – Multivariate model for predictors of Symbolic Stigma

Multivariate model for predictors of Symbolic Stigma												
	Number of variables in model											
	I		II		III		IV		V		VI	
	β	p	β	p	β	p	β	p	β	p	β	p
Female	0.345	0.025	0.307	0.036	0.281	0.067	0.310	0.048	0.258	0.101	0.250	0.114
Muslim	0.233	0.171	**0.189**	**0.275**	0.163	0.334	0.152	0.374	0.159	0.339	0.162	0.334
< 31 years	0.302	0.036			**0.229**	**0.123**	0.139	0.401	0.128	0.446	0.111	0.518
Never married	0.287	0.059					**0.212**	**0.202**	0.283	0.099	0.266	0.118
Ever tested	0.272	0.054							**0.265**	**0.071**	0.155	0.449
Prior negative	0.364	0.015									**0.179**	**0.414**

Table 11 – Multivariate model for predictors of Total Stigma

Multivariate model for predictors of Total Stigma												
	Number of variables in model											
	I		II		III		IV		V		VI	
	β	p	β	p	β	p	β	p	β	p	β	p
Female	0.303	0.022	0.281	0.034	0.265	0.056	0.295	0.039	0.249	0.083	0.238	0.097
Muslim	0.271	0.069	**0.231**	**0.129**	0.206	0.164	0.194	0.193	0.201	0.169	0.205	0.167
< 31 years	0.259	0.048			**0.189**	**0.163**	0.097	0.525	0.087	0.574	0.065	0.680
Never married	0.273	0.053					**0.215**	**0.172**	.277	0.089	0.255	0.114
Ever tested	0.243	0.063							**0.234**	**0.083**	0.091	0.620
Prior negative	0.367	0.006									**0.235**	**0.213**

Table 12 - Backward regression for predictors of stigma

Backward regression for predictors of stigma

	Instrumental Stigma		Blame		Shame		Symbolic Stigma		Total HIV Stigma		Total TB Stigma	
	β	p	β	p	β	p	β	p	β	p	β	p
Female			0.339	0.031			0.305	0.037	0.282	0.032		
Muslim	0.603	0.002			0.351	0.070						
< 31 years					0.359	0.023						
Never married			0.334	0.040			0.290	0.047	0.276	0.042		
Ever tested			0.371	0.016								
Prior negative	0.370	0.051					0.291	0.058	0.298	0.028	0.292	0.003
Constant	1.61		0.89		1.25		1.10		1.17		1.53	

Table 13 – Stigma as a predictor of HIV testing

Stigma as a predictor of HIV Testing

		HIV Stigma Instrument													
		Denial of Healthcare		Instrumental Stigma		Blame		Shame		Symbolic Stigma		Total Stigma		Total TB Stigma	
	n	mean	p	mean	p	mean	p	mean	p	mean	p	mean	p	mean	p
Testers	115	1.23	0.309	1.82	0.875	1.29	0.650	1.47	0.534	1.37	0.456	1.44	0.634	1.60	0.714
Non-testers	32	1.03		1.86		1.37		1.59		1.47		1.50		1.63	
Excluding those with prior positive tests															
Testers	99	1.31	0.152	1.81	0.409	1.28	0.280	1.50	0.181	1.38	0.146	1.45	0.221	1.60	0.628
Non-testers	21	0.95		2.10		1.52		1.80		1.64		1.66		1.66	

Table 14 – Qualitative interview subjects

Qualitative Interview Subjects

	Job	Age	Religion	Monthly church attendance	Years working with PLWHA	Family or friends living with HIV/AIDS	Lost family or friends to HIV/AIDS
1	Lab technologist	34	Protestant	2	11	yes	yes
2	Research counselor	34	Born Again	4	7	yes	yes
3	Lab technologist	34	Catholic	4	9	yes	yes
4	HIV counselor	50	Catholic	Sundays			
5	Home visitor	54	Catholic	4	10	yes	yes
6	Nurse/midwife	46	Church of Uganda	Sundays	10	yes	yes
7	Counselor	37	Protestant	4	17	yes	yes
8	TB Health Visitor	58	Catholic	Sundays	17	no	yes
9	Counselor	52	Catholic	12	24	yes	yes
10	Medical Counselor	32	Catholic	3-4	5	yes	yes
11	PPD Technician/Pharmacy Tech	52	Church of Uganda	4	20	yes	yes
12	Medical Officer	31	Roman Catholic	~4	10	yes	yes
13	Counselor	30	Christian	>4	5+	yes	yes
14	Medical officer/research coordinator	39	Protestant	1	12	yes	yes
15	Medical officer	48	Anglican	4	11	yes	yes
16	Health visitor	32	Catholic	4	6	yes	yes

