SELF-DISCLOSURE OF HIV SEROPOSITIVITY IN NAIROBI, KENYA:
TARGETS, METHODS, AND MOTIVATIONS

by

ANN NEVILLE MILLER

(Under the Direction of Donald L. Rubin)

ABSTRACT

Whether, why, to whom, and how people living with HIV/AIDS (PLHAs) disclose their diagnosis to others is a critical issue for HIV prevention and care efforts, but previous investigations of those issues in sub-Saharan African have been limited to one or two questions embedded in studies of social support or stigma. Using Communication Privacy Management Theory as a theoretical framework, this investigation employed key informant interviews, four focus group discussions, and structured interviews of 307 PLHAs to examine targets, methods, and motivations of diagnosis disclosure in Nairobi. In particular, disclosure patterns with respect to four groups were compared: partners, friends, family members, and religious leaders of PLHAs.

Results indicated that methods of disclosure, and motivations for both disclosure and non-disclosure, were often relationship-specific. Family members were the group most often disclosed to, and such disclosures were more highly motivated by duty, seeking material support, and preparing for the future than were disclosures to other groups. Non-disclosure to family members was more strongly motivated than non-disclosure to other groups by the desire to protect the other party. Disclosure to religious leaders as opposed to the other groups was more
highly motivated by seeking advice. Non-disclosure to friends was more highly motivated by believing that that the person was not HIV-positive, and by concerns about confidentiality, than was disclosure to family.

The most frequently mentioned method of disclosure for all groups was direct, face-to-face explanation. However, male PLHAs also frequently employed intermediated disclosure methods for informing partners of their status. Qualitative aspects of the research indicated that intermediaries were also regularly used as vehicles for disclosure to family, as was indirectness.

Implications for health communication practice and interpersonal communication theory are drawn in the final chapter.

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DEDICATION

To Jim
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CHAPTER 1
INTRODUCTION TO THE PROBLEM

The spread of HIV/AIDS in Kenya began two decades ago, about the time the disease was first identified among a small group of gay men in the United States (Essex & Mboup, 2002). As in the United States, it was confined at first to specific “high risk” groups—mostly commercial sex workers and the truck drivers who bought their services along the Pan-African Highway (Lyons, 2004). But that was in the beginning. By the end of 1999, the epidemic was well established in the general population; the adult sero-prevalence level among Kenyans was approaching ten percent (UNAIDS, 2003), a proportion approximately twenty times that of the United States. In some locations, 20 to 39% of all pregnant women visiting antenatal clinics tested positive for HIV (Kenya Ministry of Health, 2001). In 2000, the National AIDS Control Council of Kenya predicted that by 2005, an estimated 2.6 million Kenyans would have died from AIDS, many of them children (National AIDS Control, 2000). Although there is at last some evidence that prevalence rates in certain areas of Kenya have begun to plateau (UNAIDS/WHO, 2000; UNAIDS, 2004), the number of infected persons nationwide is still estimated to be between around two million (UNAIDS, 2003).

If the effects of the epidemic in Kenya at a national level are drastically different than in the United States, the impact of the virus on the lives of infected individuals is equally dissimilar. Most obviously, the majority of people living with HIV/AIDS (PLHAs) in Kenya, as in sub-Saharan African as a whole, still do not have access to anti-retroviral therapy; only 2% of HIV-positive persons who needed them in sub-Saharan African were on ARV treatment at the end of
2003 as compared to 84% of PLHAs in the Americas (UNDP, WHO, UNAIDS cited in Panos, 2004), and procurement of ARVs remains a complicated and labor intensive process (Medecins Sans Frontieres/WHO/UNAIDS, 2003). Although the situation is steadily improving, it is nevertheless true that at this juncture a positive HIV-diagnosis, rather than heralding the beginning of a struggle with a serious chronic illness as it now does for most persons in the United States (Greene, Frey, & Derlega, 2002), can still be tantamount to a death sentence for many sufferers in Kenya. Furthermore, the overwhelming proportion of PLHAs in Kenya, as in the rest of the sub-continent, have extremely limited access to medical care for opportunistic infections (Esu-Williams, 2000; President’s Emergency Plan, 2004). Beyond these economically-related issues, cultural attitudes toward death, disease, and sexuality within Kenyan society present PLHAs with a set of dilemmas distinct from those of their counterparts in the United States.

The present study proposes to examine one of the most critical interpersonal concerns faced by HIV-positive individuals: the decision regarding whether, why, and how to communicate their serostatus to significant persons in their lives. In the process of exploring this issue, the author purposes to analyze the appropriateness of U.S.-developed theory regarding serostatus disclosure decisions in the Kenyan cultural environment.

Understanding self-disclosure of HIV is important for several reasons. From a prevention standpoint, HIV-positive individuals who are sexually active and disclose their status decrease the risk of transmitting the disease to their social networks (Greene, Derlega, Yep, & Petronio, 2003). More broadly, when people are willing to talk about the disease and allow others to learn from their experiences, their openness may facilitate behavior change among their circle of acquaintances, and prevention efforts in society at large (Paxton, 2002). With respect to care,
PLHAs who disclose their status to selected persons may increase their access to social and material support and thereby improve both their psychological and physical health (Chesney & Smith, 1999). On the other hand, disclosure may have negative repercussions. Once their serostatus is known, PLHAs and even their family members may experience stigmatization, rejection, loss of employment, and many other hardships (Hays, McKusick, Pollack, Hilliard, Hoff, et. al., 1993; Moneyham, Seals, Demi, Sowell, Cohen, et al., 1996; Serovich, Kimbery, & Greene, 1998; Simoni, Mason, Marks, Ruiz, Reed, et al., 1995; Sowell, Lowenstein, Moneyham, Demi, Mizumo, et al., 1997). They may find, in fact, that the rewards attending transparency are outweighed by the risks incurred.

A substantial and growing literature on self-disclosure of HIV serostatus in the United States (see Greene et al., 2003, for an overview) has revealed a great deal about the nuances of these costs and benefits in that setting. However, empirical investigations of diagnosis disclosure in sub-Saharan Africa are few, and often consist of one or two questions embedded in broader studies of social support and stigma (e.g. Issiaka, Cratoux, Ky-Zerbo, Tiendrebeogo, Meda, et al., 2001; Maman, Mbwambo, Hogan, Kilonzo, & Sweat, 2001). Those that do solicit information regarding motivation almost invariably consider only reasons for nondisclosure to partner or spouse. Thus although we know a little bit about barriers to disclosure of a positive HIV diagnosis in that relational context, particularly among female PLHAs, we know relatively little about what reasons actually lead to the decision to reveal one's serostatus, nor do we have information about reasons for revealing and concealing a positive diagnosis to other significant persons such as family, friends, and religious leaders. Information about partner disclosure, of course, is a key to prevention of transmission, but information about other disclosure targets has significant implications for HIV/AIDS care efforts. Furthermore, existing studies have not
investigated strategies for HIV serostatus disclosure. Knowledge of how people who do disclose to partners and others manage that task can enable counselors to more effectively advise PLHAs on means of making their status known to those who need to be aware of it, and inform the design of effective mass media campaigns promoting partner notification.

The primary theoretical framework for conceptualizing these issues in U.S.-based communication research has been communication privacy management theory (CPM; Petronio 1991; 2002) although several models designed explicitly to explain HIV-related disclosure have recently also been proffered (e.g. Derlega, Winstead, Greene, Serovich, & Elwood, 2004; Greene & Faulkner, 2002; Serovich, 2001). Applications of CPM in studies of self-disclosure of HIV-status in that context have provided some support for its appropriateness as a theoretical lens (e.g. Greene, 2000; Greene & Faulkner, 2002; Greene et al., 2003; Yep, 2000). However, CPM has not been extended to the study of HIV serostatus disclosure in sub-Saharan Africa, and it cannot be assumed that self-disclosure either with respect to HIV/AIDS or in general operates the same way in both places (see Altman, 1977; Spiro, 1971).

Most obviously, the primarily heterosexual character of the HIV/AIDS epidemic in sub-Saharan Africa suggests that factors surrounding disclosure there may differ from the U.S. More subtly, though, the communalistic orientation that is frequently cited as the quintessential characteristic of African societies (Gyekye, 1997; Moemeka, 1996) may result in different meanings and functions of self-disclosure than in the individualistic United States. In such cultures, the choice to divulge personal information may depend not only on one’s individual needs and desires, but also on those of the community, and the community sanctions for unacceptable behavior (e.g. sexual promiscuity) when it becomes known may be severe (Long, 2000; Moemeka, 1996). Furthermore, in contrast to egalitarian U.S. ideals, the hierarchical
structure of many African cultures may confer value on self-concealment as a sign of respectful recognition of social place, leading to different criteria for selecting disclosure targets and to the privileging of indirect over direct disclosure techniques in certain situations.

The present study attempts at once to accomplish two goals: 1) to address gaps in health communication literature with respect to methods and motivations for self-disclosure of a positive HIV diagnosis in one sub-Saharan African context: Nairobi, Kenya, and 2) to draw conclusions regarding self-disclosure patterns with implications for intercultural communication theory. Although I have followed precedent in U.S. communication research by retaining the categories provided by CPM as a means of considering privacy and HIV issues, I have done so with some reticence. At each step both theory and instrumentation have been tested to ensure cultural appropriateness, and conclusions are drawn in chapter five regarding applicability of CPM as a theoretical foundation for future research in Kenya, and by extension other sub-Saharan cultural contexts.

The next chapter begins by describing in more depth characteristics and history of the epidemic in Kenya. It then presents a review of literature on self-disclosure, with particular focus on disclosure of HIV serostatus. It summarizes what is known about both self-disclosure in general and disclosure of a positive HIV diagnosis in African societies, raising questions about cultural patterns that may influence the decision by PLHAs to make their status known.
CHAPTER 2
BACKGROUND AND RATIONALE

AIDS in Africa bears little resemblance to the American epidemic, limited to specific high-risk groups and brought under control through intensive education, vigorous political action and expensive drug therapy . . . . You cannot define risk groups: everyone who is sexually active is at risk. Babies, too, unwittingly infected by mothers. Barely a single family remains untouched (McGeary, 2001, p. 37).

By now the tenor if not the specifics of the alarming statistics about HIV/AIDS in sub-Saharan Africa have become all too familiar. Out of 40 million people living with the disease worldwide in 2003, over two-thirds were on the continent of Africa (UNAIDS, 2003). Life expectancies for many African countries, which had been climbing steadily for forty years, have plummeted 15 years and more in many nations (UNAIDS 2003). Hundreds of thousands of children have lost one or both parents to AIDS, raising the specter of a lost generation with little or no adult nurturance (Facing the pandemic, 2002; UNAIDS, UNICEF, USAID, 2004). And despite predictions that the epidemic would peak by the year 2000, with few exceptions such as Uganda and Senegal, national prevalence rates have continued to rise or at best stabilized (UNAIDS, 2004).

HIV/AIDS in KENYA

East Africa was one of the first areas in the continent where AIDS escalated into a regional epidemic (Essex & Mboup, 2002). The first case of HIV was identified in Kenya in 1984 (Williams, Ng’ang’a, & Ngugi, 1997), and by 1995 over 60,000 cases had been reported
(Kenya Ministry of Health, 2001). In the early years, not unlike in the United States, there was a virtual absence of information on AIDS in the public broadcasting services (Hanssen, 1993). Policy makers feared admission of an AIDS problem would hurt the all-important Kenyan tourist industry; religious leaders protested against promotion of condoms; surveillance data were not released. When it was considered at all, AIDS was assumed to be a disease of Westerners, particularly gay men (Rau, Forsythe, & Okeyo, 1996).

Responsibility to deal with the scourge lay with the national Ministry of Health, which to its credit became increasingly vocal in its warnings about the immanent catastrophe. By the early 1990s, the first national conference on HIV/AIDS was held, the government began waiving excise duty on condoms, and the Ministry of Health partnered with a number of international organizations to institute AIDS education efforts (Nzioka, 1996; Rau et al., 1996). In November 1999, former president Daniel arap Moi officially declared AIDS to be a national disaster (AIDS disaster, 1999) and subsequently established the National AIDS Control Council to coordinate a multi-sectoral response to the epidemic (Kenya Ministry of Health, 2001). Moi’s successor, current president Mwai Kibaki, announced in March 2003 that he was inaugurating a new phase in the war against HIV/AIDS, and formed a cabinet level committee charged with responsibility for the effort. He himself assumed the role of chair (Kibaki, 2003).

As a result of these and other efforts, knowledge of means of transmission and other AIDS-related topics has steadily increased in Kenya. As early as 1994, a survey conducted among secondary school students in the capital city of Nairobi found that questions of knowledge were answered correctly on average by 77.1% of respondents (Pattullo et al., cited in Mbugua, 2004), and subsequent research has continued to indicate that overall knowledge
regarding HIV is high (ICL, 2004; Mbugua, 2004; Pratt, Obeng-Quaidoo, Okigbo, James, 2000; Volk & Koopman, 2001).

Unfortunately, it has become clear that increased awareness of AIDS does not necessarily lead to increased perception of risk (Barden-O’Fallon, deGraft-Johnson, Bisika, Sulzbach, Benson, et al., 2004) or behavioral change (Kalipeni, Craddock, & Ghosh, 2004; Kapiga & Lugalla, 2002; Kesby, 2004; Mbugua, 2004; Rugalema, 2004; Volk & Koopman, 2001). By 1997, for example, only 3% of high-risk adults in Nairobi reported using a condom with their last sexual partner (Ndingya-Achola, Ghee, & Kihara, 1997), and over two-thirds of young women surveyed in Kenya stated that they had never used a condom during sex at all (UNAIDS, 2000a). A study in the city of Kisumu indicated that although 75% of persons interviewed in clinics had engaged in intercourse during the preceding month, fewer than 20% had used a condom (Volk & Koopman, 2001). Even knowledge of HIV-status, a central tenet of the policy focus on increasing voluntary counseling and testing centers in Kenya (Ngare, Marum, Taegtmeyer, Namwebya, Gikund, et al., 2003), does not appear to guarantee cessation of risky behaviors (Kipp, Kabagambe, & Kondelule, 2001). Although a variety of explanations has been proffered for this knowledge/behavior disjunct, (e.g. African Women’s Health, 1993; Airhihenbuwa, 1995; Akeroyd, 2004; Caldwell, Caldwell, & Quiggin, 1989; Crewe, 2002; Dilger, 2003; Diop, 2000; Kebaabetswe & Norr, 2002; Obregon, 2003; Rugalema, 2004), no clear answers have emerged.

Nevertheless, some evidence indicates that HIV-prevalence in Kenya may at last be stabilizing or even declining (Marum, Mwikya, & Cheluget, 2003). The Ministry of Health (2003) stated that the epidemic reached its peak in 2000, reporting that infection rates at several sentinel surveillance sites including the capital city Nairobi have recorded gradual declines in
infection rates since that time. Although the ministry warned that recent statistics must be interpreted with caution due to shifts in reporting and modeling methods and, at times, underfunded survey efforts, the signs are encouraging. The most recent UNADS global report estimates urban prevalence rates in Kenya at 10% and rural rates at 6%, making the overall national prevalence rate around 7% (UNAIDS, 2004).

Character of the Kenyan Epidemic

The profile of the HIV/AIDS epidemic in Kenya is in most ways reflective of that in sub-Saharan Africa as a whole. Transmission of the disease is overwhelmingly heterosexual; the government estimates that 74% of PLHAs were infected through heterosexual sexual contact, 23% through perinatal, i.e. mother-to-child transmission (MTCT), and 3-5% through blood transfusion (Kenya Ministry of Health, 2001). Although prevalence rates are higher in the urban areas, the absolute number of PLHAs is larger in the countryside (Kalipeni, et al., 2004; Kenya Ministry of Health, 2001; Lyons, 2004). The poor are believed to be at higher risk than the wealthy, especially women of low socio-economic status, who may supplement their incomes with occasional or regular commercial sex work (Dilger, 2003; (Maman, Mbwambo, Hogan, Kilonzo, Campbell, et al., 2002; Nyanzi, Pool, & Kinsman, 2000; Rugalema, 2004; Seeley, Malamba, Nun, Mulder, Kengeya-Kayondo, et al., 1993; Tlou, 2002).

Unlike in the U.S. and Europe, the majority of infected adults in Kenya are women (Matasha, Ntembelea, Mayaud, Saidi, Todd, et al., 1998; UNAIDS 2000a). The highest rate of infection for women occurs between the ages of 20 to 24, with 18% of these infected within two years of sexual initiation. In that age group it is estimated that two women are infected for every infected man, with the risk of infection gradually equalizing in higher age brackets (Joesoef, Cheluget, & Marum, 2003). Transmission to men is believed to occur most frequently between
ages 30 to 39 (Kenya Ministry of Health, 2001). Although young women are at greater physiological risk of being infected than men of the same age (UNAIDS, 2000b), socioeconomic factors including their lack of access to education or personal income and low status are likely even more significant in fostering vulnerability to infection (Altman, 2004; Esu-Williams, 2000; Esu-Williams & Blanchard, 2002; Lamptey, Wigley, Carr, & Collymore, 2002; Schoepf, 2004). Some researchers have suggested the “Sugar Daddy” phenomenon as an explanation of the age/sex mismatch in these statistics. The term describes a pattern of older, often married, men looking toward schoolgirls for sex since they recognize the danger of sexual intercourse with older partners (Matasha et al., 1998; UNAIDS, 2000a). These young women likewise mistakenly assume that because their partner is married, he is probably HIV-negative (Kenya Ministry of Health, 2001).

Because individuals survive an average of about ten years after infection, deaths from AIDS tend to be highest among persons in their mid-20s to early 40s—the most economically productive segment of the population. As a result, the business sector of the economy has suffered through increased costs such as higher employee medical expenses and insurance, decreased productivity resulting from higher absenteeism and shortage of skilled workers, and declining markets (Facings the AIDS pandemic, 2002; Kenem, 1996; Rugalema, 1999). Agricultural productivity is also impacted as small-scale farming households that are forced to provide medical support for their ill members may sell assets such as livestock, land, or equipment or may forego purchasing seed, forcing them into near non-production (Facing the AIDS pandemic, 2002; Fox, Simon, Rosen, Bii, Wasunna, et al., 2003; Lamptey, et al., 2002). The educational sector faces similar challenges as a consequence of illness and death of personnel. A large increase in teacher deaths between 1997 and 2001 is assumed to reflect the
impact of HIV, and absenteeism has increased due to illness of HIV-positive teachers, not to mention the growing number of funeral days requested (Njeru & Kioko, 2004). Kenya’s Ministry for Education, Science and Technology has estimated that about 1.8% of teachers have died annually of AIDS in recent years (UNESCO, 2005). Children of families affected by AIDS may drop out of school to care for the sick or till the land (Njeru & Kioko, 2004).

Finally, the burden placed on the nation’s healthcare system is staggering. The World Bank estimates that in the typical sub-Saharan African country, the cost of treating an AIDS patient for a year is 2.7 times the per capita gross national income (Facing the AIDS pandemic, 2002). In Kenya, an estimated 51% of hospital beds were filled by AIDS patients in 2000; in some districts the proportion was as high as 70% (Kenya Ministry of Health, 2001). As a result of this overcrowding, mortality among non-HIV patients has increased (World Bank, 1999). In every sector of society, twenty years after the appearance of HIV, the devastation of the epidemic is evident.

It is with this situation in mind that we turn in the remainder of this chapter to a consideration of self-disclosure of positive HIV serostatus. Whether, to whom, and how HIV-positive persons make their status known has implications for both prevention and care in the Kenyan epidemic.

**Self-disclosure and HIV/AIDS: Costs and Benefits**

*Benefits of Self-Disclosure for Prevention*

For people living with HIV/AIDS, whether in the U.S. or Kenya, the decision to tell someone about their condition means weighing enormous potential consequences, both positive and negative (Derlega, Lovejoy, & Winstead, 1998). Most critical of these in terms of disease prevention is that revealing a positive HIV-diagnosis to a sexual partner enables that person to
take measures to protect him/herself from exposure to the virus. In the U.S., reported rates of
disclosure to at least one sexual partner have varied from less than one-third (Perry, Card,
Moffatt, Ashman, Fishman, et al., 1994) to 89% (Mansergh, Marks, & Simoni, 1995; Schnell,
Higgins, Wilson, Goldbaum, Cohn, et al., 1992). Primary partners appear to be much more likely
targets of disclosure than casual or past partners (Marks, Richardson, & Maldonado, 1991;
Rotheram-Borus, Draimin, Reid, & Murphy, 1997; Stein, Freedberg, Sullivan, Savetsky,
Levenson, et al., 1998; Stemptel, Moulton, & Moss, 1995), although it is disturbingly common
for HIV-positive persons to report avoidance of disclosure even to primary partners (Doll,
Harrison, Frey, McKirnan, Bartholow, et al., 1994; Kalichman & Nachimson, 1999; Sheon &
Crosby, 2003).

In sub-Saharan Africa, too, the proportion of PLHAs who report sharing their status with
their partners varies widely among studies. At the lowest end of the spectrum, MacNeil,
Mberesero, and Kilonzo (1999) indicate that four weeks after learning they were HIV-positive,
only 13% of married respondents reported having shared their status with their spouse and only
3.9% of participants said they had informed a boyfriend/girlfriend or other sexual partner of their
diagnosis. By six months after diagnosis, these numbers had increased to 26% and 15%
respectively. In a study of 1078 HIV-positive women by Antelman, Fawzi, Kaaya, Mbambo,
Msamanga, and associates (2001), at two months after diagnosis only 22% said they had
disclosed their condition to their sexual partner, although that proportion steadily increased to
40% after four years. Lie and Biswalo (1996) found that only about one-third of clinic patients in
Tanzania who received a positive diagnosis of HIV identified their spouse as a person with
whom they would share their status. Comparable rates were found in Burkina Faso (Issiaka et al.,
2001) as well as in Kenya, where two investigations by Temmerman and Ndinya-Achola (1990
cited in Temmerman & Ndingya-Achola, 1995; 1995) found 27% and 37% respectively of PLHAs interviewed reported having told their partners of their serostatus. More recently, 57.1% of volunteers at a study in Western Kenya swore they would never reveal their status to their partners (Songkok & Andayi, 2003), although women with higher levels of education were more likely to indicate willingness to share their diagnosis results.

On the other hand two smaller studies, also carried out in Tanzania, reported closer to two-thirds of participants telling partners of their diagnosis (Maman et al., 2001; Maman, Mbwambo, Hogan, Weiss, Kilonzo, et al., 2003), and another conducted in Kenya, Tanzania, and Trinidad found 76% of participants at all locations—both both seropositive and negative—had reported their status to their partner before their first clinic follow-up visit (Grinstead, Gregorich, Choi, & Coates, 2001). A similar project in Lusaka, Zambia found that 47% of women who tested positive had reported their status to their partner within a week of receiving their diagnosis (Siwale, Kankasa, Geibel, & Kalibala, 2003).

Knowledge of factors impacting disclosure to partners is critical for designing interpersonal and mass media interventions promoting sharing of serostatus. There is some evidence regarding reasons why PLHAs, particularly women, choose not to reveal their condition to their spouses or other sexual partners. However, currently available information addresses primarily motivation for nondisclosure of status, not reasons why one would choose to reveal one’s condition. Furthermore, there has been no investigation of strategies that PLHAs use to accomplish that disclosure, an issue that could have notable implications both for counseling and partner notification campaigns. For instance, a widely disseminated HIV/AIDS mass media campaign in Kenya, recognizing both the significance and challenge of partner notification urged couples to “Chanukeni pamoja” [trans: Be enlightened (i.e. tested) together] (see Marum, Odoyo,
Furnivall, Kamau, & Ng’ang’a, 2004). As a more complete picture of PLHA partner notification patterns is developed, other approaches may be identified.

Disclosure to partners remains a pivotal concern even as ARVs become less cost prohibitive and more accessible (Daniel, Falola, Ogundahunsi, Ogun, Odusoga, et al., 2004). According to Peter Okaalet (personal communication, October 19, 2004), Africa director of faith-based NGO MAP International, as of 2004, in the nation of Kenya only ten percent of PLHAs who needed such therapies had access to them, as compared to approximately 84% of HIV-positive persons in North America (UNDP, WHO, UNAIDS cited in Panos, 2004). Even if these numbers dramatically increase to 50% by the end of the 2006/07 financial year, as anticipated in the draft copy of the *Kenya National HIV/AIDS Strategic Plan 2005/6-2009/10* (Kimani, 2005), provision of ARVs to the approximately seven percent of the adult Kenyan population who are currently infected with the virus will continue to strain health and medical infrastructures. The same document estimates that by the year 2010, annual spending on HIV/AIDS in Kenya will be equivalent to the entire current budget of the nation’s Ministry of Health for two years (Kimani, 2005). Absent development of a vaccine or cure, intervention at the level of interpersonal transmission is key to controlling the pandemic, and disclosure to sexual partners is central to reducing interpersonal transmission (McFarland, Linden, Mandel, & Rutherford, 2002).

*Benefits of Self-Disclosure for Care*

A second benefit to disclosing serostatus is the resultant access for PLHAs themselves to diverse types of social support (Greene et al., 2003; Kimberly & Serovich, 1996; Serovich, Brucker, & Kimberly, 2000; see Albrecht & Adelman, 1984; Albrecht & Goldsmith, 2003, for reviews of literature on social support and health; see Greene, et al., 2002, for a brief review on
social support and HIV/AIDS). The link between social support and psychological and physical well being has been documented since the 1970s (Serovich, Brucker, & Kimberly, 2000). With respect to HIV/AIDS, social support and satisfaction with social support have been shown to be especially important in their relationship to both depression and coping styles (Chidwick & Borrill, 1996; Hays, Turner, & Coates, 1992; Lesserman, Petitto, Golden, Gaynes, Gu, et al., 2000; Prado, Feaster, Schwartz, Pratt, Smith, et al., 2004; Serovich, et al., 2000). For instance, social support has been associated in HIV/AIDS patients with higher levels of active coping—i.e. proactively and positively dealing with the illness—which in turn has been shown to predict greater health care satisfaction and less substance abuse (Leslie, Stein, & Rotheram-Borus, 2002). Among African American PLHAs, social support has been linked to lower levels of mood disturbance (Song & Ingram, 2002). Correlations have also been established between social support and health-related variables among PLHAs, such as number of symptoms, CD4 count, and social adjustment to illness (Parkenham, Dadds, & Terry, 1994). At the same time, negative responses to disclosure can lead to a sense of inadequacy of social support and consequently depression, a finding that suggests it is important at least for some PLHAs to be guided through the disclosure process if it is to have a net positive result (Power, Duran, Palmer, Koopman, Gore-Felton, 2004).

In the context of the U.S. epidemic, the most frequently discussed aspects of support for PLHAs are components of emotional support such as expressing love or concern, serving as confidant, offering a philosophical or spiritual perspective, interacting naturally, supplying companionship, and even providing distraction for the PLHA from his/her troubles (Barbee, Derlega, Sherbourne, & Grimshaw, 1998; Derlega, Winstead, Oldfield, & Barbee, 2003; Hays, Magee, & Chauncey, 1994). Informational support has also been found to be important to
PLHAs, buffering stress associated with HIV symptoms (Hays, et al., 1992). Along with informational and emotional support, tangible supporting including practical assistance with everyday tasks like running errands, cooking meals, or providing transportation, as well as provision of material aid such as help with medical expenses or even just sending care packages (Hays et al., 1994) has been associated with lower levels of depression in PLHAs (Hays et al., 1992). Hays and associates (1994) found that because PLHAs felt guilty about being a burden on family and friends who formed their support networks, they also highly valued the extension of various types of support to these significant persons in their lives.