Table 15 – Attitudes and beliefs about HIV and tuberculosis coinfection

Attitudes and Beliefs about HIV and Tuberculosis Coinfection (N = 148)	Agree or strongly agree n (%)
People who have HIV are more likely to get sick with TB than other people.	119 (80)
People who are sick with TB are more likely to have HIV than people who do not.	111 (75)
Most people who are sick with TB have HIV, also.	77 (53)
People who say they are sick with TB really have HIV.	42 (28)

Table 16 – HIV testing history and total stigma scores

HIV Testing History and Total Stigma Scores			
HIV Testing History	**n**	**Total HIV Stigma**	**Total TB Stigma**
Never Tested	70	1.32	1.47
Prior Negative	46	1.70	1.82
Prior Positive	27	1.30	1.63
Kruskal-Wallis p-value:		0.0435	0.0202
Total	143*	1.44	1.61

* Four subjects who had tested but did not know their results are excluded from this analysis.

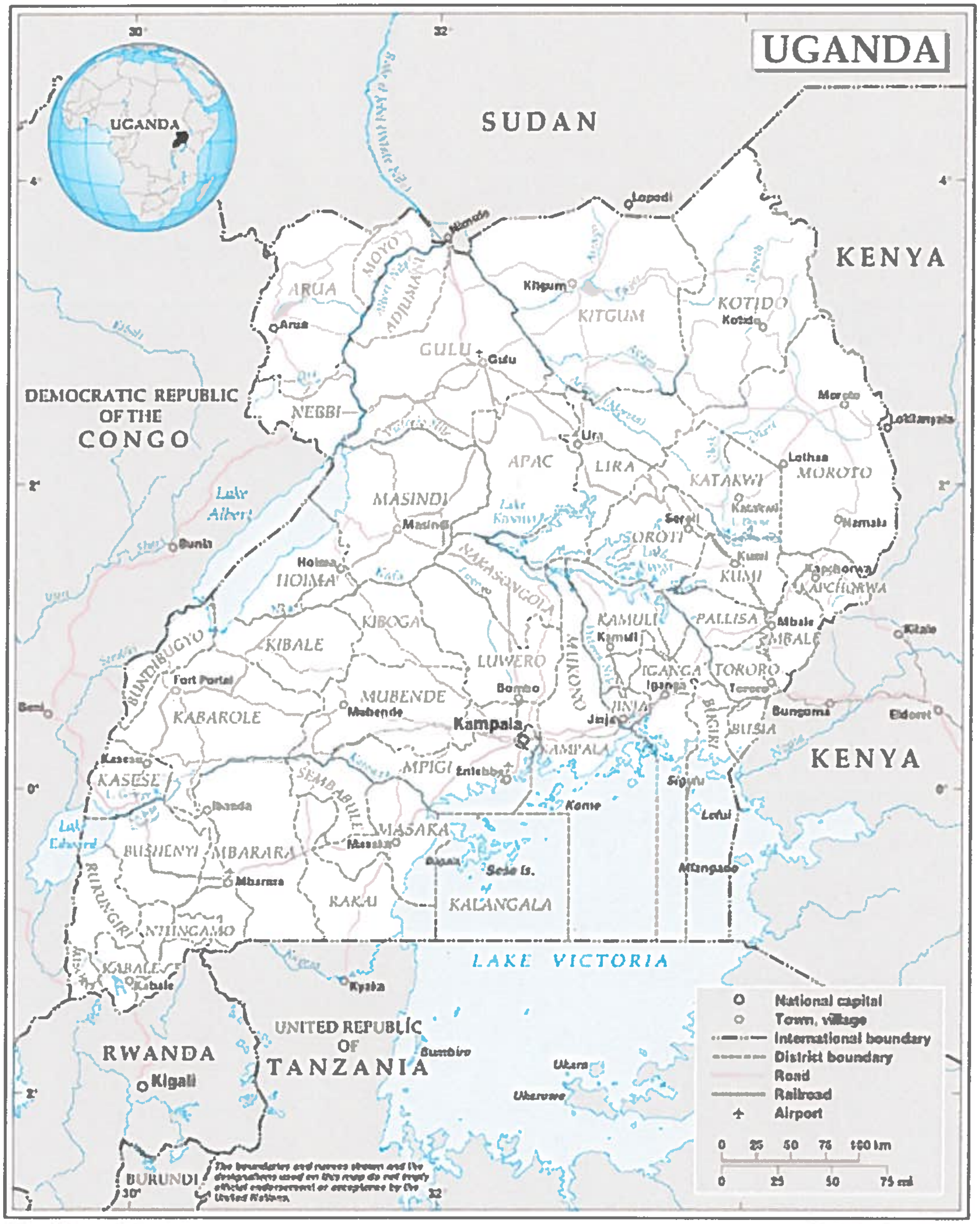
Table 17 – Comparison between HIV and TB stigma