Unfortunately many PLHAs have had insufficient sources of such support. Using data from interviews with 224 PLHAs in New York City, Smith and Rapkin (1996) found that respondents mentioned having an average of fewer than two sources of close support, and that the number of supportive individuals among both friends and family predicted satisfaction with support received. The fewer people a PLHA tells about his/her diagnosis, the fewer people are available to whom s/he can reach out for emotional and practical assistance. Conversely, fear of disclosure is among the most frequently mentioned barriers to obtaining needed support (Smith & Rapkin, 1996; Serovich, et al., 2000).

Although some studies in sub-Saharan Africa have assessed the amount of support PLHAs receive after diagnosis disclosure (e.g. Grinstead, et al., 2001; Maman, et al., 2003; Paxton, 2002), the author has located no investigations of reasons for concealing or revealing a positive HIV diagnosis to significant others aside from partners. Nor are data available regarding strategies for disclosing to such persons, even though the family network in particular is assumed to be critical for provision of material and emotional support. If PLHAs are to be
effectively counseled toward mobilization of their social networks toward meeting their HIV-related needs, understanding of these areas is essential.

As is the case with the implications for prevention, availability of ARVs does not negate PLHAs’ need for some level of diagnosis disclosure to obtain social support, although it may cause a shift in the types of support required. PLHAs still have need of financial assistance to meet the cost of treatment, and adherence to drug regimens may also necessitate logistical assistance from close friends or relatives. Understanding to whom, how, and why PLHAs disclose their serostatus within their support networks can enable health care providers to more effectively design patient education, and more efficiently mobilize those same networks for caregiving (Smith & Rapkin, 1996).

A third benefit of disclosing serostatus is that only by doing so can PLHAs gain access to medical treatment. Individuals receiving treatment at clinics, rather than languishing in isolation are in some measure enjoying one benefit of disclosure. Enrollment in medical treatment frequently opens up opportunities to benefit from other services associated with clinics such as support group meetings and AIDS-related resources outside of the PLHAs established support network.

Costs of Self-Disclosure

The benefits of revealing a positive HIV diagnosis are considerable. However, the costs of disclosure can be equally substantial (e.g. Ostrow, Joseph, Kellser, Soucy, Tal, et al., 1989). Many can be traced to the stigmatization associated with the disease. Because stigma is an overwhelming issue both in AIDS-related literature as well as in the minds of PLHAs themselves (Cline, 1989; Gerbert, Maguire, Bleecker, Coates, & McPhee, 1991; Greene, el al., 2002), a brief discussion of the concept is in order at this point.
Stigmatization. In Goffman’s classic definition, stigma is “an attribute that is deeply discrediting” (Goffman, 1961, p. 3); a mark of shame, of spoiled social image. Stigmatized persons are viewed as possessing characteristics that are a legitimate basis for excluding them or avoiding them, or even treating them as non-persons (Devine, Plant, & Harrison, 1999; Leary & Schreindorfer, 1998). Goffman (1961) described three general types of stigma: 1) physical deformities, 2) moral transgression, and 3) membership of a despised social group. Although the first has the clearest connection to medical conditions, all three types of stigma can be connected with HIV/AIDS, which is primarily transmitted through behavior society considers unacceptable, and is often more prevalent in certain ethnic groups than in the population at large. Infection with the disease may therefore elicit a doubly or even triply strong stigmatizing response, depending in part on the question of origin and responsibility for the stigma (Bailey, Reynolds, & Carrico, 1989; Crandall, 1991; Crawford, 1996; Derlega, Sherburne, & Lewis, 1998; Dowell, Lo Presto, & Sherman 1991; Herek, 1999; Leiker, Tabu, & Gast, 1995; Schwarzer & Weiner, 1991; Weiner, Perry, & Magnusson, 1988; Weiner, 1993. For other schemes of dimensionality of stigma see Fife & Wright, 2000; Gilmore & Somerville, 1994; Jones, Farina, Hastorf, Markus, Miller, et al., 1984; Leary & Schreindorfer, 1998; Parker & Aggleton, 2003).

In early stages of their infection PLHAs may be able to hide their condition, being what Goffman termed, “discreditable” rather than already “discredited.” For the discreditable, daily life entails constant and conscious effort to hide their stigma, to “pass” (Goffman, 1961). Once PLHAs’ condition becomes known and they move to a “discreditable” state, they may experience growing social exclusion (Alonzo & Reynolds, 1995; Kelly, St. Lawrence, Smith, Hood, & Cook, 1987). PLHAs have reported being targets of a number of stigmatizing behaviors such as being treated with less respect than usual, being avoided because of their illness, the sense that
others feel awkward and tense around them, negative effects on job security, rejection by family members or friends, financial hardship, being treated as less competent than usual, and even being subjected to violence (See Herek, 1999 for a review). PLHAs may internalize these attitudes and come to believe that they are not worthwhile members of the community, and in consequence experience depression, anxiety, and alienation (Armistead, Morse, Forehand, Morse, & Clark, 1999; Crandall & Coleman, 1992; Jordon, Lindner, Armistead, & Austin, 2003; Lee, Kochman, & Sikkema, 2002; Miles, Burchinal, Holditch-Davis, Wasilewski, & Christian, 1997. But see also Crocker & Major, 1989, for a discussion of the uncertainty of the link between social stigma and low self-esteem). These are the risks that PLHAs balance against the rewards of sharing their status with others. Even in the U.S. where stigmatization of HIV infection and AIDS has become less virulent as the public has become less alarmed by the presence of PLHAs in their midst (Herek, 1999; Herek & Capitiano, 1993; Herek, Capitiano, & Widaman, 2002), the decision to disclose continues to be weighty and complex (Yep, 2000).

Much if not most of the existing information on disclosure of HIV-positive status is derived from research outside of the field of communication. Investigators from health and related fields have been concerned to determine how often and to whom PLHAs reveal the secret of their status, but have infrequently anchored those inquiries in disclosure theory. Research available from a communication perspective has been generated by a small group of scholars whose names are obvious from a glance at the reference list at the end of this paper. The main theory that has been invoked in their efforts has been Communication Privacy Management theory, although other theories specific to HIV have recently been proposed (e.g. Derlega, Winstead, Greene, Serovich, & Elwood, 2004; Greene, Derlega, & Mathews, in press). The next section begins with a selected review of literature on self-disclosure, ultimately focusing on
communication privacy management theory and incorporating results of research on disclosure of HIV serostatus in the U.S. environment. It also summarizes findings about disclosure of HIV serostatus in sub-Saharan African settings and in the process raises questions about the applicability of current disclosure theorizing to that cultural context.

Laying a Foundation in Self-Disclosure Theory

*Self-Disclosure as a Positive Psychological Trait: The Legacy of Sidney Jourard*

The proliferation of self-disclosure research in psychological literature can be traced back primarily to Sidney Jourard (1972), whose popularization of the concept of the “transparent self” presaged a geometrical expansion of the study of self-disclosure during the 1970s (Parks, 1982; Rosenfeld, 2000). The topic has remained a focal point of theory, research, and pedagogy on the development of personal relationships ever since (Levesque, Steciuk, & Ledley, 2002); literally hundreds of psychological studies have examined its implications and correlates (Omarzu, 2000).

By definition, self-disclosure involves intentionally making known to others personal information about the self (Cozby, 1973; Jourard, 1964). Such information could include facts, opinions, attitudes the individual possesses, and explanations of moods and emotions (Omarzu, 2000). That is, it could be descriptive, evaluative, or affective. It could also include revealing attitudes about actions and opinions of the other party (Dindia, 2000a). Disclosures can be classified on the basis of breadth, i.e. the sheer number of topics covered, and also in terms of depth, the intimacy level of the disclosure (Derlega & Chaikin, 1977). Occasionally duration or frequency of disclosure—the sheer amount or persistence of revelation on a topic—is split out from breadth as a separate dimension (Omarzu, 2000).

Jourard’s (1964, 1972) claims regarding the merits of self-disclosure were expansive and their influence far-reaching. He declared the sharing of personal information about the self to be
a key to intimacy, a prerequisite for a healthy personality, and a contributor to good physical health. His perspective assumed that true communication at the interpersonal level is most effectively accomplished if participants honestly (but circumspectly) open their private selves to one another (Rosenfeld, 2000). One well-accepted explanation of the process by which this openness gradually unfolds is provided in social penetration theory (Altman & Taylor, 1977), which posits that as a relationship grows more intimate, self-disclosure on the part of both parties becomes broader and deeper. The progression of closeness is compared to peeling an onion; with the outer skin representing initial, superficial disclosures about the self when a relationship is just beginning, and the core representing the most personal, central information that is revealed when a relationship becomes truly intimate. Disclosure between partners functions as a medium of social exchange—a sort of relational currency the worth of which is considered in the decision to move toward or away from greater closeness (Altman & Taylor, 1977), and which, like any gift or favor, the receiver may feel obliged to reciprocate (Levesque, et al., 2002). Individuals may strategically manipulate their own levels of disclosure in order to elicit rewards or obligations from the other party.

Despite the personal and interpersonal rewards of revealing private information, it is generally recognized that with respect to self-disclosure it is possible to have too much of a good thing. Persons who habitually reveal immoderate amounts of information about themselves to indiscriminate targets may be just as maladjusted as chronic non-disclosers. Therefore Jourard (1964) postulated a curvilinear relationship between mental health and disclosure. Individuals who walk a middle path, disclosing generously to persons with whom they are very close and moderately to others, are those who are deemed most likely to be well adjusted and emotionally healthy (Cozby, 1973).
Self-disclosure has been touted as being good for physical health as well (Smyth, 1998). Although this aspect of Jourard’s theorizing was not particularly influential at the time he advanced it, more recently the existence of a relationship between how much one shares about oneself and one’s experiences of disease has become firmly established in psychological literature (Tardy, 2000). It has been suggested that the act of disclosing benefits people by providing them with social comparison information reminding them they are not alone in their experience, promoting a feeling of closeness to the person being confided in, enabling them to obtain needed social support, and providing the opportunity for sensemaking regarding their struggles (Albrecht & Goldsmith, 2003; Lesserman, et al., 2000; Lugton, 1997; McKenna, Zevon, Corn, & Rounds, 1999; Pennebaker & O’Herron, 1984; Pistrang & Barker, 1992).

In addition to these interpersonal benefits, research by Pennebaker and others indicates communication about traumatic events may produce the intrapersonal benefit of catharsis (e.g. Arond-Thomas, 2000; Henderson, Davison, Pennebaker, Gatchel, & Baum, 2001; Pennebaker, 1985), independent of whether or not it elicits social or material support. In some investigations that assess the results of journaling about difficult life experiences, intrapersonal benefits have been shown to accrue irrespective of the presence or not of a confidant. It has been proposed that self-expression may strengthen the immune system and enable the individual to avoid the rumination and preoccupation that often results from secret-keeping (Cole, Kemeny, Taylor, Visscher, 1996; Lepore & Helgeson, 1998; Lepore, Ragan, & Jones, 2000). Among PLHAs themselves there seems to be a recognition of this benefit of self-disclosure, as one motivation that is regularly identified in North American studies for revealing a positive diagnosis is that of catharsis or self-expression (Derlega, Lovejoy, & Winstead, 1998; Derlega, Winstead, & Folk-
Barron, 2000; Derlega, Winstead, Greene, Serovich, & Elwood, 2002). It appears, then, that
cconfession is good for the body.

Empirical support for these conventionally accepted benefits of self-disclosure has been
mixed. The idea that self-disclosure is inherently rewarding and the contention that people feel
compelled to reciprocate disclosure have both received a certain degree of support (Collins &
Miller, 1994; Dindia & Allen, 1995, cited in Dindia 2000b; see Cozby, 1973 and Dindia, 2000b
for additional reviews). However, Dindia (2000b) has noted that evidence of reciprocity in self-
disclosure must be interpreted with caution. Few studies have addressed level of intimacy of self-
disclosure or self-disclosure valence, so that we do not know if disclosure of secret information
such as HIV positive status, is indeed likely to be reciprocated. Evidence is also less than robust
in programs of research that treat predilection to self-disclosure as a personality trait, à la
Jourard. Attempts to discover demographic and psychosocial characteristics associated with
high and low trait disclosers have yielded few significant relations (Dindia, 2000a). Furthermore,
even though the emotional consequences of self-concealment have been associated with
increased rates of illness, seeking care, and physical symptoms (Pennebaker, 1985; Pennebaker
& O’Herron, 1984), some have argued that self-concealment is a separate construct from self-
disclosure (Larson & Chastain, 1990), making the connection between physical health and self-
disclosure potentially less than straightforward. Finally, empirical support for an association
between self-disclosure and mental health is tenuous at best (Cozby, 1973; Parks, 1982).

That these gaps in self-disclosure literature necessitate further research efforts is clear.
However, a growing number of communication scholars suggest that a more fundamental
reexamination of the conceptualization of self-disclosure is required.
Self-Disclosure as a Regulator of Opposing Personal Needs: The Dialectical Perspective

Even though most writers on the topic admit that there is such a thing as too much and inappropriate disclosure, the vast majority of research has assumed self-disclosure to be intrinsically positive behavior (Dindia, 2000a; Katriel & Philipsen, 1981; Rosenfeld, 2000). Several authors, most notably Parks (1982) in his oft-cited “Ideology of Intimacy” essay, have insisted that this historical pro-disclosure/anti-concealment bias is unrealistic, and questioned the appropriateness of equating self-disclosure with relational closeness. They assert that in contrast to the assumptions of much self-disclosure theorizing, privacy and secrecy can actually operate to benefit relationships by allowing members to hide their inadequacies and errors (T. Afifi & Schrodt, 2003; W. Afifi & Guerrero, 2000; Parks, 1982, 1995; Roloff & Ifert, 2000; Vangelisti, Caughlin, & Timmerman, 2001) and to prevent conflict (Golish & Caughlin, 2002). These same qualities can also serve to enhance intrapersonal adjustment by allowing opportunity for reflection, planning, and evaluation (Kelly & McKillop, 1996; Parks, 1982). Conversely, self-disclosure can have negative ramifications and is frequently accompanied by challenges, complications, and risks (Dindia, 2000a; Rosenfeld, 2000). Persons may avoid disclosure because they fear rejection or reprisal (Cline & MacKenzie, 2000; Kelly & McKillop, 1996), especially when the other partner holds more power in the relationship (T. Afifi & Olson, 2005; Cloven & Roloff, 1993; Samp & Solomon, 2001; Solomon, Knobloch, & Fitzpatrick, 2004; Solomon & Samp, 1998). This is perhaps nowhere so obvious as in reports by some HIV-positive individuals of experiencing stigmatization and rejection upon disclosure of their condition. Finally, these scholars point out that the valorization of the sharing of personal information as a key to intimacy implies that neither role behavior nor publicly shared norms
contribute to real personhood and meaningful relationships, a contention that is culturally limited at best (Parks, 1982; Goldsmith, 2001).

A corrective to this overstatement of the positive role of self-disclosure is available in dialectical perspectives on interpersonal relationships. Instead of conceiving of inclination toward self-disclosure as a personal quality, and categorizing individuals into disclosive “haves” and “have nots”, dialectical scholars assert that self-disclosure is more profitably viewed as an ongoing process that occurs in the context of relationships that are also ongoing. That is, it is transactional.

Even more importantly, dialectical perspectives introduce into the study of self-disclosure the assumption of contradiction (Dindia, 2000a). Social life is seen as inherently involving contradictory and opposing forces; relationships consist of “the dynamic interplay between unified opposites” (Baxter & Montgomery, 2000, p. 32). Thus persons in relationships are continuously negotiating the tensions between autonomy and connectedness, openness and closeness, stability and change (Baxter, 1990). Neither pole of these oppositions is considered to be either good or bad; both are assumed to possess potential for positive and negative relational ramifications (Montgomery, 1993). Thus, in addition to the advantages of openness claimed by many psychological theorists, Baxter and Montgomery (1996) assert that choosing to disclose exposes one to four potential risks: being rejected by the receiver, suffering a reduction of personal autonomy and integrity, losing control, and hurting or embarrassing the disclosure target. Far from negating one another, however, these opposites are interdependent parts of a coherent whole (Baxter & Montgomery, 2000). A dialectical perspective, therefore, would characterize self-disclosure not as innately positive, but as a behavior sometimes helpful, sometimes not, always in flux.
This emphasis is particularly valuable with respect to the study of disclosure of a positive HIV diagnosis, where the overwhelming focus on fear of stigmatization as an explanation for lack of disclosure has unfortunately meant that possible coping functions of nondisclosure have been little explored. Research into cancer disclosure, for instance, indicates that many persons with cancer tend not to openly discuss within their families that one of them is dying. Patients feel the need to control their own anxiety and avoid preoccupation with concerns about illness, treatment and death. So they “normalize” daily life by limiting disclosure (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Gray, Fitch, Phillips, Labrecque, & Fergus, 2000a; Muzzin Anderson, Figueiredo, & Gudelis, 1994). Similarly, a study by Brashers and his colleagues (Brashers, Neidig, Haas, Dobbs, Cardillow, et al., 2000) found that many persons living with HIV/AIDS at times chose to avoid information in order to maintain uncertainty, or because the negative information became too much to deal with. It is not difficult to imagine that such persons might choose to limit disclosure as a means of coping. In such cases, as Greene and Faulkner (2002) point out, PLHAs simply may not want to spend all of their time and energy discussing their condition.

Of the relational tensions identified by dialectical theorists, those of openness-closedness and autonomy-connectedness have been understood to have the most direct implications for understanding self-disclosure. In the dialectical view, individuals constantly face opposing inclinations both to make themselves known and to protect themselves from vulnerability. Given the continuously shifting nature of individuals’ openness needs and contrary to social penetration theory, we might then expect levels of disclosure in a relationship to ebb and flow rather than to increase in a straight linear fashion over time, a prediction that has been empirically validated to some degree (Vanlear, 1987, 1991). By extension, self-disclosure has been viewed by some
scholars as a privacy regulation device, and decisions regarding how much personal information to reveal or conceal may be cast in terms of managing the boundaries between the poles of expressiveness and restraint (Derlega & Chaikin, 1977). As Altman (1977, p. 6) explained:

Privacy is conceived of as an interpersonal boundary process by which a person or group regulates interaction with others. By altering the degree of openness of the self to others, a hypothetical personal boundary is more or less receptive to social interaction with others. Privacy is, therefore, a dynamic process involving selective control over a self-boundary, either by an individual or by a group (emphasis in original).

Communication Privacy Management Theory

The metaphor of shifting and constantly negotiated boundaries between privacy and self-disclosure is the foundation of Sandra Petronio’s (1991, 2000) communication privacy management theory (CPM; formerly communication boundary management theory). CPM has been suggested as especially appropriate to examination of HIV-status disclosure because of its focus on disclosure of unsolicited private information, its assertion of potentially high risks associated with disclosure, and its transactional nature with the attendant emphasis on relationship-level rather than individual factors (Greene & Faulkner, 2002; Yep, 2000).

The theory was initially explicated by the author in 1991, and at the time was presented as functioning on two interrelated levels—macro and micro. The macro level aimed at providing “a systems framework where communicative boundaries are regulated when private information is disclosed” (p. 313), whereas the micro level offered “an analysis of the strategic nature of the interactive process punctuated by a spouse’s unsolicited decision to disclose private information to a marital partner” (p. 313). The two levels of analysis were tied together by three shared assumptions: 1) individuals erect boundaries to control their autonomy and vulnerability when
disclosing and receiving private information; 2) in a relational system, partners strategically regulate communication boundaries to minimize risk and vulnerability; and 3) people use decision-making rules to determine when to disclose, to whom, and how much (Petronio, 1991).

The initial article skimmed the macro level of the theory briefly, concentrating on the explanation in the micro level component of marital disclosure events from the perspective of both discloser and disclosee. In more recent publications (Petronio, 2000; 2002; Greene et al., 2003), the author has shifted her attention to developing the macro level aspect more fully. However, as we shall see, the original micro level component, which has of late received little attention, contains elements with critical implications for the understanding of and counseling toward HIV serostatus disclosure. As issues drawn from both macro and micro levels will inform hypotheses and research questions in this study, an overview of each is provided below with occasional examples, when available, from literature on disclosure of HIV seropositivity.

**Macro Level**

When people reveal information related to issues that matter deeply to them, they must find a way to regulate their communication in order to manage the possible risk to themselves. They do this by erecting protective boundaries that control information flow between themselves and others (Petronio, 1991; Altman, 1975). In the macro level of CPM, this boundary management is construed within a systems theory framework, depending on the intersection of two components: a *boundary structure* and a *rule-based management system* for regulating that structure (Petronio, 2000). Each of these major components is presented as consisting of a number of dimensions which are described below.
Boundary structures. Persons develop individualized structures that they rely on for the handling of private information. These structures have been defined (Petronio, 2000) via four dimensions: ownership, control, permeability, and levels.

Ownership refers to people’s right to govern whether personal information about themselves is revealed or concealed. Because people believe such information is their own, they erect borders to protect it. The phrase, “It’s none of your business,” encapsulates this sense of proprietary rights over personal information. Just as a college student may be irritated if her roommate borrows her clothes without permission, individuals may feel violated when information about them somehow becomes known to others without their intending it.

Control expresses the sense that beyond the expectation that privacy of information is a right, revelation of that information involves risk. Boundary structures are established to minimize vulnerability through controlling what persons have access to the owned information. Thus HIV-positive individuals are dealing with issues of control when they relate concern about confidentiality of their test results.

Permeability describes the degree of access that individuals grant to their private information. Structures surrounding less risky information tend to allow a relatively free information exchange, but structures protecting highly risky material are likely to be more rigid. Most U. S. Americans would not mind, for example, if their preference for caramel macchiatos became public knowledge, but information about amount of their salary package is a closely guarded secret. Disclosure of a chronic illness, particularly of a positive HIV status, carries tremendous risks, consciousness of which may lead the “diagnosee” to develop more impermeable boundaries than for other private information (Cline & McKenzie, 2000; Greene et al., 2003). HIV/AIDS is naturally associated with secrecy, first because the latency period of the
infection can last ten years, so that a positive diagnosis can be concealed for a long time, and second, because transmission is connected to behaviors that may be considered immoral (Yep, 2000).

*Levels* of privacy boundaries indicate whether information is owned by the individual alone, or jointly with others. Secrets may be kept at the individual, dyadic, family, group, relational, or even community levels (Caughlin, Golish, Olson, Sargent, Cook, & Petronio, 2000; Petronio, 2000; Petronio, Ellemers, Gils, & Gallois, 1998). When persons choose or are forced to share ownership with others, their confidants also share responsibility for managing relevant privacy boundaries. In such situations, responsibilities for protecting or disseminating information may be defined and sanctions applied when individuals are not careful to fulfill their responsibilities as they ought. The old adage that warns family members against “airing their dirty linen in public” is predicated on a recognition of the responsibilities of such co-ownership.

*Rule-based Management System.* The way the boundary structures of ownership, control, permeability, and levels function depends on the rules that are developed to manage them. CPM has defined the privacy management system by means of four concepts: *boundary rule formation, boundary rule usage, boundary rule coordination,* and *boundary rule turbulence.*

*Boundary rule formation* describes the creation of rules to regulate the flow of personal information. People do this on the basis four major criteria: cultural, gendered, individual, and motivational (Petronio, 2000).

*Cultural criteria* affect disclosure choices because definitions of what constitutes appropriate vs. inappropriate revelation about the self vary across cultures, (Altman, 1977; Gudykunst, 1986; Spiro, 1971). The determination of disclosure targets, motivations, and methods are strongly shaped by cultural understandings of relationships, disease, and various
other factors. There is specific evidence that this is the case with disclosure of seropositivity among U.S. co-cultural groups (Marks, Bundek, Richardson, Ruiz, Maldonado, et al., 1992; Mason, Marks, Simoni, Ruiz, & Richardson, 1995; Simoni et al., 1995; Yep, 1992), although little information available regarding cultures outside North America.

*Gendered criteria*, that is, the difference between men and women’s positions, needs, or interests may also influence disclosure patterns. In fact, sex is the individual difference variable that has been most frequently studied in general disclosure research (Dindia, 2000b). In a meta-analysis of 205 studies that tested sex-differences in self-disclosure, Dindia and Allen (1992) found evidence that women disclosed more than men although the differences were small ($d = .18$) and were moderated by the sex of the disclosure target. Gendered criteria have also been connected to sexual orientation, especially with respect to disclosure of HIV seropositivity in the United States. Men who have been infected through sexual contact with other men are likely to develop different rules regarding disclosure of their condition than do persons who contracted the disease through other means. For the former, disclosure may involve a “double coming out” by revealing their sexual orientation as well as their illness (Hays et al., 1993; Marks et al., 1992; Yep, 2000). Differences between males and females regarding disclosure of HIV serostatus, on the other hand, is only just emerging as an area of research in the U.S. (e.g. Derlega et al., 2003), partly because women have been less visible than men in the HIV/AIDS epidemic there (Greene & Faulkner, 2002).

*Motivational criteria*, or the goals that people plan to achieve through disclosure and nondisclosure also shape their privacy rules including identity of disclosure targets and timing of disclosure. In HIV serostatus disclosure research, for instance, factors influencing decisions to disclose to certain relationship types (e.g., a mother) have been shown to be different from
factors influencing decisions to disclose to others, for example a friend (Derlega, et al., 1998, 2000, 2003, 2004; Greene et al., 2003; Greene, 2000), child (Greene & Faulkner, 2002; Rotheram-Borus, et al., 1997) or coworker (Marks et al., 1992; Simoni et al., 1997; Stemptel et al., 1995).

Individual characteristics also influence individual construction of privacy rules. This category is comprised of a number of factors specific to the individual such as levels of liking and self-esteem (Petronio, 2000). With respect to HIV, studies have confirmed relations between decision to disclose HIV seropositivity and past disclosure experience (Charbonneau et al., 1999), means of transmission (Hays et al., 1993), stage of disease (Holt, Court, Vedhara, Nott, Holmes, et al., 1998, with asymptomatic individuals more likely to adopt a policy of nondisclosure), and quality of relationship with the potential target (Agne, Thompson, & Cusella, 2000; Derlega, et al., 1998; Hays et al., 1993; Simoni et al., 1995).

The four types of criteria—cultural, gendered, motivational, and individual—form the basis upon which people establish their personal boundary access and protection rules. It is by assessing these factors that an individual decides on a daily basis when, how deeply, in what way, and to whom private informed should be revealed. The effects of these criteria and the relationship among them in the Kenyan context will be the subject of a number of the study hypotheses below.

Boundary Rule Usage. This component of rule-based management refers to different ways that rules may be employed. Rules used repeatedly may become ritualized. The old rule of thumb that one should avoid talking religion and politics would be an example of a societally ritualized privacy rule.
On the other hand, in novel situations individuals may find they can no longer follow established rules for revealing and concealing. Instead, they must create fresh ones. This is true after events such as divorce, when privacy boundaries must be redefined to accommodate decreased intimacy, but also when an individual is given a diagnosis of a chronic or fatal illness, such as HIV. The severity and newness of the situation often means that the rules individuals have developed over their lifetimes to guide them in making self-disclosure decisions no longer work for them (Petronio, 2002).

*Boundary Rule Coordination.* Not only must people make decisions about disclosure according to a set of rules that regulate the flow of information in and out of their privacy, they must also enact those disclosures in specific relationships. Boundary coordination may be defined as the fit between the message strategy, the expectations it communicates, and the response of the disclosure target (Greene & Faulkner, 2002; Greene & Serovich, 1996; Petronio, 2001).

*Boundary Rule Turbulence.* Finally, boundary turbulence arises when there is lack of symmetry in enacting privacy rules. This can happen when people mistreat private information owned by another person, when a would-be confidant refuses to be drawn into the privacy network, or when expectations of privacy management are misunderstood (Petronio, 2000). Although such breakdowns of privacy management are frequently unpleasant and may cause conflict, they can also be opportunities for better defining privacy rules and integrating new information into the system (Greene et al., 2003).