Comparison between HIV and TB Stigma

		HIV	TB	p-value*
1	In your community, how many mothers would not want someone with HIV/TB to hold their new baby?	1.73	**2.62**	0.0000
2	In your community, how many mothers would not want a person with HIV/TB to feed their children?	1.93	**2.64**	0.0000
3	In your community, how many people avoid visiting the homes of people with HIV/TB?	1.22	**2.24**	0.0000
4	In your community, how many people think that people with HIV/TB have brought shame on their families?	1.59	1.60	0.9244
5	In your community, how many people are uncomfortable around someone with HIV/TB?	1.45	**2.36**	0.0000
6	In your community, how many people think that if you have HIV/TB you have done wrong behaviors?	**1.74**	1.09	0.0000
7	In your community, how many people think that it is acceptable for families to insist that a person with HIV/TB move out of the house?	0.83	1.13	0.0067
8	In your community, how many people think people with HIV/TB are paying for their sins?	**1.37**	0.89	0.0000
9	In your community, how many people think that individuals with HIV/TB deserve their disease?	**1.31**	0.95	0.0001
10	In your community, how many people think that people with HIV/TB should feel guilty about it?	1.27	0.99	0.0240
11	In your community, how many people think that a person with HIV/TB is disgusting?	1.79	1.89	0.1902
12	In your community, how many people are refused medical care or denied hospital services because of their HIV/TB?	1.19	0.92	0.0121

P-values are for the Wilcoxon signed-rank test. Significantly higher values ($p<0.0042$) are in bold.

Figure 1 – Map of Uganda



The boundaries and names shown and the designations used on this map do not imply official endorsement or acceptance by the United Nations.

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Cartographic Section

Appendix 1 - Stigma questionnaire

Co-infection and Testing

Interviewers Read to Participants: **Based on your own experiences and what you've seen and heard, please tell us if you agree or disagree with each of the following statements. After each statement, I will ask you if you, *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree,* or *Strongly Disagree.***

		Strongly Agree	*Agree*	*Neither Agree nor Disagree*	*Disagree*	*Strongly Disagree*
C1.	People who have HIV are more likely to get sick with TB than other people.	0	1	2	3	4
C2.	People who are sick with TB are more likely to have HIV than people who do not.	0	1	2	3	4
C3.	Most people who are sick with TB have HIV, also.	0	1	2	3	4
C4.	You can tell someone has HIV by looking at him or her	0	1	2	3	4
C5.	You can tell someone has TB disease by looking at him or her.	0	1	2	3	4
C6.	People who say they are sick with TB really have HIV.	0	1	2	3	4
C7.	People in my community are embarrassed to be seen coming out of an HIV testing clinic.	0	1	2	3	4
C8.	Getting tested for HIV helps people feel better.	0	1	2	3	4
C9.	Getting tested for HIV helps keep people from getting sick.	0	1	2	3	4

Felt Stigma (HIV)

(Perceptions of Others' Attitudes)

Interviewers Read to Participants: **Based on your own experiences and what you've seen and heard, please tell us how many people in your community believe each of the following statements. After each statement, I will ask you how many people in your community believe it: *No One*, *Very Few People*, *Some People*, or *Most People*.**

		No One	***Very Few People***	***Some People***	***Most People***
H1.	In your community, how many mothers would not want someone with HIV to hold their new baby?	0	1	2	3
H2.	In your community, how many mothers would not want an HIV infected person to feed their children?	0	1	2	3
H3.	In your community, how many people avoid visiting the homes of people with HIV?	0	1	2	3
H4.	In your community, how many people think that HIV-infected people have brought shame on their families?	0	1	2	3
H5.	In your community, how many people are uncomfortable around someone with HIV?	0	1	2	3
H6.	In your community, how many people think that if you have HIV you have done wrong behaviors?	0	1	2	3
H7.	In your community, how many people think that it is acceptable for families to insist that a person with HIV move out of the house?	0	1	2	3
H8.	In your community, how many people think people with HIV are paying for their sins?	0	1	2	3
H9.	In your community, how many people think that HIV infected individuals deserve their disease?	0	1	2	3