Citations in this section attest to the exploration of some components of the macro level aspect of CPM with respect to HIV serostatus disclosure. To draw a fuller picture of research results in some of these areas it will be necessary to incorporate theoretical perspectives outside
of CPM. However, before introducing these other perspectives, we must first consider the second and initially more developed aspect of CPM, the micro level.

**Micro Level**

I have followed the structure of Petronio’s (1991) original article in presenting the macro level of CPM before the micro level. However, in that first elucidation of the theory, the author was clear that in terms of priority, the latter came first. Purposefully limiting herself to the context of disclosure in marital relationships, she proposed to identify how communications patterns might develop around disclosure exchanges. Most fundamentally, the theory views the disclosure of unsought private information between spouses as the intersection of two communication boundaries systems. When the needs of each person are fulfilled by the other, and that fulfillment elicits a corresponding level of satisfaction for both, complementarity develops in the relationship. That is, the partners work together toward relational happiness in a complimentary way.

The key to this complementarity in CPM is a good fit between disclosure message and partner response message strategies. Message strategies are classified into two types—explicit, or direct, strategies and implicit, or indirect, ones. Explicit messages are characterized by low ambiguity and low uncertainty, and are usually presented as direct statements (“I went for testing this week and I found out I’m HIV-positive”). Because they are high in certainty, they place high demands on the receiver, who may feel vulnerable because s/he cannot avoid responding to the clearly articulated goals of the message. Implicit message strategies, in contrast, are indirect communication tactics that contain much ambiguity and uncertainty, and less obvious demands (“You know I’ve begun spending a lot of time volunteering for an HIV/AIDS advocacy group”). The latter tactics protect communication boundaries for both discloser and disclosee, but at the
same time carry a risk of misunderstanding (Tannen, 1984, 1986); the recipient may simply miss the point. Which tactic is chosen depends upon the emotional control of the individuals and need for disclosure at the time, expectations of the results of disclosure, and nature of the information.

Petronio cited Derlega and Grzelak’s (1979) five general categories of reasons for revealing personal information—personal expression, self-clarification, social validation, relational development, and social control as potential influences on discloser expectations of disclosure. These expectations are assumed to vary by relational type and intimacy level. Disclosure message strategies are then selected on the basis of: (1) the need to tell, 2) predicted outcomes, 3) riskiness of telling this information to the partner, 4) privacy level of the information, and 5) his/her degree of emotional control at the time. Disclosees manage their own privacy boundaries by means of 1) evaluating discloser expectations; 2) attributional searches; and 3) selecting a response message strategy.

The micro level of CPM has been the subject of little empirical testing, and the issue of message strategy has not received much attention in HIV status disclosure literature (for exceptions see Greene & Serovich cited in Green & Faulkner, 2002; Greene et al., 2003). However, it has strong implications for counseling and prevention efforts, especially in the area of partner notification.

Additional Perspectives on Disclosure

Although not strictly arising out of CPM, a few additional lines of investigation into serostatus disclosure patterns in the U.S. epidemic, especially with respect to disclosure motivation, should be mentioned here. Several of these have been undertaken by researchers who have also conducted empirical tests of tenets of CPM, so the affinity with the latter is often evident.
Motivational Criteria Identified for HIV Serostatus Disclosure and Nondisclosure

Motivational criteria for HIV serostatus disclosure decisions have been examined beyond the parameters of CPM, primarily by Derlega and his colleagues. Inductively derived reasons for and against disclosure have commonly been divided into three types: other-focused, self-focused, and relationship-focused (Derlega, et al., 1998; Derlega, et al., 2000). Specific motivations identified under each category among U.S. PLHAs are identified below.

Self-focused reasons. These reasons both for and against disclosure deal with anticipated psychological costs and benefits to the discloser. Self-focused reasons reported for making known a positive HIV serostatus in the U. S. have included: catharsis/self-expression/self-clarification (Derlega et al., 1998, 2000, 2002; Holt et al., 1998; Leary & Schreindorfer, 1998; Levy, Laska, Abelhauser, Delfraissy, Goujard, et al., 1999; Yep, 2000) and seeking emotional and practical support (Agne, Thompson, & Cusella, 2000; Black & Miles, 2002; Charbonneaux, Maheux, & Beland, 1999; Derlega, et al., 1998; Holt, et al., 1998; Moneyham et al., 1996; Simoni, Davis, Drossman, & Weinberg, 2000). The finding in several studies that symptomatic seropositive individuals are more likely to disclose their status than non-symptomatic ones (Mansergh, et al., 1995; Sowell et al., 1997) may also be related to the seeking of various types of tangible assistance.

Whereas persons with non-infectious diseases whose condition is not immediately evident, such as those with diabetes or epilepsy, may choose not to reveal their diagnosis so as not to appear to be chronic complainers (Dunne & Quayle, 2002), for persons suffering from infectious diseases like HIV/AIDS, the central self-focused concern is often fear of rejection by the other party (Agne, et al., 2000; Black & Miles, 2002; Charbonneau et al., 1999; Derlega et al., 1998; Gielen, O campo, Faden, & Eke, 1997; Hays et al., 1993; Klitzman, 1999; Mason et
al., 1995; Moneyham et al., 1996; Simoni, et al., 2000; Serovich, 2001). PLHAs also commonly mention the self-focused motives for nondisclosure of exercising the right to privacy/need for coming to terms with the illness before contending with the reactions of others (Derlega et al., 1998; Gard, 1990; Holt et al., 1998; Kimberly, Serovich, & Greene, 1995; Paxton, 2002); and self-blame leading to shame (Derlega, et al., 1998; 2000). Hays and associates (1993) identified the additional self-focused motivation that there would simply be no benefit in disclosing.

Other-focused reasons. These deal with benefits or risks to others that are likely to accrue from divulging or hiding one’s seropositive status. Those regularly mentioned by U. S. PLHAs include: educating others or combating AIDS-related stigma (Derlega, et al., 1998; 2000; Paxton, 2002); and duty to inform others either to prevent them from becoming infected or forewarning them about the future (Agne, et al., 2000; Charbonneau, et al., 1999; Derlega, et al., 1998; Marks, Mason, & Simoni, 1995; Paxton, 2002; Simoni, et al., 1995; Serovich, 2001). Other-focused reasons for nondisclosure include desire to protect the other person from the burden of knowing the PLHA’s status (Derlega et al., 1998; 2003; Gielen et al., 1997; Hays et al., 1993; Marks et al., 1992; Mason et al., 1995; Simoni et al., 1995). Inability to reciprocate support received as a result of disclosure, i.e. concern that the balance of “give and take” in family and friend relationships will be disturbed, has been mentioned in Kimberly & Serovich (1996).

Relationship-focused reasons. PLHAs may also derive motivation for or against disclosure in accordance with expected benefits and costs to the relationship in question. For example, U.S. PLHAs have reported the relationship-focused reasons for disclosure of being in an emotionally close and supportive relationship with someone, testing the other person’s reactions, and similarity with another person (Derlega et al., 1998, 2000). Nondisclosure of status
has been associated with the fact of a particular relationship’s being not close either
geographically (Derlega et al., 1998) or emotionally (Agne et al., 2000; Derlega, et al., 2000;
Hays et al., 1993; Klitzman, 1999; Simoni et al., 1995).

Communication difficulties (Derlega et al., 1998; 2000) have also been cited as a reason
for nondisclosure, but they can fall into any of the three categories. One might have
communication difficulty that is self-focused (e.g. “I don’t feel ready to disclose to anyone”),
other-focused (“I don’t know how to tell so-and-so”) or relationship-focused (“There is
something going on between us when we are together that makes it hard for me to disclose to
him about my HIV status”; Derlega, et al., 2002). The motivation of sharing the responsibility
for safe sex (Holt et al., 1998; Sheon & Crosby, 2004) could likewise be classified as being self,
other, or relationship focused depending on the rationale behind it.

Derlega and associates (2002) created separate scales measuring reasons for disclosing
and not disclosing HIV status. The final 24-item disclosure motivation scale incorporates five of
the above-mentioned reasons: close relationship, similarity, testing other’s reaction, catharsis,
duty to inform/educate. The final 23-item nondisclosure motivation scale incorporated six
reasons for avoiding disclosure: right to privacy, fear of rejection, relationship not close, protect
other person, self-blame, communication difficulties. The reasons for disclosure and
nondisclosure among U.S. PLHAs identified by Derlega and associates will serve as points of
comparison and contrast with findings later in the paper.

Other Serostatus Disclosure Theories

Communication Boundary Management Theory, rechristened Communication Privacy
Management Theory, has been around for nearly 15 years and was adapted for use with HIV
serostatus disclosure soon after its formulation. In the intervening years several theories specific
to serostatus disclosure have also been advanced. Foregrounding individual decision-making, Derlega and his colleagues (Derlega et al., 2004; Greene, et al., in press) have proposed a model in which the endorsement of reasons for disclosure depends upon both distal and proximal factors. The former include: 1) the social and cultural context in which a person lives, i.e. what are cultural attitudes about HIV, close relationships, and self-disclosure; and 2) relational, individual, and temporal contexts such as the availability and supportiveness of friends and family, the length of time living with HIV, and individual characteristics of the PLHA (Derlega, Winstead, Greene, Serovich, & Elwood, in press). Once individuals have assessed the distal factors related to disclosure, they consider proximal factors—the current state of their relationship with the disclosure target, what the target’s response is likely to be, whether now is the best time or place to reveal such sensitive information—in determining whether they will actually disclose in a given situation.

Serovich’s (2001) consequence theory was initially juxtaposed with what she termed disease progression theory, a perspective that assumes the more serious an individual’s symptoms become the more s/he discloses serostatus to others. Serovich’s social exchange based model takes into account the changing experience of HIV infection in the aftermath of ARVs, and argues that now PLHAs simply calculate the rewards and punishments of disclosure before deciding to share. There need not be an increase in disclosure rate over time.

Although she proposed as a general model rather than one specific to HIV, Omarzu’s Disclosure Decision Model (DDM, Omarzu, 2000) is worth mentioning because of the role it assigns to motivation in decision-making. It proposes that situational cues first raise to salience a particular social reward. Various means of attaining the goal may be considered. If disclosure is selected as the best strategy, the individual will search for a reasonable disclosure target. Planned
disclosure to that person will then be evaluated on the basis of risks and rewards involved, and the outcome of that assessment will determine the breadth, duration, and depth of the subsequent disclosure in specific ways.

In relation to CPM, there are commonalities among these three models. Most obviously they are distinctly more parsimonious. In its original form (Petronio, 1991), CPM listed three underlying assumptions, four types of boundary coordination, three aspects of demand messages, two types of message strategies, five variables disclosers consider in structuring messages, three processes receivers go through in formulating responses, as well as reiterating the five functions of disclosure identified by Derlega and Grzelak. Later, when the macro level of the theory was expanded, it incorporated four properties of privacy boundaries, two major aspects of the boundary process, four concepts related to boundary management, and four boundary formation criteria, not to mention the three original assumptions. The number of categories was distinctly unwieldy, and a recent explanation of CPM itself (Greene et al., 2003) appears to address this weakness by shifting and simplifying the organization of the original categories. In this recent iteration, major categories of boundary rule usage and boundary rule coordination have been collapsed under the single label of boundary rule management, with the qualities originally discussed under boundary structures reduced from four to two, and also subsumed under the same heading.

Conceptually, in addition to the central fact that none of the three above models retains the transactional focus of CPM (perhaps because decisions to disclose seropositivity tend to be unilateral and to encompass a single, albeit sometimes incrementally revealed, piece of information), all argue different views of the place of motivations in disclosure. CPM places motivation alongside cultural, gendered, and individual difference criteria as a factor impacting
disclosure; Serovich’s model assumes the single overarching motivation of maximizing personal benefit and minimizing cost; Derlega and associates view motivation as an outcome of distal and proximal factors; and Omarzu places motivation as the initiator of the disclosure process. A fifth perspective on motivation might be derived from the lists of self-, other-, and relationally-oriented reasons for disclosure, which combine communication goals together with situational factors like degree of closeness in a relationship together into a single motivational stew.

None of these approaches explicitly give prominence to the emphasis recently propounded by Derlega and others (Derlega, et al., 2004), and which has regularly emerged in HIV disclosure research (e.g. Derlega et al., 1998; Hays et al., 1993; Mansergh et al., 1995; Marks et al., 1992; Simoni et al., 1995; Wolitski, Rietmeijer, Goldbaum, & Wilson, 1998), that disclosure occurs within specific relational contexts. With respect to motivation, PLHAs might be expected to express different priorities in motivational hierarchies for disclosure and nondisclosure to parents, for instance, than to partners. The original formulation of CPM admits this implicitly when it confines its explanation of disclosure events to the marital context, but no predictions are made about how that might differ from other relationship types. I will return to this issue in the discussion below of African values and disclosure practices, contending that in more strictly hierarchical societies such as those in sub-Saharan Africa, relationship type is likely to be important in determining disclosure pattern.

Summary of Application of CPM to the Present Study

In congruence with the attempt of this study to ground itself in African cultural patterns, hypotheses and research questions will be presented later, in the context of a discussion of what is known of disclosure patterns in the sub-Sahara. However, at this point it is important to summarize aspects of CPM, together with related theoretical perspectives and research cited
above, that inform this research project. First, the dialectical focus of CPM, with its recognition
that avoiding disclosure can be a functional behavior in relationships, is central to the current
investigation. Like Derlega and associates (2000; 2004), this research assumes that PLHAs may
have positive reasons for nondisclosure, and sets among its goals the attempt to identify them.

Second, the investigation will follow CPM’s identification of cultural, gendered, and
motivational criteria as shapers of disclosure in considering serostatus disclosure among Kenyan
PLHAs. Exploration of motivational criteria will also be informed by investigations outside of
CPM that consider reasons for and against disclosure in the U.S. context. The study will also
incorporate an investigation of how these criteria operate within specific relational contexts.

Third, the investigation will explore disclosure strategies, an issue that few models
besides CPM even address, but which is important with respect to HIV/AIDS diagnosis
disclosure. With methods of disclosure being by far the least studied aspect of diagnosis
disclosure, and with no investigations of the topic seemingly available in the sub-Saharan
c context, that aspect of the study will of necessity retain an exploratory stance; a preliminary
understanding of what issues are most salient to self-disclosure strategy is required before theory
testing can be conducted. However, the division of communicative strategies into direct and
indirect is a useful one for the Kenyan setting. As this investigation centers on differences in
disclosive patterns between relationships, whereas the micro-level component of CPM was
developed for ongoing marital relationships only, I have also incorporated relational-level
components from politeness theory. A description of aspects of that theory relevant to this
investigation is provided in the discussion of African communication patterns below.

CPM and indeed most self-disclosure theory, has been applied only in North American
settings. Although it admits cultural influences as one among several influences on the creation
of boundary rules, CPM does not make specific predictions regarding how culture will impact self-disclosure. There is, in fact, a gaping hole not only in CPM, but in disclosure literature in general with respect to privacy and sharing of the self in cultures outside of North America. Thus I turn at this point to review what is known about self-disclosure outside of the North American cultural milieu in order to lay a foundation for predictions regarding self-disclosure in Africa later in the chapter.

Cross-Cultural Research on Self-Disclosure

In contrast to the plethora of studies on self-disclosure in the U.S. published since the 1970s, research on disclosure in other cultures is rare (Greene et al., 2003; Yep, 2000). Some research highlighting cultural disclosure criteria of different U.S. co-cultural groups has been published (e.g. Stein, et al., 1998), but investigations of disclosure patterns outside of North America, are nearly non-existent. The few existing cross-cultural investigations of self-disclosure have turned up a number of contrasts between cultures in terms of the amount of information individuals are willing to share about themselves. For instance, Australians reported disclosing more (Cunningham 1981), and Germans less (Plog, 1965), than Euro-Americans, although the difference between German and Euro-American disclosure levels disappeared in the context of intimate relationships. A recent comparison of self-disclosure in the U.S. and Argentina found that participants from Argentina reported higher disclosure levels overall than those from U.S., albeit with some differences by topic (Horenstein, Diaz-Peralta, and Downey, 2003). Lower disclosiveness has been reported among Japanese, Chinese, and Taiwanese than U.S. Americans (e.g. Chen, 1995; Ting-Toomey, 1991) including those of African or Hispanic descent (Gratch & Bassett, 1995). Asian Americans who are more fully integrated into U.S. society have been found to disclose at higher levels than those who are less integrated (Barry, 2003). Even within
the U.S., it is clear with respect to HIV serostatus disclosure that norms vary among co-cultural
groups, with several studies indicating the Euro-Americans may disclose a positive diagnosis
more freely than other ethnic groups (Marks, et al., 1992; Mason, Marks, Simoni, Ruiz, &
Richardson, 1995; Simoni et al., 1995).

However, research findings have not been fully consistent. Other investigations have
uncovered no substantial difference between Korean (Won-Doornink, 1991) and Chinese (Rubin,
et al., 2000) disclosure levels as compared to those of Western nations and no variance in
responses between Japanese and Euro-Americans to differing disclosure levels (Nakanishi &
Johnson, 1993). It has been suggested that the general trend in evidence toward higher
disclosiveness among Western than Eastern cultures (Gudykunst, 1986; Hastings, 2000) may be
attributable in part to the value placed by Euro-Americans on individual autonomy, which
naturally leads to interpersonal communication patterns that privilege expressiveness and
assertiveness (Rubin, et al., 2000). On the other hand, the finding that Argentineans, who are
assumed to be collectivist in orientation (Hofstede, 1980), reported disclosing more than
presumably individualistic participants from the U.S. (Horenstein, et al., 2003) may point toward
additional factors at play.

Much of the research cited above employs versions of Jourard’s (1972) original
instruments that measure likelihood of disclosure across topic and target. However, a few
scholars have suggested rather than comparing the amount of disclosure across cultures, more
insight may be gained through studying its meaning and functions. For instance, Goldsmith
(2000) argues that because in U.S. culture that which is unique in a person is assumed to play a
greater part in motivating thoughts and behaviors than that which is cultural, individuating
information that is obtained primarily through self-disclosure becomes especially valuable. Self-
disclosure is then used as a primary means of reducing uncertainty about one’s interlocutor (Berger & Calabrese, 1975). Among other, more collectivistic, cultures, she suggests this may not be the case. Findings by Sanders, Wiseman, and Metz (1991) provide some support for this notion. Comparing Euro-Americans and Ghanaians with respect to functions of self-disclosure, they found that the Euro-American sample depended on self-disclosure to reduce uncertainty in interactions, presumably because they anticipated conversational partners would reciprocate. Ghanaian students, on the other hand, did not depend on self-disclosure for uncertainty reduction at all.

In a different vein, Baxter & Sahlstein (2000) point out that although from a Euro-American individualistic orientation, self-disclosure has been seen as in opposition to privacy/secrecy, there may be other ways to construe the dialectic. They were referring to dilemmas involved in the disclosure of HIV test results, but other possibilities come to mind. Hastings (2000), for example, concluded that whereas Euro-Americans privilege the autonomous self and downplay the social order through self-disclosure, Indian interviewees seemed to privilege the social order and downplay the self through self-concealment: “Whereas American friendship is enacted through expressing oneself, Indian friendship is enacted through suppressing oneself” (p. 105). Indian graduate students whom she interviewed practiced what she termed a self-suppression ritual, in which they contemplated the effect of anticipated disclosures on family or society and frequently afterward decided to suppress their thoughts so as not to disturb the social fabric. Furthermore, in contrast to the presumption in Western theorizing that the recipient of self-disclosure is the immediate hearer(s), in Indian culture absent participants appeared to be critical to the choice between disclosure and suppression. That is, Indian graduate students contemplated what their family or other significant others might think before they made
personal information known. In such an environment, we might reasonably set self-disclosure not in contradiction to privacy, but to social concern.

These last examples illustrate the necessity in cross-cultural investigations of throwing wide open the doors of disclosure theory and allowing the winds of culture to blow about and ruffle conventional wisdom. When it comes to self-disclosure in African societies it is especially difficult to predict the results of such an airing, because studies in that context are rarest of all.

Self-Disclosure of HIV Status in Sub-Saharan Africa

As indicated in chapter one, this study is designed to accomplish two intertwined tasks. First, it attempts to uncover critical information regarding the who, why, and how of HIV serostatus disclosure among PLHAs in Nairobi, Kenya, with the goal of providing information that can inform HIV/AIDS-related interventions in that environment. Second, it endeavors to integrate findings regarding self-disclosure into the corpus of intercultural communication literature. Both tasks are challenging, in part for a similar reason. The understanding of the psychological and social correlates of the HIV/AIDS epidemic began with investigations conducted in North American contexts. As a result, cultural artifacts of that environment have been at times mistaken for universal behavioral patterns related to the epidemic. With the immense outpouring of funding for research on HIV/AIDS in sub-Saharan Africa, many early misconceptions have been noted and the challenge issued and taken up to develop a truly indigenous understanding of the circumstances surrounding the spread of the pandemic (e.g. Airhihenbuwa, 1995; Kalipeni, et al., 2004; Obregon, 2003). Undoubtedly errors in perception remain, but progress has been made.

The challenge of correcting North American bias in intercultural and interpersonal communication theory is less abundantly funded by far, and reasonably seen as not so urgent a
matter. But for all that the problem is real, and particularly with respect to communication patterns in Africa. Whereas the continent is home to around 15% of the world’s population, it was the site of just 3 to 7% of research reports in selected interculturally focused communication journals over the past ten years (Miller, 2005), with nearly half of those articles reporting on communication in a single African nation, South Africa. Similarly, a recent examination of the national diversity of 43 major communication journals (Lauf, 2005) found eighty-six percent of authors of articles from 1998 to 2002 in the selected journals were from the U.S., U.K., Canada, and Australia; 3.1 percent were from East Asian nations; no African nations made the list of top 20 publishing countries. Intercultural communication journals were, incredibly (in more than one sense perhaps), least diverse of all those analyzed. Virtually all etic (Pike, 1966) structures employed in intercultural communication research derive from investigations by Western scholars, with a few Eastern alternatives also available (e.g. Chinese Culture Connection, 1987; Kincaid, 1989). African-originated candidates for universal structures are limited as this time to the concept of *nommos* propounded by afrocentric scholars (Asante, 1987; Jackson, 1999). To this author’s knowledge that construct has yet to be operationalized in a single comparative empirical study.

This dearth of research on African communication is reflected in the paucity of literature regarding self-disclosure in that context. Research related to the HIV/AIDS pandemic has begun to turn up a few answers to questions about serostatus disclosure patterns, but much remains unknown. Additional inferences must be drawn from general descriptions of African values and communication. In this section commonly mentioned qualities of African communication will be discussed, and implications for the operation of self-disclosure in African societies proposed, with specific findings from HIV/AIDS research integrated when available.
Talk About Sex as Taboo

Because of its implications for conducting research on STDs in Africa, I will begin my discussion of African values with consideration of the appropriateness of talking about sex in the African context. Unlike in U.S. society, where frank talk about sex has, at least for the last 40 years or so, been viewed as an ideal (Byers & Demmons, 1999; Herold & Way, 1988; Whitaker, Miller, May & Levin, 1999), in many sub-Saharan African societies open discussion of sex and sexually transmitted diseases is socially discouraged. This is especially the case between adults and youth (Nduati & Kai, 1997). The major exception to this prohibition occurs during rites of passage, which have typically been conducted by non-parental adults. This traditional means of sex education, however, is no longer in place in many Kenyan ethnic groups, and unfortunately no widespread alternative has yet arisen (Kebaabetswe & Norr, 2002; Kesby, 2000; Mbugua, 2004; Tlou, 2002; Williams et al., 1997). In a survey of Kenyan high school students, Mbugua (2004) found that teens were extremely uncomfortable talking with parents about sex. The major adult figures from whom they gathered information about HIV/AIDS were teachers, and the primary adults to whom they turned for personal discussion of sexual issues were same-sex relatives. Similarly, an earlier survey of adolescent girls found that 53% did not confide in anyone regarding their first coitus, 31% confided in a girlfriend, 7% in a sister, 5% in their mother, and 2% in an aunt (Yuri, 1994).

African cultural taboos also make it difficult for partners to discuss sexual issues with one another (Kebaabetswe & Noor, 2002; Kesby, 2004; Lie & Biswalo, 1996), and stigmatization associated with sexually transmitted disease exacerbates the situation (Moss, Bentley, Maman, Ayuko, Egessah, et al., 1999). Although there are apparently no studies directly comparing the amount of disclosure by PLHAs in Africa to that of PLHAs in the U.S., a study by Bungener,
Marchand-Gonod, and Jouvent (2000) that investigated disclosure patterns among European and African HIV-positive women living in France found that the European women were more willing than the African women to disclose to both family and friends. “We have no language to talk candidly about sex,” one interviewee from South Africa explained to a journalist, “so we have no civil language to talk about AIDS” (McGeary, 2001, p. 40).

An absolute taboo on discussion of sexual issues would, of course, bode ill for AIDS-related research in the African context. However, the results of numerous focus group studies (e.g. Bailey, Muga, Poulussen, & Abicht, 2002; Hart, Pool, Green, Harrison, Nyanzi, et al., 1999; Kaler, 2004; Kesby 2000; 2004; Lugalla, Emmelin, Mutembei, Sima, Sweisigabo, et al., 2004; Moss, et al., 1999; Nabaitu, Bachengana, & Seeley, 1994; Nyanzi et al., 2000) and ethnographic research (e.g. Dilger, 2002; Gysels, Pool, & Banika, 2001; Hollos & Larsen, 2004; Kaler, 2004; Lugalla et al., 2004; McGrath, Schumann, Pearson-Marks, Rwabukwali, Mukasa, et al., 1992; Nzioka, 1996) reveal a remarkable openness, in practice, to addressing of sex-related concerns. My experience in conducting key informant interviews on HIV/AIDS in the first stage of this project confirmed that within the Kenyan context, most people are not at all reticent to speak to an unknown researcher of sexual issues. The explanation for the discrepancy between reticence to speak about sexual activity in interpersonal conversation and in research studies may lie in Holtgraves’ (1990) distinction in the level of the speaker’s identification with the action, that is, “the extent to which the action is described in a way that is self-defining” (p. 194). When a conversation has an intellectual or objective tone, a speaker may be able to talk about topics that would be anathema when a higher level of personal ownership is involved (Hastings, 2000). The difference may also result from the distinction between sharing one’s personal life with those one sees on a continuous basis, as opposed to the freedom one may sense to reveal personal data to
an individual whom one is unlikely ever to encounter again. In either case, it appears that
gathering this sort of sensitive data for research purposes can be accomplished in the Kenyan
context.

Collectivism

African cultures are considered to be collectivistic as opposed to individualistic
(Gudykunst, 1998; Hofstede, 1991; Kenyatta, 1965; Mbiti, 1970; Moemeka, 1996; Olaniran and
Roach, 1994; Onwumechili, 1996). Some African scholars have cited this as the defining quality
of the African mindset (Gyekye, 1997). In collectivistic cultures, according to Hofstede (1980,
1991), people draw the greatest portion of their identity from the ingroup, which is the only
protection against the hardships of life. Breaking the lifelong loyalty owed to the group is one of
the worst things a person can do. Kenyan freedom fighter and later first president, Jomo
Kenyatta (1965), writing during the colonial era, observed regarding his own Kikuyu culture in
central Kenya, “. . . The personal pronoun ‘I’ was used very rarely in public assemblies. The
spirit of collectivism was [so] much ingrained in the mind of the people” (p. 188). The
outworking of this value orientation in communication means personal matters, no matter how
urgent they may seem, must be postponed if they are in conflict with the needs of the
community. As Moemeka (1996) explained:

If what a person has to say is not in the best interest of the community, the person would
be bound by custom to ‘swallow his (or her) words.’ Of course, the affected individual
may whisper complaints into the ears of those who may be able to help in such other
ways that would not conflict with community interest (pp. 202-203).
An inevitable corollary to African collectivism is the severity of sanctions imposed on those who fail their obligations to the community (Long, 2000; Mbiti, 1970). “This corporate type of life,” asserted Kenyan writer John Mbiti (1992):

. . . makes every member of the community dangerously naked in the sight of the other members. It is paradoxically the center of love and hatred, of friendship and enmity, of trust and suspicion, of joy and sorrow, of generous tenderness and bitter jealousies (p. 209).