		No One	*Very Few People*	*Some People*	*Most People*
H10.	In your community, how many people think that people with HIV should feel guilty about it?	0	1	2	3
H11.	In your community, how many people think that a person with HIV is disgusting?	0	1	2	3
H12.	In your community, how many people are refused medical care or denied hospital services because of their HIV?	0	1	2	3

Felt Stigma (TB)

(Perceptions of Others' Attitudes)

Interviewers Read to Participants: **Based on your own experiences and what you've seen and heard, please tell us how many people in your community believe each of the following statements. After each statement, I will ask you how many people in your community believe it: *No One*, *Very Few People*, *Some People*, or *Most People*.**

		No One	*Very Few People*	*Some People*	*Most People*
T1.	In your community, how many mothers would not want someone with TB to hold their new baby?	0	1	2	3
T2.	In your community, how many mothers would not want a person with TB to feed their children?	0	1	2	3
T3.	In your community, how many people avoid visiting the homes of people with TB?	0	1	2	3
T4.	In your community, how many people think that people with TB have brought shame on their families?	0	1	2	3

		No One	*Very Few People*	*Some People*	*Most People*
T5.	In your community, how many people are uncomfortable around someone with TB?	0	1	2	3
T6.	In your community, how many people think that if you have TB you have done wrong behaviors?	0	1	2	3
T7.	In your community, how many people think that it is acceptable for families to insist that a person with TB move out of the house?	0	1	2	3
T8.	In your community, how many people think people with TB are paying for their sins?	0	1	2	3
T9.	In your community, how many people think that individuals with TB deserve their disease?	0	1	2	3
T10.	In your community, how many people think that people with TB should feel guilty about it?	0	1	2	3
T11.	In your community, how many people think that a person with TB is disgusting?	0	1	2	3
T12.	In your community, how many people are refused medical care or denied hospital services because of their TB?	0	1	2	3

Appendix 2 - HIV/TB Stigma Qualitative Interview Guide

HIV-Related Stigma

Interview guide for investigating stigma in the community, hospitals, VCT, and tuberculosis care

Personal feelings about HIV/AIDS

- When did you first hear of HIV/AIDS? Where did you get this information?
- What were your first impressions of HIV/AIDS?
- How have your feelings and ideas about the disease changed?
- What things have changed the way you think about people living with HIV?

Stigma, discrimination, and denial

- How are people living with HIV/AIDS are treated in your community?
    - Are certain people treated differently?
    - Are men and women living with HIV/AIDS treated differently?
    - Are children and adults living with HIV/AIDS treated differently?
    - Are rich and poor people living with HIV/AIDS treated differently?
- Are people treated differently as they get sicker?
    - What are the important signs of disease progression? What signs (of disease) change the way people are treated?
        - Drugs, medical appointments
        - Inability to work (does this change the way family members treat a person living with HIV?)
        - Weight loss, skin lesions
- How do you think HIV-related stigma affects the way people with HIV think about themselves?
    - Relationships with friends? Family?
    - Comfort in the community:
        - Do people who learn they are HIV positive change their social habits (visiting, shopping)?
        - Involvement in community organizations?
        - Church attendance?
        - (Are these changes a result of the ways people with HIV are treated or the ways they think about themselves?)
    - Does it affect their health?
    - How does stigma affect the mental health of people with HIV?
- How has the treatment of people with HIV changed in the last few years? (five? ten?) Why?

HIV testing

- Why do some people choose not to have an HIV test? (Distinguish between logistical and psychological barriers)
    - What are people afraid of?
        - (Do patients have specific fears—of violence, exclusion, gossip, inadvertent disclosure—or are they generally worried about the diagnosis?)

    - More than 45% of subjects say that people in their communities are embarrassed to be seen coming out of an HIV testing clinic. Why are they embarrassed?
        - Is the embarrassment worse for some people? *(men, women, adults, children…)*
    - Are they afraid to disclose a positive HIV test to others?
    - Does the counseling component of VCT—the time, the personal questions—deter people from having HIV tests?
- Why do some people choose not to have an HIV test at the TB clinic (TB-VCT study or TBRU)?
- When we tell a patient that he or she "should have a test", what does that imply about his or her sexual practices?
    - Do patients perceive the suggestion of a test as embarrassing or offensive?
    - Is there a stigma associated with being "someone who should have an HIV test?"
- Why do so many respondents (more than 90%) agree that HIV testing helps people feel better and keeps them from getting sick?
    - Where do people get information about HIV testing?
    - Why do you think that people, who agree that testing helps, might choose not to have an HIV test?
    - What influence does the counseling have on subjects' feelings about HIV testing? What parts of the counseling change the way subjects feel about testing?

Stigma in healthcare

- How are people living with HIV treated (attitudes) by healthcare workers?
    - Give me some examples of people living with HIV being mistreated by healthcare workers?
- More than a third of respondents (in the TB-VCT study) say that some or most "people are refused medical care or denied hospital services because of their HIV?" Can you describe examples of people living with HIV being refused medical care?
    - *If respondents have no examples:* Why do participants in the TB-VCT study have the impression that people with HIV are refused care?
- How is the treatment of people living with HIV in healthcare changing?

HIV and TB

- How are people living with tuberculosis treated in your community?
    - Does this stigma and discrimination deter people from seeking care?
- How is the treatment of people with TB different from the treatment of people living with HIV?
    - Why do so many people (more than one-third) agree with the statement, "People who say they are sick with TB really have HIV"?
    - How does the stigma associated with HIV affect they way people in the community perceive tuberculosis?
- Does the stigma associated with HIV deter people from seeking care for tuberculosis?
    - What are they afraid of?

        - Being identified as a person with TB? Being identified as a person with HIV?
        - Learning that they are infected with HIV also?
- More than half of respondents agree or strongly agree that most people who are sick with TB have HIV also. Why do they say this?
    - How do people talk about the relationship between HIV and tuberculosis?
    - *(In fact, only about one-third of people with TB—in the TB-VCT study—are HIV positive.)*

Disclosure

- Why is disclosing HIV status difficult for a person living with HIV? (Describe examples of people who have had difficulty disclosing that they are HIV positive.)
    - Is disclosure different for men and women? How?
    - To whom is it difficult to disclose? Partner, parents, children, friends, neighbors, church members?
        - Sexual partners?
    - Why do some people have an easier time disclosing that they are HIV positive?
    - Is disclosure different for people who have lived with HIV for a long time? How?
    - Is disclosure different for people who are taking ARVs? How?

ARVs

- Tell me how the availability of ARVs has changed the way people living with HIV/AIDS are treated?
- Tell me how the availability of ARVs has changed people's willingness to take HIV tests?
    - (Are people less afraid of HIV-related stigma, if they believe that they will be able to access HIV healthcare services, including ARVs?)
- How can providing ARVs to people living with HIV reduce the stigma they face? Why?
    - How do you explain the stigma that remains when people have good medical care for HIV? What is the source of this discrimination and mistreatment?

Religion

- *For those who regularly attend church:*
    - What things does do you hear from religious leaders in church/mosque regarding HIV/AIDS?
- How do you think that religion affects perceptions of HIV/AIDS in the community?
    - Are people strongly influenced by statements about AIDS from their religious leaders?
    - Religious leaders often make conflicting statements about HIV/AIDS (including in the media). There is strong moralizing about both the risk-behaviors that transmit HIV and the need to care for people living with HIV. How do people in your community consider the many messages they receive?

    - How do different religious groups (Anglican, Born-again, Catholic, Muslim) respond to HIV/AIDS?
    - What is the impact of faith-based programs on people's perceptions of HIV/AIDS?

Stigma interventions

- Given the reservations about HIV testing that we have discussed, what changes could be made to make people more willing to test?
- What could be done to reduce the stigma and discrimination against people living with HIV/AIDS?
    - *More exposure/personal contact with people living with HIV*: (Why hasn't this already done more to decrease the amount of stigma in the community?)
    - *More education*: Who should be targeted? Schools, workplaces, adults, public messages (billboards, radio)?
    - How can the government help? Laws?
    - How can people in healthcare help?

Conclusion

Thank you for having this discussion with me. Before we close, I would like to ask you, how it felt to answer such personal questions during this conversation. (Offer to turn off recorder, if participant prefers.)

Are there any questions about the research that you would like to ask me?

Thank you for your time.

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