African societies have typically not only subjected the individual offender to jeering and criticism, but have castigated his or her family, too, in an attempt to convince loved ones to force their stray member to return to a proper lifestyle. The guilt and stigma of an individual is not his/hers alone, but is shared by the entire household (Moemeka, 1996).

Stigmatization of PLHAs in Kenya, as in the bulk of sub-Saharan Africa (see Banteyerga, Kidanu, Nyblade, MacQuarrie, & Pande, 2004; Nyblade, Pande, Mathur, MacQuarrie, Kidd, et al., 2004), is by some accounts severe. As in the U. S., the possibility of being stigmatized looms as probably the largest risk factor PLHAs weigh when calculating whether or not to reveal their HIV status to others. In a study of lay explanations of the pandemic, Rugalema (2004) concluded that many Africans who died suffered in silence, without ever disclosing information on the possible source of their HIV infection for fear of the social consequences. An eight month longitudinal study conducted in Western Kenya of twelve persons living with AIDS, both male and female, found that PLHAs were afraid that if the nature of their disease were known they would be even more isolated because many community members believed AIDS was a curse resulting from the immorality of the sufferer. Some asked the field worker, who had become their most important friend, to visit them only at night under cover of darkness (Kiiti et al. cited
in Long 2000). The authors of that study conceptualized stigma as operating in concentric circles, such that the PLHA in the innermost circle was most stigmatized, but PLHA families who cared for their member and guarded his/her secret when possible were also somewhat stigmatized when the cause of the PLHA’s ill health became known.

In an extensive study on stigma and HIV in Ethiopia, Tanzania, and Zambia, Nyblade and her colleagues (2004) found that although in the eyes of the communities they studied, people with HIV appeared to acquire a responsibility to disclose their status and teach others how they got the disease, most participants confessed they themselves would be unable to do so. Even talking about or obtaining HIV tests (Banteyerga, et. al., 2004; Day, Miyamura, Grant, Leeuw, Munsamy, et al., 2003; McGearry, 2001; Nyblade et al., 2004), or attending an HIV support group (Issiaka et al, 2001; Nyblade et al., 2004) have been described considered to be potentially stigmatizing. Many people indicated they would not even get tested until they themselves or their partner became manifestly ill (Maman et al., 2001).

Women in Uganda reported concerns that if they tested HIV-positive they would be kicked out of their homes and left with no means of livelihood (Pool, Nyanzi, & Whitworth, 2001), and in fact HIV-positive women with uninfected partners have in at least one study been found to be more likely to experience separation or divorce than other women (Porter, Hao, Bishai, Serwada, Wawer, et al., 2004). It should be noted, however, that among participants in Grinstead and associates’ (2001) longitudinal three-nation study, attending HIV prevention services did not overall result in high rates of negative life events as compared to persons in a control group who received basic health information. Seropositive women were slightly more likely to report the break-up of a marriage, but even among them such events were rare. Another longitudinal study, in Zambia (Siwale et al., 2003) found that not only did mothers in an ante-
natal clinic who disclosed to their partners not experience significantly more incidences of separation of physical abuse, but in fact they were more likely to report a strengthening of the relationship with their partner following disclosure that did seronegative women.

The hierarchy of preferred disclosure targets in sub-Saharan Africa appears to be different than in the U. S., where the most frequent recipients of HIV disclosure are friends and partners, followed by members of nuclear family, then extended family, and finally the general public (Greene et al., 2003; Greene & Serovich, 1996; Hays et al., 1993; Mansergh et al., 1995; Perry et al., 1990; Serovich & Greene, 2001; Stemptel et al., 1995; Wolitski et al., 1998. Note: some studies among African American females have found them to disclose to parents more often than friends or partners, Armistead, et al., 1999; Sowell et al., 1997). Rather than identifying a friend as the most likely confidant regarding their positive serostatus, 93% of Tanzanian participants in Lie and Biswalo’s (1996) study selected a family member, usually of the same sex and generation as themselves. Similarly among PLHAs on HAART in Nigeria partners were the first disclosure target of choice, followed by close family members (Daniel, Falola, Ogundahunsi, Ogun, Odusoga, et al., 2004). Antelman and associates (2001) also found that women who had already disclosed to a female relative were less likely to reveal their status to their partner. And whereas 62% of Namibian participants in Chatterjee and Murray-Johnson’s (2005) investigation had disclosed HIV-test results (either positive or negative) to partners and 55% to family members, only 32% had revealed their results to friends. Among MacNeil and associates’ (1999) participants, parents were the most likely target of positive diagnosis disclosure and participants reported an increase in support over time, leading the authors to conclude that acceptance of HIV-positive persons, particularly by family, was important in establishing a sense of support in the first few months post-diagnosis.
On the other hand HIV-infected women in Issiaka and associates’ (2001) study, while reporting a low (33%) rate of disclosure to partners, indicated even lower rates of disclosure to other significant persons in their lives. The researchers concluded that infected women in Burkina Faso may find it difficult to reveal their status to relatives because they do not dare risk the loss of family support that might attend the knowledge of their positive status.

Although past research does not uniformly support the conjecture that ownership of HIV serostatus information is likely to be familial (e.g. Banteyerga, Aklilu, & Nyblade, 2003), the balance of data appears to support that supposition. These findings regarding disclosure of HIV status to family members, in conjunction with more general communication patterns associated with collectivism in African societies (Moemeka, 1996) lead to the first of the study hypotheses regarding relationship types and disclosure:

H1: Family members will be listed more often among early disclosure targets than will friends.

There is virtually no data available regarding reasons PLHAs might have for concealing or revealing their status from family members, but based on the above literature we might conjecture that they may believe they can count on family to take them in whatever happens, whereas friends may not be seen as so trustworthy. Thus the following hypotheses are advanced:

H2: Disclosure to family members will be more strongly motivated by seeking a) emotional support and b) material support than will disclosure to friends.

H3: Disclosure to family members will be less strongly motivated by knowledge that the disclosure target is HIV+ than will disclosure to friends.

H4: Nondisclosure to non-family members will be more strongly motivated by a) right to privacy and b) fear of rejection than will nondisclosure to family members.
At the same time because the family network is so tight, PLHAs may choose not to disclose to family members so as to spare them the pain, as well as the stigma, that accompanies a positive HIV diagnosis. Therefore:

H5: Nondisclosure to family members will be more strongly motivated by other-focused reasons than will nondisclosure to friends.

Finally, a research question regarding identity of disclosure targets is posed:

RQ1: To what category of relationship will PLHAs most often report disclosing serostatus among early disclosure targets?

*High Power Distance*

Another pervasive cultural value in African societies is that identified by Hofstede (1980) as “high power distance,” or the view that differences in status among community members are natural and desirable. In contrast to the egalitarianism that is central to the Euro-American value system, in high power distance societies (such as those typical of the sub-Sahara), titles, ceremony, and other outward displays of power are valued (Olaniran & Roach, 1994). Role-determined behavior, which is dismissed in much disclosure literature as empty and impersonal communication (Parks, 1982), may in fact be central to personhood and societal functioning in such cultures.

In the family, for instance, respect and deference to parents and older relatives is a lifelong obligation. Children are not expected to make their own decisions or contradict those of their elders. In Kenyan families the power hierarchy is clearly delineated: the father is the supreme authority, followed by the mother and then frequently the oldest child (Miller, 2002). To directly question the word of the father in many families is unthinkable. When children begin school, their relationship to their teachers is similar to what they have with their parents. In
Kenyan primary school classrooms, the teacher is an authoritative figure who displays less nurturing behavior than in a similar classroom situation in many Western nations (Maleche, 1997). In the workplace, a lower level worker may feel uncomfortable ever directly addressing injustice by a superior unless there is a groundswell of popular dissent behind him/her. Even then the more likely method for redressing a grievance at work would be to approach the authority figure indirectly with hints, or through an intermediary (Moemeka, 1996).

Moemeka (1996) described the implication of this orientation for African communication:

In Africa, vertical communication follows the hierarchical sociopolitical ranks within the community. What a person says is as important as who he or she is. In other words, social statuses within the community carry with them certain cultural limitations as to what to say, to whom to say it, how to say it, and when to say it. On the other hand, horizontal communication is relatively open and usually occurs among people of the same age (sometimes, only of the same sex), those who work together, live in proximity, or belong to the same ethnic group. . . . Although elders in Africa have the right to communicate mostly verbally, young children and youths in general are, by tradition, expected to communicate mostly nonverbally (pp. 200-201).

Given this underlying value, some features of disclosure that have emerged in U.S. research might be modified in the African context. For example, the principle of reciprocity of self-disclosure might be of limited usefulness, relevant only to relationships that are clearly horizontal. Disclosure to persons of higher status, particularly those who are older, would not be reciprocal, and they might require more indirect, less verbal approaches than disclosure to persons of one’s own social status.
A substantial amount of investigation has, in fact, taken place regarding differences in conversational directness between persons from collectivistic societies (or individuals with interdependent self-construals) and persons from individualistic societies (or individuals with independent self-construals). Because by definition persons from collectivist societies are more likely to be concerned with harmony in the group, they may often use indirect means of communication so as to avoid hurting the hearer’s feelings, or to preserve their face (Gudykunst, Matsumoto, Ting-Toomey, Nishida, Kim, et al., 1996; Holtgraves, 1997; Kim, 1995; Markus & Kitayama, 1991; Singelis & Brown, 1995; Triandis, 1995). “For those with interdependent self-construal, sensitive perception of other’s perspective and flexible adaptation to the social requirements are necessary for their smooth human relations” (Hara & Kim, 2004). However, as Hara and Kim (2004) point out, sensitivity to the other and ready adaptation do not mean that persons in collectivist societies suffer from chronic communication apprehension or lack of assertive communication skills. Among collectivists, stating a message indirectly may be a sign of strength, self-control, and communicative competence rather than being a sign of communication apprehension. Nor does use of indirectness automatically introduce ambiguity. Indirect remarks formulated according to conventional patterns will be readily understood (Holtgraves, 1994). Finally, to strive for harmony among collectivists does not mean that their communication is always indirect. Indirectness may differ across relationship types and situations.

Although CPM limits itself to only one relationship type in its explanation of indirectness, one framework that claims to operate across relationship types and to cross-cultural in scope, is politeness theory (Brown & Levinson, 1978; 1987). Brown and Levinson’s framework identifies indirectness as the major sociolinguistic feature indicative of tending to
matters of face, and suggests that culturally appropriate levels of indirectness can be predicted by
the relational variables of power and social distance, plus the situational variable of magnitude of
interpersonal imposition. Although the relative weights of these factors in determining levels of
politeness in different cultures might vary, once those weights are taken into account a speaker’s
social cognitions may be revealed through how he or she chooses to communicate the same
information to different individuals (Gonzales, Manning, & Haugen, 1992; Holtgraves & Yang,

Unfortunately, most investigations of politeness theory have been limited to the speech
acts of requesting, inviting, or complimenting (Craig, Tracy, & Spissak, 1986; Pan, 2000;
Wilson, Kim, & Meischke, 1991). Some application has been made to advice giving (e.g.
Goldsmith, 2000), compliance gaining (e.g. Baxter, 1984; Wilson, Aleman, & Leatham, 1998),
persuasion (O’Keefe & Shepherd, 1987), negotiation (Wilson & Putnam, 1990), and courtroom
discourse (Penman, 1990), among other issues. Appropriateness of politeness theory to the study
of self-disclosure is not well established (although see Schimanoff, 1987).

A model in the tradition of politeness theory that addresses politeness phenomena across
interaction types is available in Scollon and Scollon’s (1995) analysis of Athabaskan
communication. The authors locate three overarching politeness systems: solidarity (used among
persons who see themselves as equal in power and close in social relations and therefore
comprised of direct communication with one another), deference (used when persons are equal in
power but want to emphasize differences using indirectness) and hierarchical (used in
asymmetrical relationships where persons on the top use direct communication and subordinates
use indirect). The appropriateness of this framework to African contexts cannot, of course, be
assumed (in fact, Gough, 1995, raised questions about the applicability of certain aspects of
politeness theory to some African cultures), but it does raise the possibility that indirectness may operate across speech acts within certain relational systems.

In addition to indirectness, the African pattern of communication elucidated by Moemeka (1996) contains an element related to what this paper will term “intermediated communication,” referring to disclosure that takes place by use of an informal interpersonal intermediary. The use of intermediaries, formal vs. informal, has long been acknowledged as distinctive in some cultures (Condon & Yousef, 1977), but the idea has attracted very little attention in intercultural communication literature in the three decades since, particularly as an etic variable on which various cultures might be compared. There is some evidence, particularly in qualitatively oriented research, that use of third party intermediaries in health and interpersonal communication is a phenomenon that appears with regularity in a variety of cultures (e.g. Kenen, Arden-Jones, & Eeles, 2004; Muira, 2000). In U.S.-based HIV research this concept is most closely approximated in the explanation by Greene and her colleagues (2003) of mode of disclosure, a category that encompasses whether a person discloses face-to-face, non-face-to-face through a letter or email, or via a third party. In those rare instances in which third party disclosure is mentioned, it is primarily as the violation of a discloser’s privacy by leaking of information by a confidant. In many African cultures, however, third parties are used frequently and intentionally to disclose personal information.

Although it may be tempting to view intermediated communication as an extreme form of indirectness, the two are more profitably seen as orthogonal dimensions with four possible combinations: 1) face-to-face/direct communication (Jane tells her father, “Dad, I am HIV-positive”); 2) face-to-face/indirect communication (Jane hints to her father that she has not been feeling well lately); 3) intermediated/direct communication (Jane requests her mother, “Could
you please be the one to tell Dad I’m HIV-positive?”); 4) intermediated/indirect communication
(Jane hints to her mother that her father may not be aware of certain changes in her life lately,
such as her repeated infections and her volunteer work for an HIV/AIDS advocacy group).

Although there is little explicit guidance available in literature that would enable
confident prediction of indirectness and intermediation of disclosure among Kenyan PLHAs,
based on politeness theory, the following hypothesis is advanced:

H6: Persons of higher status than PLHAs will be more likely, relative to persons of equal or
lower status, to be the targets of (a) indirect disclosure and (b) intermediated
communication, than will low or equal status disclosure targets.

Bearing in mind statements in both CPM and politeness theory regarding the impact of
closeness on indirectness, I also posit the following regarding the relationship of closeness of
relationship to disclosure strategy:

H7a: A mathematical function of participants' reported closeness to their disclosure targets
will discriminate disclosers who used indirect strategies from those who used direct
communication when disclosing their serostatus to those targets. The function will
reflect a positive relation between closeness and the disposition to disclose directly.

H7b: A mathematical function of participants' reported closeness to their disclosure targets will
discriminate disclosers who used indirect strategies from those who used face-to-face
communication when disclosing their serostatus to those targets. The function will
reflect a positive relation between closeness and the disposition to disclose face-to-face.

In addition to the influence of relational closeness and comparative social status, the type
of relationship—whether family, friend, or sexual partner—may also be related to disclosure
strategy. The close family system provides a ready network of communication channels, some of
which may be intermediated. This makes it likely that PLHAs would use intermediated communication more with family members than with non-family members. Thus hypothesis 8 states:

H8: Disclosure to family members will be more strongly motivated by seeking intermediation than will disclosure to non-family members.

CPM also suggests that risks of disclosure and need for disclosure will also influence indirectness in disclosure strategy, although it does not specifically indicate how that influence will be manifested. Therefore two more research questions were investigated:

RQ2: Will motivations for disclosing HIV status (duty to inform, catharsis, test other’s reaction, close and supportive relationship, similarity, intermediation) predict whether or not a disclosure is (a) indirect and (b) intermediated?

RQ3: What types of disclosure strategies will be most characteristic of each relationship target?

Finally, although it appears that motivations for nondisclosure differ between male and female PLHAs, no data are available on how they differ in terms of strategies for disclosure. Therefore another research question is posed:

RQ4: How will female and male PLHAs differ in terms of (a) indirectness and (b) intermediation of disclosure strategies to partners?

Gender Roles

Because HIV is primarily a heterosexual disease in Africa, gender, rather than sexual orientation, is a likely criterion of privacy rule foundations surrounding HIV/AIDS in most of sub-Saharan Africa. As noted above, differences in levels of self-disclosure between men and women in the U.S. context have generally been found to be small (Dindia, 2000; Dindia & Allen, 1992), although Derlega, Winstead, Oldfield, and Barbee (2002) found a few gender-based
differences in motivations for disclosure of HIV serostatus. Females were more likely than males to endorse catharsis and testing other’s reactions as reasons for disclosing to friends, testing the other’s reactions as a reason for disclosure to an intimate partner, and similarity as a reason for disclosing to a parent. Regarding nondisclosure, the same study found females were more likely than males to endorse self-blame/self-concept difficulties and protecting the other as reasons for not disclosing to parents. Females were also more likely to cite fear of rejection as a reason for nondisclosure to intimate partners.

Strictly delineated gender roles with respect to sex in many African cultures (Akeroyd, 2004; Esu-Williams, 2000; Esu-Williams & Blanchard, 2002; Kesby, 2004; McGrath et al., 1992; Rugalema, 2004) appear to result in different self-disclosure rules between men and women. Men in Tanzania, for instance, reported being little concerned with anticipating their wives responses to news of their HIV status (Maman et al., 2001). Among urban Nigerian women, in contrast, only 30% dared confront their husbands with questions concerning extramarital sexual relationships, although they knew that husband’s behavior put them at risk for AIDS and other diseases (The percentage willing to question their husbands’ fidelity was higher among women in rural areas who the researcher concluded were more protected by the buffering effect of collectivism through the extended family and so less vulnerable to unilateral decisions of husbands, Orubuloye et al., 1997 cited in Long 2000).

Respondents in focus groups comprised of female HIV peer educators in Zimbabwe stated that poor communication between couples on sexual issues made articulation of desires extremely difficult in their own private lives (Kesby, 2004). Decisions regarding sex were seen as falling within the man’s purview, and couples who had mutually negotiated, pleasurable and loving sexual relations were thought to be in the minority. Discussing HIV with partners was
rarely attempted (Kesby, 2004). Women in Burkina Faso gave as reasons for not disclosing to their partners fear of rejection and negative financial consequences (Issiaka et al., 2001). Accordingly, Hypotheses 9 and 10 are advanced with respect to gendered criteria for disclosure:

H9: Nondisclosure will be more strongly related to fear of rejection among female PLHAs than among male PLHAs.

H10: Disclosure will be more strongly motivated by seeking material support among female PLHAs than among male PLHAs.

H11: In comparison to female PLHAs, male PLHAs will be more likely to report at least one sexual partner among early disclosure targets.

Restatement of Hypotheses

Thus far this chapter has organized the hypotheses and research questions above in accordance with the African values that give rise to them. However, they might as easily be organized with respect to targets, methods, and motivations for disclosure, and that arrangement will be more congruent with the statistical analyses required to test them. The alternative organization of hypotheses appears in Table 1 below.

Table 1

Restatement of Hypotheses

<table>
<thead>
<tr>
<th>Targets</th>
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<tbody>
<tr>
<td>H1: Family members will be listed more often among early disclosure targets than will friends.</td>
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<tr>
<td>H11: In comparison to female PLHAs, male PLHAs will be more likely to report at least one sexual partner among early disclosure targets.</td>
</tr>
</tbody>
</table>
RQ1: To what category of relationship will PLHAs most often report disclosing serostatus among early disclosure targets?

Motivations

H2: Disclosure to family members will be more strongly motivated by seeking a) emotional support and b) material support than will disclosure to friends.

H3: Disclosure to family members will be less strongly motivated by knowledge that the disclosure target is HIV+ than will disclosure to friends.

H4: Nondisclosure to non-family members will be more strongly motivated by a) right to privacy and b) fear of rejection than will nondisclosure to family members.

H5: Nondisclosure to family members will be more strongly motivated by other-focused reasons than will nondisclosure to friends.

H8: Disclosure to family members will be more strongly motivated by seeking intermediation than will disclosure to friends.

H9: Nondisclosure will be more strongly motivated by fear of rejection among female PLHAs than among male PLHAs.

H10: Disclosure will be more strongly motivated by seeking material support among female PLHAs than among male PLHAs.

RQ2: Will motivations for disclosing HIV status (duty to inform, catharsis, test other’s reaction, close and supportive relationship, similarity, intermediation) predict whether or not a disclosure is (a) indirect and (b) intermediated?

Methods

H6: Persons of higher status than PLHAs will be more likely, relative to persons of equal or lower status, to be the targets of (a) indirect disclosure and (b) intermediated communication, than will low or equal status disclosure targets.

H7a: A mathematical function of participants' reported closeness to their disclosure targets will discriminate disclosers who used indirect strategies from those who used direct communication when disclosing their serostatus to those targets. The function will reflect a positive relation between closeness and the disposition to disclose directly.
H7b: A mathematical function of participants' reported closeness to their disclosure targets will discriminate disclosers who used indirect strategies from those who used face-to-face communication when disclosing their serostatus to those targets. The function will reflect a positive relation between closeness and the disposition to disclose face-to-face.

RQ3: What types of disclosure strategies will be most characteristic of each relationship target?

RQ4: How will female and male PLHAs differ in terms of (a) indirectness and (b) intermediation of disclosure strategies to partners?

In summary, prior research on serostatus disclosure and on self-disclosure in general in sub-Saharan Africa suggests that patterns of revealing and concealing a positive HIV diagnosis may differ from those of the U.S. in terms of number and identity of confidants as well as gender and motivational differences in disclosure, among other issues. However, these findings are derived from studies conducted in a variety of nations and cultures, and generalization to the rest of the continent is risky. Furthermore, conclusions regarding self-disclosure of HIV/AIDS serostatus are most frequently derived from single items in larger studies, studies that tend to neglect potential communication variables relevant to disclosure. In particular, reasons for disclosing a positive diagnosis and strategies for doing so are little explored. Based on the theoretical framework provided by Communication Privacy Management theory, this study aims to elucidate how disclosures related to HIV/AIDS actually do take place within Kenyan cultural environments. That is, it will attempt to distinguish rule-based management systems shaping disclosure practices of Kenyan PLHAs. An understanding of these issues will not only contribute knowledge of the most effective means of helping PLHAs manage their own private information and social support, but also facilitate discussion on HIV-related issues among families and communities. In these ways, it is anticipated that this study will
advance theories of self-disclosure, further the study of intercultural communication, and provide knowledge that can be useful in the battle against HIV/AIDS in sub-Saharan Africa.
CHAPTER 3

METHODOLOGY

International researchers are by no means immune to the affliction of ethnocentrism. Like anyone who traverses cultural boundaries, they are inclined to view their new environment through the lens of their own cultural assumptions, a lens that may go unnoticed, but that colors everything they see including their choice of research methods and measures. That cultural coloring is, of course, another name for bias. In intercultural research three types of biases are particularly common (Van de Vijver, 2001). 1) Construct bias is responsible for errors in which the construct measured is not identical across cultural groups, so that behaviors that constitute the domain of interest in one culture may leave important aspects of the concept not addressed in another (in other words the researcher ends out unknowingly comparing apples to oranges). 2) Method bias is comprised of errors arising from sources like instrument characteristics, tester and interviewer effects, and differences in social desirability of response across cultures. 3) Finally, item bias arises in situations in which specific items in an instrument favor certain cultural groups over others (also called item differential functioning).

The challenge for the present study was to integrate methodological wisdom from the substantial literature on serostatus disclosure in the U. S., and at the same time innovate where necessary in order to assure cultural appropriateness within the African setting. The review of literature in Chapter 2, has already made it evident that a wholesale importing of U.S.-developed instruments may introduce construct bias. Disclosure in the West may in a number of ways be a different phenomenon than disclosure in the sub-Sahara.
Methodological bias, too, is possible at virtually every step. Even beyond issues of accurate linguistic translation, a number of questions on this issue arise from the very outset of the project: Given the peculiarities of talk about sex in Sub-Saharan Africa, what is the impact of the gender of the interviewer? Would PLHAs in Kenya share freely with researchers about their condition? Are Likert-type scales an appropriate means of measurement?

Cultural bias might also easily be present in individual survey items, as lists inductively developed in the U. S. of potential disclosure targets, motivations for revealing and concealing a positive HIV diagnosis, or means of disclosure may well omit options that are common in Kenya but unknown in the U.S. cultural context, and vice-versa.

With such obvious complications besetting the scholar with U.S. research training, a great deal of groundwork was needed prior to embarking on the large study itself. Therefore the research was undertaken in three phases: (1) key informant interviews, (2) focus group discussions, and (3) structured interviews. The following section describes the steps taken to assure as much as possible a culturally appropriate study design.

Key Informant Interviews

Arriving back in Nairobi after a full two-year absence, I felt a strong need to initially explore issues related to the research project through conducting key informant interviews. Thus I arranged meetings with two HIV/AIDS counselors, one administrator and one field worker at a Nairobi-based HIV/AIDS intervention, three African university lecturers who had taught interpersonal communication courses, one pastor, the author/director of a locally produced HIV/AIDS-related drama, and two contacts who were intimately familiar with U.S. as well as Kenyan interpersonal communication patterns. Seven key informants were Kenyan; one of the university lecturers and the playwright were Ugandan; the field workers was Ethiopian; and the
administrator was a U.S. American who had lived all of his life in East Africa. Seven interviewees were female, and four male.

During my discussions with these eleven persons, I was struck by several issues. First, it was confirmed to me that a fair amount of day-to-day disclosure in the Kenyan environment, particularly on sensitive issues, appeared to take place indirectly and/or through intermediaries. In the course of one interview, in fact, I learned to my surprise that my husband, Jim, had inadvertently performed an intermediary communication function between the interviewee and his wife. (It seems that during a Bible study meeting that both couples attended the wife mentioned, apparently light-heartedly, that she hoped to have a third child even though her husband was convinced that their two healthy boys were sufficient. The husband realized what we direct Americans did not, that the statement was designed as an indirect appeal to the rest of the group to support her position. Unaware of the implications of his response, my husband jokingly prodded the man about how important it was for a father to have a little girl on whom he can lavish attention. The man contemplated these comments and concluded, “If this older man is advising me in this way, I need to give the idea more serious consideration.” A year later, when they became proud parents of a daughter, the couple thanked my husband as the person in a large measure responsible for her arrival. He was mystified until my interview happened to uncover the explanation.)

Other participants, including the communication lecturers, gave further examples of indirectness and intermediation between spouses, friends, and family members. One interviewee, when asked to verbalize rules for this sort of communicative technique offered an explanation that bore striking resemblance to aspects of politeness theory. The use of a go-between for
sensitive communication, he assessed, depends upon the closeness of the relationship between
two individuals, their relative social positions, and how sensitive the topic is.

In addition to providing information about general communication patterns associated
with disclosure, the key informant interviews also confirmed what I had already gathered from
studies cited above from various African nations, that the identity of disclosure targets for
PLHAs in the Kenyan context were likely to be different than in the U.S., with family in many
cases being more privileged than friends. They also revealed to me the first inklings of
distinctive disclosure techniques such as PLHAs asking their sexual partners to go together for
HIV/AIDS tests without revealing that they already knew themselves to be infected. Some of
these disclosure strategies then informed the prompts I provided within the focus group interview
schedule.

Focus Group Discussions

After getting a sense of the situation in Kenya I launched into the next phase of my
formative research. Because many questions remain unanswered about African disclosure
patterns in general and with respect to HIV/AIDS serostatus in particular, and following standard
technique frequently employed in formative stages of instrument development within health
communication (Morgan, 1997), focus groups were used to develop a culturally informed
understanding of issues related to disclosure from the point of view of the target group (Krueger,
1994).

Locations and Participants

Four focus groups of ten to fourteen persons each were conducted in cooperation with
three HIV/AIDS community development outreaches located in the Nairobi environs. Two focus
groups were composed of HIV-positive women; and two of HIV-positive men. One women’s
program is located in the Ongata Rongai peri-urban area just outside of Nairobi. Women in the project are of low socio-economic status, but make a wage at the center that places them above the poverty line. The second women’s program is near the heart of Nairobi, and was selected to provide a sample of women who were more wholly urban in their outlook. Participants there were of low to middle-class socio-economic status. The men’s focus groups were conducted at an urban intervention in the BuruBuru area of Nairobi, tapping urban participants of low to lower middle-class socio-economic status. All three locations are mixed ethnically.

Staff of the organizations identified persons from their programs who: 1) had known they were HIV-positive for at least two months, 2) were over 18 years old, 3) were judged by medical personnel to be physically and mentally able to provide reliable responses to focus group questions, 4) spoke either Swahili or English fluently, and 5) were willing to spend one to one-and-a-half hours discussing issues related to talking about a positive diagnosis of HIV (see Mansergh et al., 1995; Marks et al., 1992; 1992; Simoni et al., 1995, as justification for inclusion criteria). Staff at all three organizations indicated that rather than individual monetary payment, they wanted participants to be provided with refreshments, which was done.

Focus groups were held on the premises of the programs themselves in three cases, and in the fourth case at a local church where a support group sponsored by the organization met weekly. The groups were facilitated by research assistants of the same sex as the participants. Both lead research assistants were in their early 30s, and thus likely to neither intimidate younger participants nor have difficulty securing the respect of older participants. Both facilitators had lived extensively in both rural and urban environments so that they were comfortable interacting with participants from both types of backgrounds. The interview guidelines were initially formulated in English then translated into Swahili with back-translation into English to assure
accuracy (see Appendix A for English version). Participants were asked to choose whether they preferred the discussion to take place in English or Swahili; all groups ended taking place in a mixture of the two languages. Discussion in both men’s groups was primarily in English. In the urban women’s group discussion was divided about half and half between the two languages. The peri-urban women’s group discussion took place mostly in Swahili.²

Researcher assistants were trained prior to conducting the groups, and paid afterward in accordance with market rates.

Procedure

The purpose of the research was explained by research assistants to focus group discussants at the outset of the meetings. Discussions with several researchers experienced in HIV/AIDS research had confirmed that on sensitive topics, being asked to sign a form before speaking could make people feel suspicious and threatened³. Both the IRB at UGA and the Kenyan Ministry of Education, Science and Technology acceded to my request to waive written consent. The script for obtaining oral consent of participants in focus groups is found in Appendix B. Personnel at all three organizations indicated audiotape recording should not be a problem, and permission to do so was obtained orally from participants at the beginning of the meeting.

After consent was obtained, participants were asked to respond to questions regarding disclosure of their positive HIV diagnosis. After all questions had been addressed, participants were invited to ask the research assistants questions, after which refreshments were served. Actual discussion time ranged from around 50 to 75 minutes.

Relevant portions of tapes of focus group discussions were then reduced to typescript and Swahili portions translated. I listened to all tapes, but relied primarily on the transcripts for data
analysis because my Swahili is only semi-fluent. Discussions were inductively coded for reasons for disclosure and nondisclosure, methods of disclosure, and disclosure targets.

Results

Analysis of the focus group data indicated some changes needed to be made in the preliminary version of the questionnaire that had been created based on U.S.-based instrumentation. A fuller report of the findings of the focus groups available in the next chapter (see also Miller & Rubin, 2005), but methodological implications of those findings for the final study will be mentioned here.

Perhaps most notable of these was the frequency with which, unprompted, focus group members mentioned pastors and other religious leaders as targets of disclosure. The version of the questionnaire that was developed after prospectus approval had inquired into motivations and methods of disclosure to three groups of people in the lives of PLHAs: sexual partners, family members, and friends. Based on the results in the formative phase, a fourth section, identical to the others, was added with questions on self-disclosure to religious leaders.

PLHAs who were participants in the focus groups expressed many of the same reasons for disclosing and not disclosing their status as have their counterparts in the United States. Reasons for disclosure listed on Derlega, Winstead, Oldfield, and Barbee’s (2002) U.S.-based scale that also arose in the Kenyan focus groups were: having a close relationship, duty to inform/educate, and similarity. However, similarity was mentioned only in the sense of sharing the same HIV serostatus. Motivations that have been indicated in U.S. studies but are not included in the Derlega and associates’ disclosure motivation scale that emerged from focus group research were enabling loved ones to plan for the future or protect themselves, seeking emotional support, and assurance that the target would respect the PLHA’s confidentiality. As in
the Derlega and associates’ nondisclosure motivation scale, motivations for nondisclosure included protecting loved ones, communication difficulties, and fear of rejection.

However, there were also differences. Catharsis and testing others’ motivations, both of which are assessed in Derlega and associates’ disclosure motivation scale, did not explicitly arise in the discussions; nor were U.S.-identified motivations for nondisclosure of self-blame leading to shame and right to privacy per se mentioned, although fear that the target could not keep a PLHA’s status secret was a recurring concern. On the other hand, several motivations not evidenced among U.S. PLHAs appeared with regularity in the focus group transcripts. Participants were frank about their need for material support as a motivation for disclosure. As anticipated, several participants also indicated that they chose certain family members as confidants so that person might serve as an intermediary to inform someone else. Not anticipated was the disclosure motivation of seeking advice on how to tell another person. A number of participants also noted that they told various persons in their lives because their condition would be obvious in any case.

Specific changes to the scales based on these findings are described below in the section on measures.

As right to privacy did not emerge in focus group discussion as a distinct reason for nondisclosure separate from the issue of confidentiality, hypothesis 4 was reworded as follows:

H4: Nondisclosure to family members will be more strongly motivated by fear of rejection than will nondisclosure to friends.

Focus group discussion also elicited the following common methods of disclosure of HIV serostatus: direct disclosure, verbal hints, non-verbal indirect, directly asking a third party to inform the target, and going together for the test and being informed at the same time by clinic
personnel. It was also recognized that significant others in PLHAs’ lives might be informed without their permission, or that they might deduce on their own the positive serostatus of the PLHA without being told at all. Thus these possibilities were also added to the list of ways in which discloses might learn a participant’s HIV-status. Finally, from discussion with key informants I had also heard mention of PLHA’s informing one person and trusting that person to inform anyone who should know, particularly within the family system. It appeared possible, too, that a PLHA might hint to another person about his/her status and hope that individual would inform a particular person, so both of these options were added to the list. Thus a total of ten possible methods of disclosure were listed.

Specific instruments used for measuring disclosure message strategy are described in the section on measures below.

Structured Interviews

The final phase of the project involved structured interviewer-administered questionnaires, to which PLHAs at selected clinics and outreaches in the Nairobi area were asked to respond. The revised questionnaire was first written in English and then translated into Swahili with back-translation to assure accuracy. It was then pre-tested at one of the organizations where focus groups had been held, but with PLHAs who had not participated in focus group discussion. Participants were identified by organizational personnel according to the criteria previously mentioned. Two research assistants with experience in counseling HIV-positive persons were recruited to conduct pilot tests. Pilot study participants were asked to choose the language they preferred for the interview; all chose Swahili. Following administration, research assistants debriefed participants by soliciting their assessment of the clarity and appropriateness of the instrument.
Sampling Procedure

Samples for the study of disclosure of HIV serostatus cannot by nature be randomly selected, and are obviously imbued with pro-disclosure bias. First, of the estimated 1.7 million HIV-positive persons in Kenya only a fraction are certain of their serostatus. Second, only those who have informed someone of their status (clinic personnel or support group leaders, for example) can be located for interviewing; one simply cannot go up to individuals on the street and ask if they are HIV-positive and expect an honest answer. Third, even among those who can be identified, only those who are willing to disclose their status to yet another person—the interviewer—will participate in research. Thus at every step along the way the least disclosive will have already been weeded out. In this study the additional complication arose that to an individual researcher with very shallow pockets, governmental facilities where a large number of PLHAs go for treatment were not available sites.

Therefore, my final sample was wrapped round with constraints. I turned to non-governmental organizations (NGOs) to source participants. In order to access these organizations I first obtained a research permit from the Kenyan Ministry of Education, Science and Technology. Locating non-governmental organizations through word of mouth and a “snowball”-like approach, I called each, briefly described the purpose of the study, and requested an opportunity to meet with the appropriate staff member, usually the program manager. Every organization I approached agreed to participate, and staff members were uniformly helpful and interested in the project.

In this manner I located seven sites, purposively selected to provide a variety of urban vs. peri-urban clients, a socio-economic range from low to middle class, and a balance between potentially more disclosive support group members and possibly less disclosive individuals
dropping in to clinics for medication checks and other services. No rural sites were used, because the difference between the rural and urban environment in Kenya, as in much of the continent, is substantial. Western cultural influence has penetrated urban life much more thoroughly than it has daily living in the countryside, and any study attempting to generalize to both contexts would require double the sample size, a course of action I was financially unable to consider.

The final administration yielded 307 usable questionnaires. Of these, forty-six interviews were conducted at a women’s organization on the western side of downtown, 73 in another women’s organization on the northeast side of downtown, 58 in homes of contacts of another organization located in the large Kibera slum on the southwest side of town, 77 at a clinic in a Catholic hospital north of town in a peri-urban area, 34 in a support group sponsored by the same hospital, and 19 at two smaller organizations located on the east side of town.

Clinic personnel assisted in identifying persons from their programs who: 1) had known they were HIV-positive for at least two months, 2) were over 18 years old, 3) were judged by medical personnel to be physically and mentally able to provide reliable responses to questionnaires, 4) spoke either Swahili or English fluently, and 5) were willing to spend thirty to forty-five minutes answering questions about disclosure of their positive HIV diagnosis.

*Data Collection Mode*

Although it would have been much less expensive to use self-administered questionnaires, the complexity of the topic, low educational level of some members of the target audience, unfamiliarity of the questionnaire format in Kenya, and the resulting risk of getting a large number of incomplete questionnaires made it imperative that face-to-face interviewing be used to collect the data. Also, I anticipated interviewers would be able to elicit fuller, more complete responses to open-ended questions than would a self-administered questionnaire.
(Singleton & Straits, 1999). Even though the questionnaire was not by American standards especially long, taking just 30 to 45 minutes from start to finish, it was likely to appear burdensome if self-administered in Kenya.

By the end of the data collection this decision had been, to my mind, resoundingly affirmed as older respondents especially evidenced some hesitation with aspects of the structured questionnaire format that were only overcome with difficulty and patient explanation by interviewers. I realized that many Kenyans exist in a different research environment than do North Americans. It did not make sense to many participants, especially older ones, for researchers to tell them they wanted to know about participant experiences and then reel off a list of questions the participants might not be especially interested in answering. From the perspective of my interviewees, the logical approach seemed to be for them to take charge of the direction of the questioning themselves, and just narrate what they saw as relevant to the topic. (U.S. Americans, of course, especially the college students we so frequently deal with, are a notably compliant lot when it comes to research. There is an exception to this rule when it comes to telephone surveys at dinner time, but as a rule, you ask them to rate their attitudes on a scale from one to five regarding the health benefits of pepperoni—yes, I did participate in a survey on that topic once upon a time—and they happily oblige.) This difference in research experience would undoubtedly have resulted in a number of partially completed instruments had the instrument been self-administered.

In the end, 307 out of 327 interviews that were initiated were completed satisfactorily, a 94% success rate. Given that clinic and organizational personnel were asking clients whether they would be willing to participate in research and only channeling those to researchers who expressed an interest in doing so, this sort of high response rate is to be expected. Of those 20
questionnaires that were unusable, nine were filled out incorrectly, eight of them by a single interviewer (see below), one was of a respondent younger than 18 years of age, three involved participants who had known their diagnosis less than two months, one turned out to have TB but not HIV, and six questionnaires were incomplete. Questionnaires were considered to be incomplete if they were missing either one entire disclosure/nondisclosure scale or the equivalent number of items.

Research Assistants

Research assistants for the final phase of the project were recruited from communication students at Daystar University just outside Nairobi, where I am currently on faculty, as well as from staff at one of the participating NGOs. The three research assistants from NGO were hand picked by administrators as those most experienced in conducting research, and were paid according to organizational guidelines. All undergraduate research assistants had completed or were nearing completion of the undergraduate research methods course. Students currently enrolled in the course were asked to conduct two interviews apiece at support group meetings on three separate occasions at two locations. They were paid the cost of their transportation plus a small allowance. Students who worked entire days were initially paid a per diem rate, however by the end of the data collection I had realized that was not an efficient use of my funds, and shifted to paying per completed questionnaire.

All assistants were trained in two sessions prior to data collection, with training lasting from two to five hours, depending on the group. In the first session research assistants were informed as to the general purpose of the research, overall research design, and structure of the questionnaire. In the second session they were familiarized with the entire instrument item by item and given instructions for recording responses. Common problematic responses that had
arisen in pilot testing were highlighted and directions given on ways to deal with them. They were also introduced to basic interviewing techniques regarding establishing rapport, probing without biasing responses, and asking questions exactly as written. It was suggested that they explain from the beginning something of the nature of the structured discussion that would take place during the interview, e.g. “Now my instructions are to read all of these questions word for word, which may be a bit uncomfortable but . . .”, in order to acclimate participants unused to participating in research to the standardized communication that would take place. A demonstration interview was conducted with the interview schedule. Overall performance of research assistants was good, as evidenced by the consistency and detail of the data, although about half of the questionnaires by one of the NGO-provided assistants had to be thrown out because of irreconcilable inconsistencies in the answers.

Quality control of the data collection process was assured in three ways. First, in all data collection sites except that covered by NGO personnel, I was able to arrange situations where organizational or clinic personnel were intimately involved in channeling participants to the interviewers, ensuring that it would have been extremely difficult for research assistants to fabricate completed interviews. I myself was present for a good portion of the time at all support group data collections and was also able to check on various research assistants periodically. At all locations except that staffed by the NGO, research assistants had no alternative but to stay at the sites the entire time, thus there was virtually no incentive not to collect data. In the case of the NGO staff data collection, such accountability was not present and it was impossible for me to contact interviewees after to ascertain that interviews had taken place. I was therefore dependent upon the project administrator, a former Daystar University student as it happened, to select experienced staff whom she knew to be trustworthy and capable.
At the Catholic clinic and in the house-to-house data collection by the NGO staff, both of which took a total of five days, I also arranged to touch back with interviewers after their first day of interviewing to see if there were any questions or difficulties. At support group data collections, which were conducted within a matter of several hours, I skimmed completed questionnaires and requested some missing coding or incomplete information to be filled in before paying assistants. Unfortunately I was unable to catch all errors in that way, but I did manage to spot a number of issues while research assistants were still present.

After data collection was complete, I debriefed research assistants several at a time, asking what their impressions were from their interviewing, what had struck them about the responses they received, what patterns they observed, and in the case of the students from the research methods class, what they had personally learned from the experience about HIV/AIDS and research methods.

Procedure

Participants were informed about the purpose of the research at the beginning of the interview asked to choose the language in which they preferred for the interview to be conducted, and informed consent obtained orally in the appropriate language (see Appendix C for consent script). Research assistants then administered the questionnaires to participants.

One unexpected difficulty that arose in pre-testing was that research assistants were reticent to use the Swahili questionnaires. They preferred to read the English questionnaires to themselves and translate on the spot into Swahili for their interviewees. The issue, as it turned out, was one of language function in Kenyan society. Swahili is an African language and therefore close to people’s hearts. Even those who have a deeper vocabulary in English may use Swahili for day-to-day conversation, although to a great extent they mix the two. On the other
hand, the preferred language for reading is English. It is the language of education from primary school onward. It’s prevalence as the written medium is illustrated by the circulation of Nairobi’s four daily newspapers: the three English papers are thumbed by multiple thousands of hands every morning. The single Swahili daily has a tiny readership and at some newsstands is not even available. In fact, Nairobi Swahili is a street language—grammatically sloppy and much further from the written version than is the case in oral and written U. S. English. My research assistants simply didn’t feel comfortable reading it aloud.

Consulting about the situation with a Kenyan communication researcher I was told that my problem was a common one, but that if I insisted, my assistants would be fully capable of adhering to the Swahili translation. I did, and they were, as evidenced by the final count of 108 usable Swahili questionnaires out of a total 307.

From the beginning, the goal was to pair male research assistants with male clients and female with female. However, as early as the focus group discussions when the occasional member of the opposite sex wandered into the group, it appeared that the presence of a member of the opposite sex during discussions of this sort was not considered unusual. At each interview site I spoke with organizational staff about the issue, requesting that if possible clients be paired with same sex interviewers. Although they were generally compliant with this request, they also all indicated that they had workers of both genders working with both male and female clients, and they did not foresee any difficulties with mixed-gender interview pairs. In the end, because of the unpredictability of the number of male participants available, some women were interviewed by men.

After completing the interview, research assistants thanked interviewees for their participation. Depending upon the suggestion of site personnel, incentives were then given to
interviewees as a token of appreciation. I was all too aware that, as participants in one focus group complained with irritation, even as the most basic level assistance meant for PLHAs frequently does not reach them. To guard against that eventuality, I was able at all sites but one to arrange to observe participants incentives handed out and signed for to PLHAs themselves. Among 296 participants represented at these sites, I discovered only the equivalent of just over four U.S. dollars that I could not account for, which I suspected was because one person at a particular support group forgot to sign for the money.

The other site, where eleven interviews took place, was from the beginning less controlled and I was not surprised when about five dollars of refreshment money disappeared into the pockets of the two support group leaders. Given the size of the sums I had already expended on data collection this was, of course, a negligible loss. What was distressing was that it later became clear that these same leaders had also given PLHA participants only half of the incentive money sent for them. It is probably also worth observing that the fact that individuals would risk so obviously misappropriating a sum as small as twelve dollars and ruining any future relationship with the researcher indicates something of the economic situation in which many of my study participants found themselves.

Upon completion of the interviews, data were entered and then all data points on all cases were double checked for accuracy. Statistical analyses were conducted using SPSS 11.0.3 statistical software. Qualitative analyses were conducted as described in chapter 4.

**Measures**

The final survey employed a combination of structured and unstructured approaches (see Appendix D). For gathering data on the more frequently studied issue of motivations for disclosure, highly structured questions were used, with provision for additional reasons at the
end of each scale in the form of an open-ended question. Because methods of disclosure have been little studied in any context and were particularly difficult to predict on the basis of existing literature in sub-Saharan Africa, the primary tool for exploring disclosure strategy was an open-ended question regarding disclosure method for each of the four relationship types. Specific measures are explained below.

Demographic information

Participants indicated their gender, age, and marital status. Age of interviewees ranged from 18 to 70, with a median age of 36.75. Of total number, 125 indicated they were currently married, 66 were widowed, 19 divorced, 47 single, 6 traditionally married, 3 polygamously married, and 41 were separated. Eighty-six participants were male, 219 were female, and two questionnaires did not indicate participant gender. Although I would have preferred a higher proportion of males, it took a concerted effort to obtain even the approximately one-third of the final number who were men. Male PLHAs in Kenya are much more likely to hide their status and less likely to seek help than are female PLHAs, a fact that one focus group even commented upon. (A social worker with USAID with whom I shared my frustrations about the scarcity of males to interview commiserated with a laugh, “They’re hard to find.”)

Illness-related information

Participants were next asked several questions related to their HIV infection:

Date of diagnosis. This was obtained in day/month/year, but for statistical purposes recorded only by year. Among interviewees the earliest diagnosis date was 1987, and the most recent just before the cut-off point of two months prior to the interview. The mean year of diagnosis was 2001; median was 2003; mode was 2004. Data collection took place in 2005.
Stage of illness. Participants were asked to self-report their own stage of illness: asymptomatic or symptomatic. Among my sample, 176 indicated themselves to be asymptomatic and 114 reported themselves symptomatic. Seventeen questionnaires had no indication of symptomaticity. It is worth noting that one year earlier when I was beginning my key informant interviews, it could be assumed that unless one was extremely wealthy, once one became symptomatic one remained that way. The intervening months, however, have brought a dramatic increase in the availability of ARVs in Nairobi, mostly as a result of the WHO’s 3 x 5 initiative, so that a number of participants who narrated stories of having been extremely ill in the past were able to describe themselves as symptom-free at the time of the interview.

Use of ARVs. A single yes-no question assessed this variable. One hundred ninety-one participants reported they were using ARVs, 114 said they were not, and two questionnaires did not indicate either.

Means of transmission. A single multiple choice question was used to determine means of transmission (Derlega et al., 1998). In addition to categories employed in the U.S. such as heterosexual transmission, men who have sex with men (MSM), injection drug use, blood transfusion/medical procedure, and “don’t know”, categories of and mother-to-child transmission (MTCT) and infection through caring for a PLHA were also included. Furthermore a distinction was made in heterosexual transmission between whether the infection was passed within marriage or outside of it. Questionnaires indicated that 107 participants believed they had contracted the infection from heterosexual activity with someone who was not their spouse, 110 believed they had been infected by their spouse, one reported being infected by sex with a person of the same gender, five by transfusion or other medical means, two by caring for someone who
was HIV-positive, one through MTCT, one through injection drug use, 72 were uncertain, and five by other means (three by rape, one by tattoo, one by shared nail clippers).

**Disclosure Measures**

*Four target relationships.* Based on the format of Derlega, Winstead, Oldfield, and Barbee (2002), participants were instructed that they would next be asked to think back to the time they first learned that they were HIV. They were told that they would be asked about several people whom they might or might not have told about their diagnosis, and that for each person they would be asked about whether or not they had told that person, reasons they had for telling or not telling, what gender the person was, how close their relationship was at the time, what the person’s social status was relative to theirs, and if they had informed the person about their positive diagnosis of HIV, how they had done so. The four target relationships addressed were sexual partner, friend, family member, and religious leader.

To identify an intimate partner for purposes of the first set of scales in the questionnaire, they were instructed to “think of the first person with whom you started a romantic or marital or sexual relationship after you learned about the diagnosis or someone with whom you were in a romantic or marital or sexual relationship when you learned about your HIV diagnosis”. To identify a friend, for purposes of the second set of scales, they were told to “think of a friend of either sex whom you knew very well when you learned about your HIV diagnosis but with whom you were not romantically or sexually involved.” To identify a family member for the third set of scales, interviewers requested them to “think of a family member at the time you learned about the HIV diagnosis”; and to identify a religious leader for the fourth and final set of scales, they were told to “think of a person you considered to be a religious leader in your church/mosque/temple or other area of your life when you learned you were HIV-positive.”
Research assistants were instructed that either a disclosure or nondisclosure scale should be filled out in all four sections of every questionnaire unless there was not a person of that relationship within the life of the participant. This could, of course, be the case regarding religious leaders. Some respondents might well have no religious connections in their lives at all. It was also possible in the case of sexual partners, in cases where participants reported they had not been tested for the disease until after their spouse had already died of AIDS-like symptoms, and they had not had any sexual partners since. For these participants, the partner category was legitimately null.

*Status differential in relationship and gender.* After the participant had thought of an individual within the specified relationship category, they were asked the gender and relative social status for that individual. The concept of social status was initially explained as follows: “What we mean by status is that there are some people whom we consider to be our equals, for example our agemates. Other people would be above us in terms of social standing and we have to treat them with more respect, such as an elder among certain tribal groups, your father’s oldest brother, a boss at work, and so on. Finally, some people have lower status than we do, such as children, people who work for us, and so on.” Higher status targets were coded as “1”, equal status targets as “2”, and lower status as “3”, creating a three-level ordinal variable. The hypothesis related to this issue collapsed low and equal status targets into a single category, leaving a dichotomous variable, but because this issue is virtually unexplored the additional data were gathered. In assessing status differential by means of a single item measure, I limited myself to being unable to accurately establish reliability for the item. However, as there is no precedent for measuring this construct, a self-reported single item was deemed the most feasible means of obtaining the data.
Pre-testing indicated participants understood the concept of social status readily. The only occasional confusion related to the word “status” being frequently used to describe whether or not one is infected with HIV. Although the English questionnaire itself did not use the term in both senses, and the words are entirely different in Swahili, common parlance apparently brought the HIV-related use to some people’s minds even so. In such cases research assistants were instructed to explain in more detail the difference between the two usages.

Quality of relationship. Research on HIV/AIDS disclosure has measured quality of relationship among motivations for disclosure and nondisclosure, as in Derlega and associates’ (2002, 2005) research, but it has not assessed quality of relationship as a separate variable. As there is no scale that has been established in this line of research as useful for tapping that variable, quality of relationship was assessed by asking participants to indicate on a scale of 1 to 5 “In terms of your feelings and commitment to ______ how emotionally close would you say you were to that person.” Pilot testing indicated participants did not have difficulty with this concept as worded. In order to streamline administration and minimize confusion, all subsequent Likert-type scales in the instrument were constructed with five points as well.

Motivations for disclosure and nondisclosure. Early research on motivations for disclosure among U.S. PLHAs used open-ended questions (e.g. Derlega et al., 1998; Hays et al., 1993; Holt et al., 1998; Mason et al., 1995; Moneyham, 1996; Siegel & Schrimshaw, 2002; Simoni et al., 1995). Eventually Derlega and his colleagues (Derlega et al., 2000) developed Likert-type scales on which respondents were asked to indicate on five-point scales from 1 = “not at all a factor” to 5 = “very likely a factor” how much various reasons may have influenced their desire both to disclose and not to disclose about their positive diagnosis to a specific disclosure target.
Based on the motivations generated within the focus group discussion, the items on the disclosure and nondisclosure motivation scales were adjusted for the Kenyan context by adding items representing each of the above-mentioned motivations. Revised motivations for disclosure were: soliciting advice (phrased generally so as to potentially include advice regarding HIV/AIDS resources, relational issues, spiritual matters, and so on), closeness of relationship, desire for emotional support, trust in target’s ability to keep the secret, duty to inform/educate, need for material support, preparing loved one for the future, similar HIV-serostatus, seeking assistance in informing others, and condition would be obvious to disclosee. Revised motivations for nondisclosure were: fear of rejection, fear of target not keeping the secret, target’s not being HIV+, not causing the other person pain, not causing the other person worry, and relationship not close.

The adjusted scales, therefore, included ten motivations for disclosure and seven motivations for nondisclosure. This was an increase from the five and six motivations respectively explored in Derlega and colleagues’ scales. Furthermore, the decision to compare motivations between four relationships rather than the two that has been common practice in the U.S. made the instrument even longer. From a previous data collection effort (Miller, Fellows, & Kizito, 2005) it was evident to me that Kenyan respondents were likely to become fatigued earlier in the interview process than their American counterparts for whom survey research has become to some degree a part of cultural life. The decision was therefore made to use single-item measures for each motivation. This meant the sacrifice of the ability to assess reliability, a price that I was loathe to pay, but that was ultimately unavoidable. Content of the scales, as noted, was changed from that of U.S.-based research in accordance with focus group findings. The final
disclosure and nondisclosure motivation scales were ten and seven items respectively. Selection of items has been discussed above.

There is evidence that Likert-type scales have been used effectively with urban populations in East Africa (Gatere, 2000; Kihara, 2004; Lyaro, 1992; Mbogo, 2002; Mugo, 2003; Nzioka, 2000; Wanjiku, 1998), and most participants in this study were able to accommodate the type of thought process requirement to complete it. However, some older respondents were inclined to select mostly “1”s or “5”s, which may signify that the idea of reducing their attitudes to a something more nuanced than agreement or disagreement did not come naturally. Younger respondents complied readily with the task.

All participants as well as research assistants in the pilot study expressed confusion about the convention of asking about reasons both for and against disclosing for all relationships as employed by Derlega and colleagues. They insisted it did not make sense to discuss reasons one had for not revealing one’s HIV status to an individual whom one had in fact informed of one’s status. After in-depth discussions with both pilot study research assistants, the decision was made to drop the bi-directional approach and inquire into reasons for disclosure from those who indicated having disclosed, and reasons against disclosure among those expected few who said they had not informed a given person.

Thus, although all participants responded to all four possible targets of disclosure, the design was not a balanced repeated measure. That is because any given participant might have chosen to disclose to some of the four targets and not to have disclosed to the others. In that case, the participant would have completed the motivation to disclose scales to the first group of targets, and the motivation not to disclose scales for the second set. The configuration of which sets of scales (motivation to disclose or motivation not to disclose) was completed would differ
from one participant to the next. In fact only 27 participants provided full repeated measures data on the disclosure motivation scales, that is, they disclosed to all four targets, and just six did so on the nondisclosure motivation scales. Anticipating the possibility of decreased power as a result of this circumstance, the goal for minimum sample size was increased from 200 to 300. Data analysis procedures employed in response to this situation are described in Chapter 4.

*Strategies of disclosure.* Although a number of studies have addressed disclosure strategy through qualitative means (Agne et al., 2000; Cusick & Rhodes, 1999; Gray et al., 2000a; Gray, Fitch, Phillips, Labrecque, & Fergus, 2000; Limandri, 1989), few have done so in a quantitative format. Derlega and associates (2000) attempted to do so by simply asking participants whether they had informed targets directly or indirectly. However, this approach does not address the other issue of concern to the current study, interpersonal intermediation of disclosure. My solution was to present an open-ended question soliciting a narrative of each specific disclosure event.

The open-ended question regarding disclosure had one additional benefit. Early in the formative phase of research I became aware—not only through information given to me by key informants but also through simply looking around me—that a major thrust in mass media HIV-prevention efforts at the time was being made toward encouraging infected individuals to inform their sexual partners. Had the questionnaire contained only the listing task, social desirability bias might have led some participants to indicate they had revealed their status to their partners when they had not. However, when asked for a description of the disclosure event it is likely that far fewer persons would be willing to fabricate a socially desirable answer.

At the same time, because audio-tape recording and analyzing each of the projected 300 interviews was not feasible for me working as an individual, I was concerned that the
information provided by research assistants on the questionnaire itself would not be sufficient to
code all responses adequately (an assumption which later proved justified). Therefore the
decision was made to include a closed ended list for assistants to code themselves after recording
participants’ descriptions of the disclosure event. Options on the closed ended question included:
(1) informing the target directly, face-to-face; (2) informing the target face-to-face but indirectly;
(3) leaving non-verbal hints for the target such as appointment slips or medication around the
house; (4) asking the target to go together for VCT testing even though the participants already
knew him/herself to be HIV+; (5) Going together to a VCT clinic and finding out at the same
time; (6) directly asking a third party to inform the target; (7) hinting to a third party to inform
the target; (8) trusting a third party to inform everyone who needed to know; (9) someone told
the target though the participant did not want them to know; (10) target figured out that the
participant was HIV+ without being told; and (11) other.

*Targets of disclosure.* The most frequently used means of discovering targets of HIV
serostatus disclosure in U.S.-based research has been to present participants with a list of types
of relationships, e.g. mother, father, sister, brother, closest friend, intimate lover, and ask them to
indicate yes or no as to whether they have disclosed their status to at least one person within that
category (e.g. Hays et al., 1993; Mansergh et al., 1995; Marks et al., 1992; 1995; Mason et al.,
1995; Perry et al., 1994; Simoni et al., 1995; Sowell et al., 1997; Stemptel et al.,1995; Wolitski et
al., 1998). Sometimes overall disclosure scores have been calculated using the percent of
applicable targets informed (Mason et al., 1995; Simoni et al., 1995). Variations on this method
have also been used with HIV and other illnesses. Some studies have participants generate their
own list of targets in response to an open-ended question (e.g. Armistead et al., 1999; Bungener
et al., 2000; Figueiredo, Fries, & Ingram, 2004; Greene & Faulkner, 2000). Most available
research on targets of disclosure among sub-Saharan Africans appears to have used this method (e.g. Bungener et al., 2000; Issiaka et al., 2001; Lie & Biswalo, 1996). Another approach, used by Henderson and associates (2001) dispatched with the dichotomous yes/no response and asked participants to indicate “the degree to which you talked with the following individual about your cancer in the month following diagnosis” on a scale from 1 = “not at all” to 4 = “very much.” Also studying cancer, Pistrang and Barker (1992) had participants list persons to whom they had confided about their cancer and rate each on a five-point scale from 1 = “talked about none of what I felt” to 5 = “talked about all of what I felt.”

There are shortcomings to the “at least one person per category” approach. As Serovich and her colleagues (2000) point out, evidence that PLHAs disclose more to friends and partners than family members should be interpreted with caution. In the extremely mobile U.S. society, it could be that families of PLHAs are small and far away, and friends are plentiful and close. Because many studies have not even asked the number of persons disclosed to in each category, let alone the percent, it is inappropriate to assume that PLHAs feel uncomfortable discussing their diagnosis with family members absent additional evidence. Several studies on serostatus disclosure to health care providers address this weakness by asking participants to estimate the percent of non-diagnosing medical or dental personnel to whom they have revealed their status (e.g. Charbonneaux et al., 1999; Rotheram-Borus et al., 1997; Sowell et al., 1997), as does Serovich and associates’ (2000) study of social support provided by friends and family.

I chose the listing option. Originally, the listing task requested participants to name everyone to whom they had disclosed their status, when, the gender of the person, and whether the disclosure target was known to be HIV-positive at the time of disclosure. As pilot testing indicated and now appears obvious, this was too much. Some (though by no means all) people
who had known their status for many years had disclosed to nearly everyone they knew. It was impossible to ask them to list everyone to whom they had revealed their status. Thus the task was changed to solicit information on the first five persons to whom the participant had disclosed, based on Lie and Biswalo’s (1996) rationale that decision on who to tell first about the diagnosis is a critical first phase of reaction to news of the infection.
CHAPTER 4

RESULTS

Chapter 3 alluded to certain focus group findings as they impacted the culture-sensitive development of the final questionnaire. The present chapter returns to those focus group data for a more in-depth qualitative analysis as they bear on the central issues of this dissertation: targets, motivations, and methods of HIV/AIDS disclosure in a sub-Saharan population. The qualitative findings from the smaller focus group sample serve as a backdrop that enriches understanding of the larger interview study, the results of which are presented later in this chapter.

Results of Focus Group Discussions

Participants in the focus groups reported a wide range of degrees of self-disclosure of their HIV status, from several persons who indicated they had told no one about their status other than the people in the support group they were attending that day, to one man who claimed that virtually everyone in his acquaintance knew he was HIV-positive. Timing of first disclosure varied from a few hours, to several weeks, to three years after diagnosis. Participants also mentioned a wide range of disclosure targets as well as a variety of persons or groups from whom they were trying to keep their status secret. On the other hand, several patterns did emerge across all four groups. I have elected to categorize those patterns by disclosure target rather than by motivational, gendered, and situational criteria, as motivations and methods of disclosures discussed in the groups seemed to be associated with the type of relationship involved. Quotes from focus group discussion that have been translated from Swahili are indicated in bold below.
Disclosure to Spouses and Sexual Partners

Among male participants, wives were frequently mentioned confidantes, and those who told their wives did so primarily out of the motivation of enabling their spouses to protect themselves from infection. Although a few told their wives the day they learned the truth themselves, or within the following week, others spent time considering how to reveal the devastating news and often seeking advice about the matter. Sources of advice most frequently discussed were clinic personnel, however a few men spoke of asking friends for this type of assistance. A man who waited six months before informing his wife described his dilemma, “I was really willing, but due to her emotions, the trust we had, I knew it could not be very easy for her so I had to take time and see how to go about it. To seek advice from the [support] group members.” Still others admitted to never yet having told their wives of their condition, in one case even years after diagnosis:

So, you know when I tested positive the way I was feeling in my body was different. And my wife was also feeling different. So I started having this problem, having stomach ulcers. So when I, the doctor treating me the ulcers is when I started telling my wife, “Now I’m using very [laugh] very sensitive medicine. Now we should use what? Condom. You see? Just. . . (Moderator: You have not yet told her. . .) I have not yet told her.

Indirect approaches to disclosure. Men who disclosed to their spouses reported a range of indirect approaches. Several suggested to their wives that they should both go to a voluntary testing and counseling (VCT) center for testing together, not revealing that they themselves had already been tested. This technique was mentioned as recommended by clinic personnel and seemed to accomplish the purpose. In one case, in fact, clinic personnel told a male participant to
bring his wife back and tell her he was being tested for malaria; they would find a way to
approach her and convince her to be tested for HIV once she arrived.

Others spoke of dropping hints and gradually leading up to the revelation. One man, for
instance, first sought advice from a friend at work, who gave him 500 shillings (around US $10
at the time) to go home, buy his wife something she really liked, and then gently work toward
breaking the news to her. The idea seemed good to the participant, so on his way home he bought
his wife a slab of liver. (Focus group members found this amusing.) Even after having thus
presumably induced a receptive mood, he was still careful not to attack his subject directly. The
extent of information he gave her that evening was that he wanted to go see his parents (another
ploy suggested by his friend). She became curious, insisting on knowing why he needed to see
them so badly, but her husband would explain no further. Two days later he followed up by
drawing her close to him and asking whether she still loved him. She assured him that she did
but begged to know why he was asking such a question. “So I told her, ‘If in case today I lose
my eye or my leg, will you still love me?’ ‘Yes.’ . . . ‘I know if I die you will run away from me. .
. . you will just bury me and forget about me.’” She pledged that she would always be with him.
He then stated frankly, “I am dying.”

The man quoted above who secured his wife’s protection by telling her that his doctor
had prescribed a sensitive medication that necessitated their using condoms is another example
of indirectness. After his narration, the focus group moderator posed the obvious question: “And
she didn’t ask why?” “No,” the participant responded, “She knows. She knows very well.” But in
the entire decade since his diagnosis and since they have started using condoms, they have never
discussed his condition openly.
Only a few women spoke of telling their husbands. One woman explained that she wanted her husband and children to know her status as soon as possible, while she was healthy, and thereby to prepare them to support her once her health failed. Another female participant who discovered her status during antenatal testing chose an indirect route to inform her husband. When the child was born she did not breastfeed it, and the husband wanted to know why. Whether the participant then directly informed her husband of her status at that point was not clear from the taped discussion, but it was definite that they negotiated use of condoms in their sex life. “It reached a time,” the woman concluded, “when he told me that he cannot use a condom. I told him if he can’t use one, then go out and look for someone out there, but with me use a condom. When he refused, he went away, and I have raised the child.” The child has since tested HIV-negative.

Others, both men and women, felt they had little choice but to tell their spouses, either because their spouses were already suspicious of their prolonged bouts with illness, or because the spouses themselves were further advanced in the illness than the participants. In one case, a man’s wife saw his hospital attendance card and deduced the situation. Several women mentioned that their husbands had already died, and that they themselves had gone for testing after witnessing their husbands’ illnesses.

No women and only one man described telling past sexual partners after learning their diagnosis. Several women explained that there were no other sexual partners in their lives besides their husbands; they had been faithful to their men throughout years of marriage. The one man who reported seeking out past girlfriends estimated that he had located the first one a month or so after his diagnosis, and the second about five months after that.
Spousal responses to disclosure. Most participants who told their spouses found them supportive, albeit sometimes after an initial period of shock. In several cases the couple developed joint ownership of the information and carefully guarded it from outsiders. “We have lived in that status, one man explained. “My family [wife and children] knows and the outsiders just wonder what is wrong with me because of my poor health, because I have not revealed my status to anybody else.” Another described a similar situation:

So after knowing our status, both of us, we thought it wise to keep cool and to take care so that whoever we are going to inform next could be a member of the family that we have studied for a very long time and got assurance that this member of the family is not going to stigmatize us, is not going to talk about it in public. Again, we thought it wise to seek advice before we inform the other members of the family.”

Nevertheless, in several cases among focus group participants, the spouse had left after learning a partner was HIV-positive. The situation of one female participant has already been mentioned. A participant in one of the male focus groups revealed that he had never disclosed his status to anyone since he learned it eight years ago. He has been ill, however, and a number of his friends have begun to shun him. His wife had left him less than two months before the focus group took place. “I was taking medicine and I did not have food supplements so I was very weak, and she saw with the state of my illness I cannot get well. . . ” he explained, trailing off.

Disclosing to Friends

Although a few men such as the participant who bought the offering of liver did mention revealing their status to a friend, most participants of both sexes were much more inclined to list their friends among those they definitely did not want to discover their positive HIV status. Many indicated once they knew they were HIV-positive they went about developing a new set of
friends among those they met who shared their status. Once secure with that revised support network, they left the old friends behind. This was a consistent theme across all groups. Several men mentioned above who had informed their wives of their status indicated that no one else knew except for their support group friends. A woman elaborated:

I think the reason why most of us do not disclose to our friends is because. . . . these are the people who spread the [gossip] such that you cannot move out of your house. [They] are with you when things are ok, but are not available when [you are] in need. . . . They will even tell their children and your child will be told ‘you go away, your mother has HIV’.

A man expressed a similar concern about gossip, “There are very few friends of mine I have disclosed to, and they have kept quiet. If you go on telling your friends, ‘What, what, what,’ they go spread it. . . there are people who don’t keep secrets.” Another man replied to the question regarding persons he did not want to know his status by mentioning his village neighbors, among whom rumors and gossip were, in his view, constantly flying.

In addition to concerns about confidentiality, participants also sensed that if they told their friends they would be rejected. Even friends who suspected because of participant illness were seen as often making themselves scarce. “Once you are down,” a woman concluded regarding old friends, “they would like to finish you [off] completely.”

The shift from old to new friends was not entirely ascribed to stigmatization by old acquaintances, however. Participants also felt that their lives and concerns had changed, and old friends would not understand. Female participants particularly felt this shift. As one explained, “With HIV once you know you have it you kind of put off the old friends because you do not belong together. They want to go out with you and drink, and sometimes you want to be alone
and do your other things. . . . you feel you are not as excited as they are when you go to those
dances.” Another echoed her sentiment, “There are times when my old friends request to take me
to the centre, and I feel bad because I know they will not fit in that class. Every time we are busy
attending seminars, traveling. They ask, where does ___________ go every day, she is ever
busy. So, sometimes you lose friends gradually.” A third woman related, “All the friends I had, I
just dropped them and I got new friends from group therapy. When the old friends call I have
nothing to say to them because, for one, I have lost a husband and we used to go out together as
couples.”

On the other hand, there were exceptions to this trend. One man was visited by a group of
friends one evening soon after he was tested and he informed them all together. He wondered if
he had done a wise thing, but they stood by him afterward. The man who estimated that almost
all of his friends and relatives now know his status reported that his friends did not treat him
badly. In fact, his revelation of his own condition freed up an old friend who had known himself
to be positive for over four years to make his first disclosure of that fact, to the participant.

Disclosure to Family Members

Many participants mentioned family members other than their spouses as early disclosure
targets. Participants reported sisters, brothers, cousins, parents, and family members in general as
being among the first persons to whom they revealed news of their infection. One woman whose
husband had previously died went to her mother with news of her status and found that the
family had already suspected the participant would soon discover she was HIV-positive. They
had observed her husband’s illness and had even been aware that he was being taken by his
sisters to various hospitals without his wife’s knowledge. Their suspicions were confirmed when
the baby, whom she delivered just before her husband died, failed to thrive and passed away.
Her family had waited for her to come to them rather than broaching the subject themselves, but once she revealed her status they were very supportive and encouraging.

Participants spoke of carefully selecting a relative with whom they were close—a cousin or a sibling, usually—to whom they initially revealed their status, sometimes even before informing their spouses. Such persons were often chosen on the basis of their ability to keep the secret from those who should not know. Frequently these persons took up intermediary roles with the rest of the family. In some cases the PLHA would send the individual with explicit instructions to inform those in the family who needed to know of the diagnosis. One male participant tapped a female cousin for this role, and asked her to inform his elder sister; another chose his younger sister. One female participant first told her twin brother, whom she anticipated would then tell her mother and sister, which he did. Some participants reported these intermediary family members continued their special role by providing to material assistance.

One woman explained:

It is only my cousin who knows my status, when I am too weak he brings me the medicine and he knows how to assist, so when he tells my family that I am unwell they know how to help me either by sending me food. Or when my family comes and finds that I am too sick and they want to take me to hospital it is only my cousin who knows where to take me. He takes me alone, not in their company; they just give him bus fare.

The positive response by this individual’s family was typical of that reported by focus group participants. They stated that their family members assisted them financially, for instance by paying their children’s school fees, and also by providing emotional support and prayer. Several participants related specific encouraging comments by family members about the
possibility of their still living a meaningful, normal life, about trusting God, and about always being assured of family support.

In contrast, some participants mentioned family in specific or general as persons whom they did not want to know about their illness. One man, for instance, was careful not to tell his mother. “My mother is high tempered, very aggressive. . . If I tell her, she could not imagine such a thing could happen in her family because they really trusted me.” Despite researcher probing, it was never clear whether this participant was concerned that his mother, with her hot temper, would reject him, or whether he was more concerned that the disappointment in his situation would be painful for her. Others explicitly mentioned concern that they would cause their relatives difficulties. One man who described himself as head of his extended family said that he felt his younger relatives were not prepared to deal with the possibility that he might be dying and what that would mean to the family system. Another man did not want his father to know because, “I was concerned that my father might collapse under the shock.” A woman feared her mother might kill herself at hearing the news; another woman did not want a sister who depended upon her to worry about her condition.

As with spouses, family members were sometimes informed simply because the truth could not be hidden from them. For one male participant this meant revealing his status to his stepsister. Various members of his extended family had begun to wonder why he, who had previously held a good job, was no longer assisting them financially (“In the African culture, our resources are . . . shared with almost all of our relatives. They were asking, ‘Why are you not helping us?’”). He told them he was having to purchase certain expensive drugs, but did not explain any further. After some time he became so ill that he lost his job. It was at that point his stepsister arrived at his house and insisted on escorting him to a VCT center for testing. He did
not tell her he already knew he was HIV-positive. “And then when I went out and she asked me what were the results, I told her that they found out that I was HIV positive. And she comforted me and told me that she was going to support me since I am not working; she was going to support me with medical check-ups and everything.” He summarized, “She is the one who came to me. I never went to her because it reached a point whereby I had given up hope and decided to die.” Ultimately he also disclosed to his sister and brother-in-law, and informed other family members that he was going regularly to a VCT center, from which indirect information he assumed they inferred the truth. He found most of them, like the stepsister, to be supportive. They assisted him with food and money.

In contrast to the proclivity for disclosing HIV status to new friends who were known to be likewise infected, HIV status of family members did not appear to be a condition for disclosure. Only in one case did a participant mention that she had sought out a family member she knew to be infected:

I just told my close cousin, her husband is my cousin and the husband died of HIV. . . I wanted to know how she lives with the disease because it has been ten years since her husband died—her husband died in 1996 and I was tested in 2002—so I wanted her to advise me on what she does, if she was treated.

A few participants feared rejection by family if their condition were known. “I didn’t want to tell my immediate family . . . because they will reject me,” one woman stated. “So I said in the beginning I will not share with them, but later I may tell them after considering various issues.” A male participant stated, “In our family, if you are known to have this disease, no one would want to talk to you.” Participants like this usually had told no one other than their support group, with the possible exception of their spouse, in whom they confided. In the case of
the man who informed his stepsister, his full sister and brother pointedly refused any help. He described their leaving messages telling him they were busy and would visit him another day, etc. “So it is something that has really been trying. . . . because if your real sister cannot even bring you food, if she is scared even to sit with you, you find it is very hard to disclose and talk to her, [especially] about HIV.”

Most participants, though, viewed family as a secure refuge to whom they could turn in their time of need. “We just inform our immediate family members, because it is hard for the family to expose us,” noted a female participant. “As for me,” another woman explained:

I would not want any other person to know apart from my family. Because if other people came to know about it they would have given me stress, because you will hear them gossiping negatively and that thing is not good. But I would rather leave them suspecting so that they are left on the balance, guessing instead of knowing the truth. . . It’s good when your family knows. The family will protect you.

**Disclosure to Pastors**

Pastors were mentioned as targets of disclosure by participants with similar frequency to family members, sometimes being the first person a participant informed:

The first person I felt I should tell was my pastor, because my pastor, I could talk to him and he could counsel me, we could pray and he could advise me on how to live with HIV/AIDS. And again . . . I took him to be a nice person who would not go out broadcasting [the information].”
Another voiced a similar motivation:

For me, at the time I got a positive diagnosis I did not have a problem with my health, so I kept quiet. Later I felt within me that this is a journey I shouldn’t travel alone, and I felt I should tell someone. So I went directly to my pastor without hesitation and I told him fact-to-face how things were. He listened to me and counseled me and he accepted me as I am. And he has continued to support me to this date.

Participants who revealed their status to pastors were generally rewarded with a supportive reception. One man, for instance, who said that he had disclosed to his pastor, with whom he was very close, reported the pastor’s response: “When I approached him, he told me it was good that I have talked about it, because most people come and they don’t say anything. They get married in the church and then they spread this thing through the church. . . then he offered to pray for me.” Another female participant revealed her status to a pastor, who announced that the church should be praying for God to heal her. When this pastor observed worshippers shunning the participant, squeezing into other seats so as not to come into contact with her, he chastised his congregants. “You might reject [an HIV-positive person] in church,” the participant quoted him as warning, “but that evening you will eat with another at the table in your own house.” Yet another woman revealed her status to church leadership and they offered to sponsor her for peer-educator training, even going so far as to pay her way to an HIV-related conference in Uganda.

In addition to seeking a sympathetic ear, participants mentioned motives for disclosure that centered on obtaining needed support: spiritual, emotional, and material. A female participant highlighted the first two:
The reason why I told my pastor is because I wanted to be encouraged and prayed for. I also felt my pastor would lead me to a place I could get support and be with people of my kind, and [he brought me] to this place where I have met other brothers and sisters with the same problem.

Most individuals who told their pastors related positive outcomes of the disclosure, but not all. “When pastors hear that you have HIV they assume that you went sleeping out with men,” remarked a female participant, “Like our friend here, she contracted the disease from her husband. Let pastors accept the HIV victims so that they can be helped.” Another woman who disclosed to her pastor after telling her brother and cousin was shocked three weeks later when he likened PLHAs from the pulpit to persons who are bewitched; they should not be prayed for in church. Yet another pastor proclaimed a female participant’s status to the world, she said, “as if it were on Kameme [a local radio station].”

If participants were generally trusting of their pastors, they were less so of their fellow congregants. Church members were frequently mentioned as a group from which participants wanted to hide their status. “I didn’t want the people I fellowship with at the church to know because they would . . . feel that if you are positive it’s because you have sinned,” one said. Several participants concurred. Their primary worry was that if they revealed that had HIV, fellow believers would judge them without even having any idea of how they were infected, that the automatic assumption if one was HIV-positive would be that one was personally guilty of immorality. Participants expressed a related concern that this judgment would lead to extensive gossip among the membership of the church. Some, in fact, left their churches to avoid this scenario: “When I became weak and then my appearance was changing,” remarked a male focus group member, “I did not want to go and expose myself to the Church and [have] people start to
speculate, ‘What is happening to him. . .’” Several located other, less stigmatizing churches, though one mentioned it had caused him to leave church altogether.

Some participants spoke more generally about their objections to discrimination they perceived from church leaders and congregations. A female participant, for example, explained, “The church should give these people, these HIV people, love. They should love them more and they should not stigmatize them. Actually the role of the church, is . . . they have to love these people who are sick.” Her sentiments were echoed by a woman in the other female group, who urged, “What I would say is that churches should realize that this thing is real and it shouldn’t cause discrimination. This thing can affect everybody: the pastors, and everybody in the congregation.”

**Summary of Focus Group Findings**

PLHAs who were participants of the focus groups in this study, therefore, expressed many of the same reasons for disclosing and not disclosing their status as have their counterparts in the United States. However, there were also differences. A number of reasons commonly cited by PLHAs in the United States for disclosure did not explicitly arise in the discussions, such as self-blame leading to shame, testing other’s reaction, catharsis, and desire to decrease societal stigma of HIV/AIDS. Several motivations not evidenced among U.S. PLHAs appeared with regularity in the focus groups, but which exemplify some of the differences between lived experience of the disease in the two nations. Focus group discussants were motivated by the need for material support and to prepare for the future, especially to ensure that their children were adequately cared for after their own deaths. Finally, PLHAs in the four groups also shared their status out of a need for advice, including guidance on how to inform other significant persons in
their lives about their condition. Results of the larger, primarily quantitative, interview study elaborated on these findings, and it is to the component of the research that we now turn.

Results of the Interview Study

At the end of Chapter 2, hypotheses and research questions for the project were arranged according to categories of targets, motivations, and methods. The following sections retain that organizational framework, presenting results of hypothesis testing via statistical analyses of questionnaire scales, as well as accompanying qualitative analyses from open-ended questions as they relate to each topic. Significance levels for all statistical analyses were set at .05 for rejection of the null hypothesis and then adjusted as appropriate in accordance with the Bonferroni rationale. Certain post hoc analyses on emergent issues that had not been hypothesized are also presented in the final section of this chapter.

Disclosure Targets

Hypothesis 1 and Research Question 1 addressed issues of identity of disclosure targets. H1 stated that family members would be listed more often among early disclosure targets than would friends. It was tested using data from the final listing task that simply asked participants to list the first five individuals to whom they had disclosed their positive serostatus. Participants were also asked to supply the relationship between themselves and each of these five earliest disclosees (e.g. sister, father, friend, ladies’ leader in church). For purposes of data analysis, those relational descriptions were placed into one of the same four relational categories by which motivation to disclose data had been collected: (1) spouse/partner, (2) friend, (3) family member, and (4) religious leader. In the process of categorization, however, it became evident that another category needed to be created, that of HIV-related targets. Disclosure targets coded under this category were HIV-related counselors, medical professionals involved
with treating HIV-related symptoms, and, most commonly, support groups. The category of HIV-related targets, it should be noted, did not include medical personnel at the clinic where the participant was initially diagnosed as seropositive. It did include individuals at other clinics or organizations where participants sought HIV-related assistance. It included voluntary support groups at the diagnosing organization, because in order to join such a group, participants would have to make a disclosure decision. HIV-related targets accounted for 18% of the early disclosure targets mentioned by participants.

Notwithstanding the addition of this fifth, emergent category of disclosees, certain other early disclosees mentioned by participants in this section of the interview were simply unclassifiable. These included, for example, a participant’s lawyer and the nephew of a neighbor. Four percent of early disclosure targets were therefore classified as “other” and excluded from further analysis.

Tabulating the first five disclosure targets was not so straightforward as it might appear. The listing task was placed at the end of the questionnaire because it then served as a kind of summary, closing off discussion of disclosure tasks. However, locating it at the end was not without drawbacks. Having already spoken of an individual earlier in the interview might incline participants to omit that information on the listing task. Therefore in the training, interviewers were given clear and specific instructions that they should ask participants to repeat any disclosure targets who had already been discussed, as well as dates that those targets had been disclosed to, and so on. Data collectors were told to emphasize that the question was intended to identify the individuals disclosed to in order.

Even so, the occasional questionnaire omitted mention on the listing task of individuals for whom dates had already been given for disclosure and who according to the dates provided in
the earlier part of the questionnaire were evidently informed ahead of individuals included on the list. Furthermore, some participants understandably did not recall their disclosure targets in order initially and would double back to mention someone they had forgotten, meaning that the person listed in the second position might in fact have been disclosed to fourth, and so on. Therefore entering data for that portion of the questionnaire required careful comparison of information throughout the entire questionnaire and reorganizing the order if necessary depending on the dates the respondent provided.

Once data were entered, frequencies indicated that out of 300 participants who answered the question, 178 (59.3%) mentioned fewer than five participants to whom they had disclosed, and 122 (30.7%) participants had disclosed their status to at least five persons, i.e. their list was full. Fifty-three participants (17.6%) listed only four disclosees; 53 (17.6%) listed three; 34 (11.3%) mentioned two; 32 (10.7%), one. Of those who had only told one person, in 21 cases (65.6%) that person was their spouse or partner. Six (2%) indicated they had told no one of their condition. Seven (2.3%) individuals did not engage in the listing task.

Table 2 gives frequency counts of responses to the listing task of the first five people participants reported informing of their status. Among the first five persons informed, family members were over twice as frequently listed as were friends. A one-sample chi-square test between friends and family (collapsing across target positions one to five) was significant ($\chi^2 (1) = 77.223, p < .001$), indicating family members were more likely to be reported as being one of the first five targets of serostatus disclosure than were friends. Thus Hypothesis 1 (that family members would be listed more often among early disclosure targets than would friends) was supported.
Table 2

Frequency Counts of First Five People Informed of HIV-Status, by Category

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<thead>
<tr>
<th>Category</th>
<th>1st</th>
<th>2nd</th>
<th>3rd</th>
<th>4th</th>
<th>5th</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td>123</td>
<td>21</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>162</td>
</tr>
<tr>
<td>(Longstanding)</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>38</td>
<td>61</td>
<td>42</td>
<td>27</td>
<td>17</td>
<td>185</td>
</tr>
<tr>
<td>Family</td>
<td>83</td>
<td>114</td>
<td>87</td>
<td>72</td>
<td>41</td>
<td>397</td>
</tr>
<tr>
<td>Religious</td>
<td>6</td>
<td>17</td>
<td>25</td>
<td>20</td>
<td>18</td>
<td>86</td>
</tr>
<tr>
<td>HIV-related</td>
<td>36</td>
<td>38</td>
<td>61</td>
<td>35</td>
<td>26</td>
<td>196</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>10</td>
<td>8</td>
<td>14</td>
<td>11</td>
<td>47</td>
</tr>
<tr>
<td>Not identified*</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>294</td>
<td>262</td>
<td>228</td>
<td>175</td>
<td>122</td>
<td>1081</td>
</tr>
</tbody>
</table>

\[ \chi^2 \] 147.64 125.31 91.46 76.69 29.49 414.97

|   | <.001 | <.001 | <.001 | <.001 | <.001 | <.001 |

* e.g. research assistant recorded only a name in the space without indicating the person’s relationship to the participant.

** \( \chi^2 \) tests likelihood of each relationship category appearing within each target position.
Several more points should be made with reference to the data in table 2. First, although a number of participants chose not to inform their spouse or partner of their status, spouses/partners were the most likely of the five groups to be informed first ($\chi^2 (4) = 147.46, p < .001$). Family members began appearing with most frequency at the second respondent position ($\chi^2 (4) = 125.31, p < .001$), a fact probably related to the strong tendency for partners to be informed first if they were informed at all. The number of long-time friends informed remained fairly consistent across target positions. Religious leaders were least often mentioned among the first five confidants, but the fact that 86 of 480, or nearly one-fifth, of non-family and non-partner targets mentioned were religious leaders or church members confirms the impression from the focus groups that they are worth consideration as a category on their own.

HIV-related targets were mentioned second only in frequency to family members in the listing task, and were disclosed to in approximately equal proportions across all five target positions. That is, they were selected as early disclosure targets more than either friends or religious leaders. Although the use of support groups as a source of participants for the study would obviously mean that these participants would by definition have disclosed to at least one such group, on the other hand it would not necessitate that that group was among the earliest disclosure targets. Thus the prevalence of HIV-related targets is an unexpected but notable finding.

Another way to consider these proportions is in terms of the number of participants for each relationship category who disclosed to at least one person in that category. It was noted in Chapter 3 that this device has been a commonly used in U.S. disclosure studies (e.g. Mason, et al., 1992; Marks et al., 1992) as an index of frequency of disclosure to various relationship types. Of the 243 participants who indicated they had had a sexual partner or spouse since diagnosis,
161 (66.2%) listed at least one partner in the first five individuals they had informed. Eighty-six (32.3%) of the 266 participants who said they had a religious leader, had disclosed to at least one church leader or church group among the first five disclosees. Of the 300 participants who completed the listing task, 161 (53.6%) had informed at least one friend; 205 (68.3%) and had told at least one family member; and 150 (50.0%) had confided in at least one HIV-related person (or support group).

*Rate of Disclosure to Partners*

The finding that around two-thirds of participants listed partners among their early confidants can be triangulated with information provided as part of filling out the motivation to disclose/conceal scales. Among the 243 who indicated that they had had a sexual partner since their diagnosis, 172 (68%) indicated in the motivation scale data collection that their partner knew of their status. Of the 183 who chose to respond with reference to spouses, 161 (88%) indicated they had informed their spouses of their serostatus and 43 (12%) reported that they had not done so. In contrast, of the 60 participants who elected to describe disclosure motivations to extramarital partners only 29 (48.3%) said they had told their partners of their status, whereas 31 (51.7%) indicated they had not. Participants in this study were thus substantially more likely to describe disclosure as opposed to nondisclosure when the partner they were referring to was a spouse as opposed to a boyfriend or girlfriend (χ² (1) = 41.64, p < .001). The slightly higher proportion of participants in the disclosure motivation section versus the disclosure target listing section of the questionnaire is due in part to the fact that three participants indicated on the motivation scale that their partner knew of their status, but not because the participant had disclosed that information; the partner had figured it out him/herself. It may also be because the target identification list solicited only the first five disclosure targets, so that persons informed
after the fifth position would not have appeared on the lists. That is, in some cases a partner might have been informed, but not among the first five disclosures.

Hypothesis 11 predicted that in comparison to female PLHAs, male PLHAs would be more likely to report at least one sexual partner among early disclosure targets. Across all five disclosure targets, male PLHAs reported disclosure to 60 partners and females to 101 (see table 3). Because of the gender imbalance of the sample, these raw frequencies corresponded to 75% of men and 48% of women who reported having had at least one sexual partner since their diagnosis having revealed their status to a partner. After removing from analysis all cases in which the participant indicated s/he had not had a sexual partner since diagnosis, a chi-square test of gender by partner disclosure/no partner disclosure yielded a value of 4.15 (1), \( p = .04 \).

Therefore Hypothesis 11 was supported. Tests regarding the other categories were carried out by splitting the data file according to relationship type, and weighting expected values according to the proportion of male and female disclosures out of the total disclosures reported. Results indicated no significant association between gender for the proportion of participants who listed friends, family members, or religious leaders among the first five disclosure targets.

Table 3

<table>
<thead>
<tr>
<th>Relationship</th>
<th># mentions by male PLHAs</th>
<th># mentions by female PLHAs</th>
<th>Total # mentions</th>
<th>( \chi^2 )</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>109 (40%)</td>
<td>284 (38%)</td>
<td>397 (37%)</td>
<td>.13</td>
<td>.72</td>
</tr>
<tr>
<td>Mother</td>
<td>24 (8%)</td>
<td>40 (5%)</td>
<td>64 (6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship</td>
<td># mentions by male PLHAs</td>
<td># mentions by female PLHAs</td>
<td>Total # mentions</td>
<td>$\chi^2$</td>
<td>$p$</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------------</td>
<td>-----------------------------</td>
<td>-----------------</td>
<td>---------</td>
<td>-----</td>
</tr>
<tr>
<td>Father</td>
<td>7 (3%)</td>
<td>12 (2%)</td>
<td>19 (2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sister</td>
<td>24 (8%)</td>
<td>82 (10%)</td>
<td>106 (10%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brother</td>
<td>22 (7%)</td>
<td>45 (6%)</td>
<td>67 (6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cousin</td>
<td>5 (2%)</td>
<td>14 (2%)</td>
<td>19 (2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aunt</td>
<td>4 (1%)</td>
<td>16 (2%)</td>
<td>20 (2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uncle</td>
<td>4 (1%)</td>
<td>7 (1%)</td>
<td>11 (1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>3 (1%)</td>
<td>11 (1%)</td>
<td>14 (1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brother-in-law</td>
<td>5 (2%)</td>
<td>9 (1%)</td>
<td>14 (1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>6 (2%)</td>
<td>45 (6%)</td>
<td>51 (5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other family</td>
<td>5 (2%)</td>
<td>7 (1%)</td>
<td>12 (1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV-related</td>
<td>45 (16%)</td>
<td>151 (20%)</td>
<td>196 (18%)</td>
<td>2.07</td>
<td>.15</td>
</tr>
<tr>
<td>Support group</td>
<td>34 (12%)</td>
<td>124 (16%)</td>
<td>158 (15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counselor</td>
<td>4 (1%)</td>
<td>10 (1%)</td>
<td>14 (1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical prof.</td>
<td>7 (3%)</td>
<td>17 (2%)</td>
<td>24 (2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>41 (15%)</td>
<td>144 (19%)</td>
<td>185 (17%)</td>
<td>1.75</td>
<td>.10</td>
</tr>
<tr>
<td>Partners</td>
<td>60 (22%)</td>
<td>101 (14%)</td>
<td>162 (15%)</td>
<td>4.14</td>
<td>.04</td>
</tr>
<tr>
<td>Spouse</td>
<td>55 (19%)</td>
<td>84 (11%)</td>
<td>139 (13%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extramarital partner</td>
<td>5 (2%)</td>
<td>15 (2%)</td>
<td>20 (2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fiancé</td>
<td>0 (0%)</td>
<td>3 (0%)</td>
<td>3 (0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religious</td>
<td>19 (7%)</td>
<td>67 (9%)</td>
<td>86 (8%)</td>
<td>1.18</td>
<td>.18</td>
</tr>
<tr>
<td>Relationship</td>
<td># mentions by male PLHAs</td>
<td># mentions by female PLHAs</td>
<td>Total # mentions</td>
<td>( \chi^2 )</td>
<td>( p )</td>
</tr>
<tr>
<td>-------------------</td>
<td>--------------------------</td>
<td>-----------------------------</td>
<td>------------------</td>
<td>----------</td>
<td>------</td>
</tr>
<tr>
<td>Rel. leader</td>
<td>18 (6%)</td>
<td>58 (7%)</td>
<td>76 (7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Church group</td>
<td>1 (0%)</td>
<td>9 (1%)</td>
<td>10 (1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>16 (5%)</td>
<td>30 (4%)</td>
<td>47 (4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not identified</td>
<td>2 (1%)</td>
<td>6 (1%)</td>
<td>8 (1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>292 (100%)</td>
<td>789 (100%)</td>
<td>1081 (100%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Because gender was not indicated on several questionnaires, responses of males and females do not always add up to the total.

Other Disclosure Targets

Research Question 1 explored disclosure targets more specifically, asking to what individuals PLHAs most often reported disclosing serostatus among early disclosure targets. This question was explored using the set of unaggregated target relationships supplied by participants in response to the open-ended target listing question. Sub-categories in table 3 above indicate the specific identity of disclosure targets. Among family members, female PLHAs mentioned sisters as their family confidantes twice as often as the next most frequently cited categories of brothers, mothers, and children. For male PLHAs, sisters were mentioned with about the same frequency as mothers and brothers. Cousins, aunts, and fathers were mentioned regularly but less often by both males and females. Once again, it is possible to triangulate findings about the identity of disclosure targets using data derived from the motivation questions. In those questions, prior to filling out a disclosure or nondisclosure scale about a given relationship, participants were asked to identify the specific person about whom they would be thinking as they responded (again, see...
Appendix D for wording of questionnaire). Family members on whom PLHAs selected to fill out disclosure motivation scales followed a similar pattern, with sisters selected most frequently, followed by mothers and brothers in about equal numbers, then other family members.

*Generational Homophily of Disclosure Targets*

In light of observations that East African PLHAs were likely to turn to a relative of the same generation for their disclosure target (Lie & Biswalo, 1996), a chi-square analysis was conducted on generation of family target. The 51 mentions of disclosure to children were omitted from the analysis. Results indicated that a significantly larger proportion of family disclosure targets mentioned by participants in the study were of the same (220, or 66%) as opposed to an older generation (114 or 34%) relative to PLHA participants ($\chi^2 (1) = 33.64, p < .001$).

*Gender Homophily of Disclosure Targets*

Similarly, I followed up on reported observations that East African PLHAs’ disclosed most readily to targets of their same gender (Lie & Biswalo, 1996). Not including 166 disclosure targets that may have included both genders (e.g. a support group or unspecified gender), 59% of targets listed by female participants were females, but only 37.6% of targets listed by males were males. Chi-square test of gender of participant by gender of target yielded no significant association ($\chi^2 (1) = .73, p = .39$).

*HIV Homophily of Disclosure Targets*

It was anticipated that participants would disproportionately seek out HIV positive persons among their first five disclosure targets, especially when the target was a friend. Before analysis, the “don’t know” option of HIV-status of targets was collapsed into the “HIV/AIDS negative” category, with the reasoning that if PLHAs did not know the HIV status of a potential disclosure target, they probably were not seeking out that person because s/he was seropositive.
A one sample chi square test was then conducted with 10 and 90 entered as the a priori expected values for HIV+ and HIV- respectively, based on population estimates of the HIV prevalence rate among persons 15 to 49 years old in Nairobi (UNAIDS, 2004). Participants were overall found to have been more likely to selected HIV-positive targets for disclosure than targets who were not known to be HIV-positive ($\chi^2 (4) = 742.33, < .001$). This finding held true even after the category of HIV-related targets (e.g. support group members, VCT clinic workers) was removed from analysis ($\chi^2 (4) = 227.77, p < .001$).

When the data were examined by relationship category separately it was found that this tendency to preferentially disclose to known HIV+ individuals was not statistically significant with respect to family members or religious leaders (see table 4), but it was among friends.

Table 4

*Frequencies of HIV+ vs. HIV- Targets by Relationship Category*

<table>
<thead>
<tr>
<th></th>
<th>Partners</th>
<th>Friends</th>
<th>Family</th>
<th>Religious</th>
<th>HIV-related</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV+</td>
<td>95 (59%)</td>
<td>63 (34%)</td>
<td>24 (6%)</td>
<td>3 (3%)</td>
<td>149 (76%)</td>
</tr>
<tr>
<td>HIV-</td>
<td>53 (33%)</td>
<td>92 (50%)</td>
<td>320 (81%)</td>
<td>62 (72%)</td>
<td>33 (17%)</td>
</tr>
<tr>
<td>Missing</td>
<td>14 (8%)</td>
<td>30 (16%)</td>
<td>53 (13%)</td>
<td>21 (24%)</td>
<td>14 (7%)</td>
</tr>
<tr>
<td>Total</td>
<td>162 (100%)</td>
<td>185 (100%)</td>
<td>397 (100%)</td>
<td>86 (100%)</td>
<td>196 (100%)</td>
</tr>
<tr>
<td>$\chi^2$</td>
<td>482.89</td>
<td>161.74</td>
<td>3.49</td>
<td>2.09</td>
<td>1044.49</td>
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<tr>
<td>$p$</td>
<td>&lt;.001</td>
<td>&lt;.001</td>
<td>.062</td>
<td>.148</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
This relationship-specific finding adds weight to the support obtained for Hypothesis 3 (that disclosure to family members would be less strongly motivated by knowledge that the disclosure target is HIV+ than would disclosure to friends, see results below).

**Timing of Disclosure.** Research Question 5 asked at what point after diagnosis are disclosures of HIV likely to occur. Time until disclosure was calculated by subtracting diagnosis date from date of disclosure to a given target. Time from diagnosis to disclosure to the first target ranged from the same day (as indicated in other portions of the questionnaire) to fourteen years later. Mean time in years from time of diagnosis to disclosure to first target was .45 years ($n = 286, SD = 1.74$); from diagnosis to disclosure to second target was 1.139 years ($n = 251, SD = 2.45$); to third target was 1.81 years ($n = 209, SD = 2.89$); to fourth target was 2.32 years ($n = 162, SD = 3.32$); and to fifth target 2.26 years ($n = 113, SD = 3.45$). Modal values for first to fourth targets were zero years and for fifth target was one year. Medians for first and second year were zero years, and one year for third, fourth, and fifth targets.

A two-way ANOVA was also run with gender of participant (male, female) and relationship to target (partner, friend, family, religious leader, HIV-related individual) as independent variables and time to disclosure as the dependent variable. There was no statistically significant interaction effect ($F(4, 954) = .17, p = .10, \eta^2 = .001$) or effect for gender ($F(1, 954) = .03, p = .86, \eta^2 = .000$). However, parallel to findings above regarding the tendency of partners to be the first disclosure target if they were told, there was an effect for relationship to target ($F(4, 954) = 6.91, p < .001, \eta^2 = .03$), with mean time until disclosure to partner significantly less than to any other group.

**Motivations for Disclosure and Nondisclosure**

Hypotheses 2, 3, 4, 5, 8, 9, and 10 and Research Questions 2 and 5 dealt with motivational
criteria for boundary rule formation. Some mention has already been made in Chapter 3 about the fact that despite participants’ all responding to multiple possible disclosure targets, the design of this portion of the study could not be a repeated measure, because only 10% of participants reported either consistent disclosure or consistent nondisclosure to all four target groups. Participants filled out different motivation scales—that is, different dependent measures—for disclosure as opposed to concealment. Accordingly, the analysis had to be conducted as if participants were nested in targets. In fact, most were partially nested and partially crossed. This means that between-subjects error terms were used to test all $F$ and $t$ statistics. Using between-subject error when in fact some of that variance really was within-subject had the ultimate effect of inflating error terms, hence the results presented here should be viewed as more conservative than they would have been had participants behaved in a systematic but unrealistic way and either chosen to disclose to all four targets or chosen not to have disclosed to all four targets.

Hypotheses regarding disclosure and nondisclosure motivation were examined by means of two two-way MANOVAs. Disclosure target (type of relationship: partner, friend, relative) and gender were the independent variables in each analysis. Dependent variables for the first MANOVA were the ten motivations for disclosure (wanted advice, close relationship, duty to inform, seeking emotional support, trusted confidentiality, seeking material support, prepare for future, seeking intermediation, knowing target is HIV-positive, condition would be obvious). For the second MANOVA, dependent variables were the seven motivations for nondisclosure identified in focus group research (fear of rejection, fear of target telling, didn’t want target to experience pain, relationship not close, didn’t know how to tell, didn’t want target to worry, target not HIV-positive). Means and standards deviations for both reasons for disclosure and
nondisclosure are listed in tables 5 and 6. (See Appendix E for dependent variable
tercorrelations, as well as an additional table displaying an average of those correlations across
all four relationship types.)

Table 5
Means and Standards Deviations of Disclosure Motivation by Relationship and Gender

<table>
<thead>
<tr>
<th></th>
<th>Partner</th>
<th>Friend</th>
<th>Family</th>
<th>Relig. leader</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M$ ($SD$)</td>
<td>$M$ ($SD$)</td>
<td>$M$ ($SD$)</td>
<td>$M$ ($SD$)</td>
<td>$M$ ($SD$)</td>
</tr>
<tr>
<td>Advice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>3.23 (1.66)</td>
<td>3.86 (1.44)</td>
<td>3.49 (1.51)</td>
<td>4.36 (0.95)</td>
<td>3.59 (1.53)</td>
</tr>
<tr>
<td>(n = 61)*</td>
<td>(n = 36)</td>
<td>(n = 47)</td>
<td>(n = 22)</td>
<td>(n = 166)</td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>3.81 (1.50)</td>
<td>3.94 (1.50)</td>
<td>3.86 (1.51)</td>
<td>4.36 (1.12)</td>
<td>3.95 (1.44)</td>
</tr>
<tr>
<td>(n = 100)</td>
<td>(n = 122)</td>
<td>(n = 144)</td>
<td>(n = 73)</td>
<td>(n = 439)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>3.59 (1.58)</td>
<td>3.92 (1.43)</td>
<td>3.77 (1.52)</td>
<td>4.36 (1.08)</td>
<td>3.85 (1.47)</td>
</tr>
<tr>
<td>(n = 161)</td>
<td>(n = 158)</td>
<td>(n = 191)</td>
<td>(n = 95)</td>
<td>(n = 605)</td>
<td></td>
</tr>
<tr>
<td>Closeness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>4.18 (1.13)</td>
<td>4.53 (0.70)</td>
<td>4.55 (0.95)</td>
<td>3.32 (1.43)</td>
<td>4.25 (1.11)</td>
</tr>
<tr>
<td>Females</td>
<td>4.29 (1.06)</td>
<td>4.22 (1.16)</td>
<td>4.39 (1.07)</td>
<td>3.59 (1.37)</td>
<td>4.19 (1.17)</td>
</tr>
<tr>
<td>Total</td>
<td>4.25 (1.08)</td>
<td>4.29 (1.08)</td>
<td>4.43 (1.04)</td>
<td>3.53 (1.38)</td>
<td>4.20 (1.16)</td>
</tr>
<tr>
<td>Duty to tell</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>4.43 (0.99)</td>
<td>4.14 (1.15)</td>
<td>4.38 (1.11)</td>
<td>3.82 (1.25)</td>
<td>4.27 (1.11)</td>
</tr>
<tr>
<td>Females</td>
<td>4.56 (0.97)</td>
<td>3.77 (1.40)</td>
<td>4.22 (1.13)</td>
<td>3.88 (1.28)</td>
<td>4.11 (1.24)</td>
</tr>
<tr>
<td>Total</td>
<td>4.51 (0.98)</td>
<td>3.85 (1.35)</td>
<td>4.26 (1.12)</td>
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*Cell sizes of males and females the same for all motivations

Table 6

*Means and Standards Deviations of Nondisclosure Motivation by Relationship and Gender*
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<td>(n = 95)</td>
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Gossip

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Didn’t want to cause pain

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Relationship not Close

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Didn’t know how to tell

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<td>(n = 420)</td>
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<tr>
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<td>Friend $M$ (SD)</td>
<td>Family $M$ (SD)</td>
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*Cell sizes for males and females the same for all motivations

It should be mentioned here that sample sizes were unequal in two respects: 1) there were only about half as many reasons for disclosure scales filled out about religious leaders than for each of the other three groups (and correspondingly more reasons for nondisclosure to religious leader scales filled out), and 2) there were two-and-a-half times as many women as men in the sample. Both of these situations were unavoidable, as mentioned in Chapter 3, but they did have statistical implications. As differences in cell size appeared in the light of the literature review to be representative of population differences in percent of disclosure to each group (see for example Bungener, 2000; Grinstead, et al., 2001; Maman et al., 2001, 2002; Songok & Andayi, 2003), a weighted approach was taken to the computation of marginal means (Maxwell & Delaney, 2004, pp. 271-297).
Analyses with unequal sample sizes are not robust to violations of the homogeneity of variance assumption, therefore homogeneity of variance tests were conducted for all analyses (see Appendix F for univariate homogeneity of variance results). Results of Box’s $M$ tests for homogeneity of variance on both multivariate analyses (disclosure: $M = 713.174$, $p < .001$; nondisclosure: $M = 290.830$, $p = .003$) indicated the null hypothesis should be rejected. However, as Box’s is an extremely powerful test (Huberty & Lowman, 1998), and converted $F$-scores for both analyses were not high (1.703 for disclosure; 1.308 for nondisclosure), it was determined that homogeneity of the covariance matrices could be nonetheless assumed.

For univariate analyses on which the tests indicated homogeneity of variance between groups could not be assumed, nonparametric analogues of parametric tests were employed. Kruskal-Wallis tests were conducted to failsafe accuracy of $F$-tests, and Mann-Whitney $U$ tests were run to check $t$-tests in paired comparisons. (See Appendix G for comparison of results of parametric and non-parametric tests on those analyses). No changes were made as a result of this exercise, although a few comparisons that did not yield statistically significant relationships with parametric tests did attain significance when analyzed with the non-parametric tests. Parametric tests are reported in all cases in order to ensure what are evidently more conservative results.

_Hypothesis Tests Regarding Reasons for Disclosure_

Hypotheses 2, 3, 8, and 10 concerned reasons for disclosure. Hypothesis 2 predicted that disclosure to family members would be more strongly motivated by seeking a) emotional support and b) material support than would disclosure to non-family members. Hypothesis 3 stated that disclosure to friends would be more strongly motivated by knowledge that the disclosure target is HIV+ than would disclosure to family members. Hypothesis 8 posited that disclosure to family members would be more strongly motivated by seeking intermediation than would disclosure to
friends. Hypothesis 10 predicted that disclosure would be more strongly motivated by seeking material support among female than male PLHAs.

Results of the 2 (gender: male or female) x 4 (relationship type: partner, friend, family, or religious leader) MANOVA indicated a main effect for target group, or relationship, (Wilk’s $\Lambda = .68$, equivalent to $F(30, 1726.572) = 8.18, p < .001, \eta^2 = .12$) with respect to reasons for disclosure. A multivariate main effect also emerged for gender (Wilk’s $\Lambda = .96, F(10, 588) = 2.52, p = .006, \eta^2 = .04$). No significant interaction between gender and relationship type was indicated type (Wilk’s $\Lambda = .96, F(10, 588) = .77, p = .81$).

Subsequent univariate ANOVA analyses were run separately for each of the ten motivations for disclosing. Gender by relationship type cell means for these analyses have been presented in table 5. Univariate tests revealed no statistically significant differences between relationship types with reference to emotional support ($F(3, 597) = 1.21, p = .31$), trusting the confidante not to tell anyone ($F(3, 597) = .03, p = .99$), seeking intermediation ($F(3, 597) = 2.03, p = .11$), and the belief that the PLHA’s condition would be obvious to the target ($F(3, 597) = 1.77, p = .15$). Therefore Hypothesis 2a (predicting that the need for emotional support would motivate disclosure to family members more than to friends) was not supported. Hypothesis 8 (that participants would report experiencing higher motivation to seek an intermediary when disclosing to family than to friends) was likewise not supported. (However, for a different perspective on this latter issue, see the data from open-ended questions on disclosure technique below).

On the other hand, univariate ANOVAs did reveal the following statistically significant differences between relationship types with respect to the remaining disclosure motivations. $F$ statistics reported are from univariate analyses of the remaining seven scales indexing motivation
for disclosing. As noted above, all pairwise contrasts were adjusted as per the Bonferroni rationale to preserve a family-wise alpha of .05.

Respondents were more strongly motivated by seeking advice \( (F(3, 605) = 5.36, p < .001, \eta^2 = .03) \) when disclosing to a religious leader \( (M = 4.36, SD = 1.08) \) than when disclosing to partners \( (M = 3.59, SD = 1.58) \) or family members \( (M = 3.77, SD = 1.52) \).

Having a close relationship with a target \((F(3, 605) = 14.75, p < .001, \eta^2 = .07)\), was a more intense reported motivation for disclosing to partners \((M = 4.25, SD = 1.08)\), friends \((M = 4.29, SD = 1.08)\), and family members \((M = 4.43, SD = 1.04)\) than for disclosing to religious leaders \((M = 3.53, SD = 1.38)\).

Respondents reported being more strongly motivated by duty to tell the disclosure target when informing partners \((M = 4.51, SD = 0.98)\) than when revealing their status to friends \((M = 3.85, SD = 1.35)\) and religious leaders \((M = 3.86, SD = 1.29)\) \((F(3, 605) = 10.87, p < .001, \eta^2 = .05)\). Participants also reported higher motivation for seeking material support when disclosing to partners \((M = 3.70, SD = 1.64)\) and family \((M = 3.54, SD = 1.67)\) than when disclosing to friends \((M = 2.97, SD = 1.70)\) or religious leaders \((M = 2.97, SD = 1.67)\) \((F(3, 605) = 6.83, p < .001, \eta^2 = .04)\). Therefore Hypothesis 2b, which stated that disclosures to family would be more highly motivated by seeking material support than would disclosures to friends, was supported. With respect to preparation for the future \((F(3, 605) = 10.02, p < .001, \eta^2 = .05)\), participants rated this motivation more highly in deciding to disclose their status to family members \((M = 4.53, SD = 1.01)\) than in disclosure to either a friend \((M = 3.99, SD = 1.36)\) or religious leader \((M = 3.84, SD = 1.39)\), and more highly in relation to partners \((M = 4.36, SD = 1.18)\) than religious leaders.
Finally, participants were more strongly motivated toward disclosure by knowledge that the target was HIV+ with respect to partners ($M = 2.93, SD = 1.78$) than to friends ($M = 1.99, SD = 1.64$), family members ($M = 1.38, SD = 1.04$) or religious leaders ($M = 1.20, SD = 0.79$). They also reported it to be a stronger motivation in the decision to disclose to friends than to religious leaders ($F(3, 605) = 44.45, p < .001, \eta^2 = .18$). Thus Hypothesis 3, which asserted that participants would be more powerfully motivated to disclose by the knowledge that their target was also HIV-positive when that target of disclosure was a friend, as compared to when the target was a family member, was supported.

By Cohen’s (1965) guidelines, the effect of relationship type on knowledge that the target was HIV+ as a motivation for disclosure was large, that on closeness of relationship was medium-sized, and the remaining effects of relationship type on disclosure motivation were small.

The ten univariate ANOVAs also yielded information regarding gender main effects. Hypothesis 10 predicted that disclosure would be more strongly motivated by seeking material support among female than male PLHAs. Female participants did report seeking material support to be a stronger motivation for disclosure ($F(1, 603) = 6.81, p = .009, \eta^2 = .01$) than did men ($M = 3.05, SD = 1.70$). They also rated seeking advice as a stronger motivation than did men ($F(1, 603) = 7.47, p = .006, \eta^2 = .01$). Therefore Hypothesis 10 was supported. Females also indicated that knowing the potential target was also HIV-positive was motivation for disclosure more strongly than did men ($F(1, 597) = 7.73, p = .006, \eta^2 = .01$). There were no statistically significant gender effects on the motivations of seeking advice ($F(1, 597) = 3.36, p = .07$), having a close relationship ($F(1, 597) = .04, p = .83$), having a duty to tell ($F(1, 597) = .57, p = .45$), seeking emotional support ($F(1, 597) = .42, p = .52$), trusting the disclosee not to tell ($F(1,$
Effects for gender on motivation were, therefore, quite small (Cohen, 1965).

Hypothesis tests regarding reasons for nondisclosure. Hypotheses 4 and 5 referred to reasons for nondisclosure. H4 stated that nondisclosure to non-family members would be more strongly motivated by fear of rejection than would nondisclosure to family members. Hypothesis 5 predicted that nondisclosure to family members would be more strongly motivated by other-focused reasons than would nondisclosure to friends. Hypothesis 9 posited that nondisclosure would be more strongly related to fear of rejection among female PLHAs than among male PLHAs.

As an initial step to explore these hypotheses, a 2 (gender: male or female) x 4 (relationship type: partner, friend, family, or religious leader) MANOVA was run on the cluster of seven motivations to withhold disclosure. A main effect was obtained for relationship type (Wilk’s Λ = .82, $F(7, 406) = 4.10, p < .001, \eta^2 = .07$). However, no significant multivariate effect was found for gender (Wilk’s Λ = .98, $F(7, 406) = 1.23, p = .28$), or for the gender by relationship type interaction (Wilk’s Λ = .96, $F(7, 406) = 1.17, p = .83$).

Given the statistically significant multivariate effect for relationship type, separate univariate ANOVAs were run for each of the seven motivations to withhold disclosure. Gender by relationship type cell means have been presented in table 6. No differences were found among relationship types with reference to fear of rejection ($F(3, 412) = 1.10, p = .35$), not knowing how to go about telling the potential target ($F(3, 412) = 1.20, p = .31$), or thinking that potential target was HIV-negative ($F(3, 412) = 1.42, p = .23$). Therefore Hypothesis 4
(nondisclosure to non-family members will be more strongly motivated by fear of rejection than will nondisclosure to family members) was not supported.

Statistically significant differences between relationship types for the other nondisclosure motivations are listed below. $F$ statistics reported are from univariate analyses; all pairwise comparisons were subject to Bonferroni adjustments.

Concern about breach of confidentiality was reported as a larger concern regarding friends ($M = 4.11$, $SD = 1.40$) than for partners ($M = 2.77$, $SD = 1.67$), family members ($M = 3.12$, $SD = 1.74$), or religious leaders ($M = 3.45$, $SD = 1.56$) ($F (1, 419) = 11.86, p < .001, \eta^2 = .08$).

Concern that the potential target not experience pain over the PLHA’s condition was a greater motivation for not telling family members ($M = 4.09$, $SD = 1.24$) than for not confiding in partners ($M = 3.12$, $SD = 1.63$), friends ($M = 3.31$, $SD = 1.49$), or religious leaders ($M = 2.82$, $SD = 1.51$) ($F (1, 419) = 15.22, p < .001, \eta^2 = .10$).

Similarly, not wanting the potential confidant to worry about the PLHA’s condition was a stronger motivation for nondisclosure to family members ($M = 4.09$, $SD = 1.24$) than to friends ($M = 3.31$, $SD = 1.49$), or religious leaders ($M = 2.32$, $SD = 1.61$) ($F (1, 419) = 15.55, p < .001, \eta^2 = .10$). Hypothesis 5 (nondisclosure to family members will be more strongly motivated by other-focused reasons than will nondisclosure to friends) was supported, as the motivations of not wanting the target to experience pain, and not wanting the target to experience worry were the two other-focused motivations on the scale.

Finally, lack of closeness to the potential disclosure target was a more important motivation for not telling religious leaders ($M = 3.03$, $SD = 1.56$) than for not disclosing to
friends ($M = 2.45, SD = 1.44$) or family members ($M = 2.42, SD = 1.44$) ($F(1, 419) = 5.02, p = .002, \eta^2 = .04$).

Effect sizes of relationship type on not wanting the target to experience pain or worry, and concerns about breach of confidentiality could be considered by Cohen’s (1965) general guidelines to be medium-sized, and that for lack of closeness could be considered by the same guidelines as small.

*Additional Reasons for Disclosure and Nondisclosure: Analysis of open-ended responses.* The questionnaire included options on all disclosure and nondisclosure scales for participants to mention additional reasons they had for revealing or not revealing their status to the person in question. In all about 275 additional reasons were recorded, and about 25 reasons gleaned from open-ended items that encouraged participants to recount disclosure narratives. Although these comments about disclosure motivation were not formally subjected to quantitative content analysis, qualitative inspection suggested that around two-thirds of these additional motivations were actually either repetitions or elaborations of reasons already mentioned in the scales. Approximately one hundred open-ended comments offered additional reasons for either disclosure or nondisclosure that had not appeared with enough frequency in either key informant interviews or preliminary focus groups to warrant inclusion on the revised scales.

Each additional reason for disclosure or for withholding disclosure that was elicited via open-ended questions was read and analyzed at least three times: once when entering data, a second time when transcribed from questionnaires, and a third time when categorizing them for discussion herewith. In the following sections, answers to open-ended questions are included in quotes. However, it must be remembered that the words being cited verbatim are not those of the participants themselves, but of the interviewers retelling the story—sometimes in first person,
sometimes in third. One final note: because interviewers were under some time pressure to record answers, it is not surprising that some spelling and grammatical errors occurred. I have corrected these while retaining Kenyan English expressions, but not otherwise altered their phrasing of respondent answers.

Some of the elaborations of the motivations already identified on the scales are worth mentioning, first because they arose so often and second because they are indications of the difference between the impact of the epidemic in sub-Saharan Africa as compared to the United States. Frequent among these were variants on the statement, “I wanted to prepare ________ for what might happen to me.” Around forty-five individuals made it clear that the most important future plans that could be made were to find someone to care for their children in case of their death. Typical of this response was a woman who disclosed her HIV serostatus to her sister because “she is the only one who can take care of my kids if I die.” This motivation was voiced especially often with respect to revealing HIV-status to a family member, followed by partner, then friend, with just one individual indicating she wanted her religious leader to assist her in ensuring care for her children.

A number of participants also elaborated on the fear of rejection as a reason for withholding disclosure by adding that they were concerned about stigma. From the perspective of these participants, the term “stigma” seemed to encompass a wider range of effects than did rejection, including a loss of reputation and isolation beyond relationship with the immediate potential target. The issue of community rejection was most frequently raised in conjunction with reasons for nondisclosure to religious leaders, but arose regularly with respect to the other three groups as well.
In an unexpected twist to the motivation of wanting the disclosure target to inform certain other people (seeking an intermediary), some participants explained that they told friends or relatives in the hope that these people could convince their reluctant spouses to go for HIV testing or treatment.

Some respondents also elaborated on the motivation of “duty to tell” others. Especially with respect to their family members and friends, these PLHAs indicated that they were concerned about the lifestyles of certain important persons in their lives and they wanted their own status to serve as a warning to them to change their ways. For example, a female interviewee stated, “I wanted her to be more careful with her life for she’s been reckless and I didn’t want her to go through the same thing [that I did].” Others suspected significant people in their lives had AIDS and wanted them to get the type of medical care they themselves had located. “I wanted to tell her so that she would go to a VCT or hospital and live longer,” explained one respondent of her friend, “because from my experience I knew she had AIDS. So it was to help her.” Several men whose wives were manifestly ill went for testing themselves when their wives refused because it was the only thing they could think of that might assist in pushing their wives toward appropriate diagnosis and treatment. Others felt a duty, for example, to inform their mothers-in-law what disease their wives had died of, or to tell various relatives what sickness their children were suffering from. In two cases, respondents had been engaged and required by their pastors to go as a couple for testing. When one party was found to be HIV-positive and the other negative, these individuals felt they had to explain to concerned parties why their weddings were suddenly called off.

The questionnaire also listed “My condition would be obvious to _____” as a potential reason for disclosure. A number of people revealed their status to friends and family to preempt
damage to their reputations. Because they assumed these important persons in their lives would have figured out their status from the physical symptoms of themselves or their partners, they revealed their status to these people so they could explain that they had not contracted the disease through promiscuity, but through medical contamination or through the unfaithfulness of their spouses. “She told the friend because she wanted to clear out that she was not a prostitute but she got if from the husband who was unfaithful,” was a typical explanation of this type.

In addition to elaborations on reasons already listed in the scales, several issues that had not arisen in the focus group discussions also emerged. A few participants mentioned that they told their partners about their status in order to test the level of commitment in their relationships; four mentioned feelings akin to the catharsis motivation for disclosure; and around ten spoke of not disclosing their status for reasons of personal privacy, especially in regard to their religious leaders and friends. “It is my secret,” insisted one participant who reported that he had told no one of his condition, “Once you tell a secret to someone it is no longer a secret.” The motivations mentioned in these few open-ended responses were similar to several identified in the U.S. by Derlega and colleagues (2002). A number of people revealed their status to friends whom they realized were HIV-positive in order to obtain informational support, a motivation not incorporated into Derlega and associates’ scales but identified in other U.S.-based research (e.g. Hays et al., 1992). They hoped that these old friends could connect them to HIV/AIDS-related resources in their communities.

Finally, several reasons for disclosure that had not been previously identified either in focus groups or in U.S. research arose with regularity. Not surprisingly, some participants explained that they had told their pastors their HIV-status in order to receive spiritual strength and to be prayed for. Also, several people told their partners about their status to establish fault
for their infection. “I wanted to know who brought the virus to our relationship,” was one woman’s expression of this motivation. Others had no doubt about who was at fault: “I wanted him to know he had ruined my life,” another woman stated flatly. In fact, this same motivation was present to a lesser degree for nondisclosure. A few participants indicated they had not told their partners about their status because they figured their partners had been the source of the infection, in which case the partners in effect deserved what they got.

**Disclosure Message Strategies**

Hypotheses 6, and 7 and Research Question 3 addressed factors that might lead to different methods of disclosure. Hypothesis 6 predicted that persons of higher status than PLHAs, relative to low or equal status disclosure targets, would be more likely to be the targets of (a) indirect disclosure and (b) intermediated communication. Hypothesis 7 stated that the closer their reported relationship with the target of disclosure, the more likely PLHAs will be to use (a) direct strategies and (b) face-to-face communication when disclosing their serostatus.

**Effect of Disclosee Social Status on PLHAs’ Choice of Method of Disclosure**

Prior to conducting analyses, options for methods of disclosure provided on the questionnaire were collapsed into three categories: (1) direct, face-to-face disclosure; (2) indirect, face-to-face disclosure; and (3) intermediated disclosure, in line with the hypotheses. As Hypothesis 6 did not distinguish between equal and low status disclosure targets with respect to the dependent variables, those data were also collapsed, with the lower and equal status categories of social status merged into a single category before testing it. A chi-square test of association indicated social status of the disclosee was associated with disclosure method ($\chi^2 (2) = 6.30, p = .04$). To determine the location of the effect, the data file was split according to strategy type. A one-sample Chi-squared analysis was run for relative status of target, with
expected values assigned according to proportion of total disclosures made to each target status.

There was a statistically significant association between social status and use of indirect strategies (see table 7), but in the opposite direction predicted, with indirect strategies used more frequently with equal and lower status targets.

Table 7

Frequency of Disclosure Strategy by Relative Social Status of Disclosure Target

<table>
<thead>
<tr>
<th></th>
<th>Direct F2F</th>
<th>Indirect F2F</th>
<th>Intermediated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Higher SES target</td>
<td>294 (59%)</td>
<td>11 (37%)</td>
<td>46 (61%)</td>
</tr>
<tr>
<td>Lower/equal SES target</td>
<td>201 (41%)</td>
<td>19 (63%)</td>
<td>29 (39%)</td>
</tr>
<tr>
<td>Total</td>
<td>495 (100%)</td>
<td>30 (100%)</td>
<td>75 (100%)</td>
</tr>
</tbody>
</table>

\[ \chi^2 \] .163 5.891 .248

\[ p \] .686 .015 .618

As this analysis was based on only 30 responses, however, it should be interpreted cautiously.

There was no statistically significant association between social status and the number of people electing an intermediated strategy. Thus Hypothesis 6 was not supported. No statistically significant association between social status of the disclosee and use of direct, face-to-face strategies was found either.
Effect of Relational Intimacy on PLHAs’ Choice of Disclosure Method.

Hypothesis 7a posited that a mathematical function of participants’ reported closeness to their disclosure targets would discriminate disclosers who used indirect strategies from those who used direct communication when disclosing their serostatus to those targets. It was expected that the function would reflect a positive relation between closeness and the disposition to disclose directly. Similarly, hypothesis 7b predicted that a mathematical function of participants' reported closeness to their disclosure targets would discriminate disclosers who used indirect strategies from those who used face-to-face communication when disclosing their serostatus to those targets. A positive relation between closeness and the disposition to disclose face-to-face was predicted.

Both components of the hypothesis were tested by means of a discriminant analysis with the continuous variable of closeness of relationship as the independent variable and type of disclosure strategy as the grouping variable. The null hypothesis on Box’s $M$ test for homogeneity of variance was rejected ($M = 13.87, p = .001$), and log determinants of covariance matrices were not sufficiently similar (direct disclosure = .43; indirect = -.07; intermediated = -.21) to assume homogeneity of group covariance matrices (Huberty & Lowman, 1998). In any case, no canonical discriminant functions were found to significantly distinguish between the groups ($\Lambda = .99, \chi^2 (2) = 1.25, p = .54$), and only 41.9% of cross-validated cases were classified correctly. Thus Hypothesis 7 was not supported.

Effect of Disclosure Motivation on PLHAs’ Choice of Disclosure Method

Research Question 2 asked whether motivations for disclosing HIV status would be related to whether or not a disclosure is (a) indirect and (b) intermediated. This question was also explored by means of a discriminant analysis, with the ten motivations for disclosure as
independent variables and type of disclosure strategy as the grouping variable. Although the null hypothesis on Box’s M test for homogeneity of variance was rejected (M = 186.72, p < .001), the equivalent F value in this analysis was not high (1.51) and log determinants of covariance matrices were sufficiently similar (direct disclosure = 5.34; indirect = 5.23; intermediated = 3.34) that it was deemed appropriate to assume equal variance for purposes of this analysis (Huberty & Lowman, 1998).

A single canonical discriminant function was found to significantly distinguish between the groups (Wilk’s Λ = .94, \( \chi^2 = 36.96, p = .01 \)), with an eigenvalue of .05, accounting for 74.6% of the variation in the system. Pooled within-groups correlations between the discriminating variables and standardized canonical discriminant functions indicated that two disclosure motivations—seeking material support (.41) and preparing the target for the future (.27)—were the strongest influences in the linear discriminant function. Specifically, the group mean for seeking material support was 3.35 for those choosing a direct disclosure strategy, 2.96 for those choosing an indirect strategy, and 3.87 for those choosing an intermediated disclosure strategy. Group means for preparing the target for the future were 4.25 for those utilizing a direct disclosure strategy, 3.97 for those utilizing an indirect disclosure strategy, and 4.33 for intermediated disclosure strategies. A total of 86.8% of cross-validated cases were classified correctly by the discriminant function. In short, two strategies in particular were significantly related to choice of disclosure strategy. PLHAs who disclosed in order to obtain material support were likely to choose intermediated modes of disclosure and unlikely to use direct disclosure. PLHAs disclosing in order to prepare their disclosee for the future were least likely to choose indirect modes of disclosure.
Although Hypotheses 6 and 7, which were based on politeness theory, were not supported, there is nevertheless an indication of face concerns operating in these findings. It is likely that the reason that persons motivated by that goal choose intermediated methods of diagnosis disclosure was to save positive self face.

**Effect of Relationship Type on PLHAs’ Choice of Disclosure Method**

Research Question 3 asked what disclosure methods would be most typical of each relationship. Table 8 gives frequencies for each type of strategy by relationship type. In total, 499 targets (83%) were informed directly, face-to-face; 30 (5%) were informed indirectly, face-to-face; 76 (13%) were told by intermediated means.

**Table 8**

*Frequency of Disclosure Strategy by Relationship Type*

<table>
<thead>
<tr>
<th></th>
<th>Direct</th>
<th>Indirect</th>
<th>Intermediated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner</td>
<td>117 (63%)</td>
<td>10 (5%)</td>
<td>60 (32%)</td>
</tr>
<tr>
<td>Friend</td>
<td>142 (93%)</td>
<td>9 (6%)</td>
<td>2 (1%)</td>
</tr>
<tr>
<td>Family</td>
<td>158 (88%)</td>
<td>10 (6%)</td>
<td>12 (6%)</td>
</tr>
<tr>
<td>Religious</td>
<td>82 (97%)</td>
<td>1 (1%)</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Total</td>
<td>499 (82%)</td>
<td>30 (5%)</td>
<td>76 (13%)</td>
</tr>
</tbody>
</table>

\[ \chi^2 \] 13.679 2.88 84.099

\[ p \] .003 .409 < .001

*Note: The number of partner disclosures is higher in the strategy-related data than with respect to disclosure motivation data because several participants who were tested at the same time as their partners did not fill out disclosure motivation scales.*
In all relationship types, then, by far the most frequent strategy reported was that of direct, face-to-face disclosure. However, there was an association between strategy and relationship type ($\chi^2 (2) = 100.70, p < .001$). To determine the location of the effect, the data file was split by disclosure strategy. A one-sample chi-squared analysis run for relationship type, with expected values assigned according to proportion of total disclosures to each relationship type. Results are presented in table 8. With respect to disclosure to partners, nearly one-third of participants reported using intermediation. Specifically, 21 participants asked their partners to go together with them for testing together without informing the partners that they already knew themselves to be seropositive, and another 37 stated that they learned their own status at the same time after testing along with their partner, while four PLHAs mentioned asking a person besides clinic/VCT personnel to inform their partner for them.

Effects of PLHA Gender on Their Method of Disclosing to Partners

Research Question 4 asked how males and female would differ with respect to disclosure strategies to partners. A chi-square test confirmed that there was a significant difference in the strategies chosen by men and women ($\chi^2 (2) = 17.46, p < .001$). Separate analysis on strategy types were run by splitting the data file and entering expected values in accordance with the proportion of male and female participants disclosures to partners. Table 9 indicates reported strategies for partner disclosure by gender. Females were more likely than males to employ direct disclosure strategies to inform their partners of their seropositivity. Once again, this may be a function of the difference in felt face needs between females and males in the present cultural context. Because of their lower relational position to start with, women may not have felt much threat to face inherent in the act of disclosure of a positive serostatus as did men. Politeness theory would suggest that those in the lower power position would be less direct, but
it is also conceivable that higher power males might feel more vulnerable when admitting a life shattering problem like HIV infection, and therefore adopted a less direct approach.

Table 9

*Frequency of Disclosure Strategy to Partner by Gender*

<table>
<thead>
<tr>
<th></th>
<th>Direct F2F</th>
<th>Indirect F2F</th>
<th>Intermediated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>29 (35%)</td>
<td>4 (50%)</td>
<td>21 (51.2%)</td>
</tr>
<tr>
<td>Females</td>
<td>53 (65%)</td>
<td>4 (50%)</td>
<td>20 (49.8%)</td>
</tr>
<tr>
<td>Total</td>
<td>82 (100%)</td>
<td>8 (100%)</td>
<td>41 (100%)</td>
</tr>
</tbody>
</table>

\[
\chi^2 = 7.786 \quad .766 \quad 2.713
\]

\[
p = .005 \quad .382 \quad .100
\]

Finally, a proviso should be inserted here with regard to the issue of directness. The categorization of an act of disclosure as direct or indirect was based on the description of participants themselves. A comment by a PLHA that, “I just told her straight out,” was coded as use of a direct disclosure method. However, whether what a Kenyan participant considered “straight out,” would be seen as such by an American researcher who observed the scene is not certain. In other words, directness and its synonyms are relative terms.

*Qualitative Evidence Regarding Disclosure Method*

Each questionnaire included open-ended questions on disclosure method for each target group, in which participants were asked to tell the story of the disclosure event. They were
specifically asked to relate as part of their narratives the response of the person to whom they had disclosed their HIV serostatus. A few of these stories actually turned out to describe nondisclosure incidents, and a number were not strictly focused on the question at hand, diverting rather into reasons for disclosure. A total of 531 relevant disclosure stories were recorded: 162 regarding disclosure to spouse/partner, 126 regarding disclosure to friends, 167 with describing disclosure to family members, and 86 with reference to disclosure to religious leaders.

Each story was analyzed at least four times: once when entering quantitative data in case additional reasons for disclosure were revealed by the stories themselves; once when transcribing them into 118 pages of typescript; once when categorizing them according to target and method of disclosure for analysis in this chapter; and an additional time in which prototypical stories were identified as illustrations for those categories. A preliminary list of categories for disclosure technique and results was developed based on focus group data and previous U.S.-based research. The typology of disclosure outcomes was revised inductively based on issues that emerged from the first two readings of the disclosure narratives.

As in the previous section, quotations are actually paraphrases recorded in situ by the interviewers. In reducing those interviewer accounts to typescript, spelling and grammar errors were corrected.

*Self-disclosure techniques.* Techniques for revealing serostatus that were mentioned quite commonly in interviews were variations of straightforward, face-to-face revelations of the participant’s diagnosis. Many disclosure events as described could hardly have been more direct, as in the following narrative by a female PLHA who informed her boyfriend, “I called him to my house and told him, ‘You know I have been sick for a long time with TB, etc. I have been tested
for HIV and I am positive. I don’t know if it’s you or me who has infected the other but you need to go for testing.’”

Other disclosures ended up being direct, but more gradual, as participants warmed up their audiences and/or gathered their own courage. In such cases the conversation might begin on the general topic of HIV or sexual behavior and became more personal, as with one male PLHA who related, “[My younger brother] visited me. I started giving him advice on how to live in this dangerous life. I asked him do you know why my wife died? He said no. So I told him she died of AIDS and I am also a sufferer.” A female PLHA informed a friend in similar gradual fashion.

I started by asking her a question: How does someone with AIDS live? She answered the question and asked why I had asked her. I was silent for five minutes, then I told her that I was pregnant and I had been told in hospital that I was HIV-positive and that that was the reason my husband killed himself.

Often the direct approach was facilitated by the revelation by the other party that he or she was infected, making it easier for the participant to reciprocate disclosure. An instance of this was recounted by a female respondent regarding disclosure to a friend, “We used to be close, so we were talking about AIDS. I never knew she was HIV-positive so when she told me that she was I decided that it was time to tell her.” Nearly all direct disclosures were accomplished face-to-face, although one participant said he had emailed his wife who was living in the U.S., and a female participant indicated she had called her brother long distance to relay the news.

A few interviewees did describe less direct routes to disclosure, dropping hints over a period of time, as in the case of a female participant who explained, “My friend and I were in a restaurant in town so I gave her hints the first day—I went back home without telling. The next time we met I systematically told her that I was positive. She told me she was positive too.”
Others hinted non-verbally by, for instance, leaving their medications or results slips out in the open to be discovered by family members. One female PLHA, in a combined indirect and intermediated disclosure technique, sent her daughter to read out her husband’s death certificate to her mother-in-law, by which means the mother-in-law knew her son’s cause of death and surmised her daughter-in-law’s condition before being told outright. Another told her father she could not understand her results slip, although in fact she knew it indicated she was HIV-positive, and asked her father to explain to her what it meant. She thus put him in the position of assuming he was breaking the news to her.

More commonly mentioned than such indirect means of disclosure were intermediated methods. Among these, the oft cited methods involved being tested together with a partner, or agreeing to be taken for testing by a friend or relative, even though the participant already knew him/herself to be infected. In such situations the medical professional was cast in the role of an intermediator as participants gave him/her permission to apprise them of their status in front of the other party.

Participants who described going together to VCT centers for testing did so in two ways. Some persuaded their spouses or partners to go together without informing them that they themselves had already been given a positive diagnosis. “He was tested and found positive in February this year but couldn’t tell her straight,” an interviewer explained regarding one participant. “He told the wife they needed to be tested. So they came to Nazareth [Hospital] and were tested together and found positive.” In other cases they decided to go together to be tested and were informed together of the results. Another participant remembered, “I told her since I can see we are not faring well health-wise we need to go for testing; she refused. When she was pregnant she had to be tested after a lot of persuasion. So we were tested at the same time and
confirmed positive. She didn’t complain; she suggested maybe it is God’s will (she is very religious).”

In other cases couples were not tested together, but participants nevertheless requested medical personnel to serve as intermediaries to inform their partners or family members, as exemplified in the statement of one participant, “I was admitted at Nazareth and tested for HIV/AIDS and confirmed positive. The doctors asked me if I am going to tell my husband or they should tell him. I told them to tell him. So he was told by the doctor but I was not around.” “She took me to hospital,” another explained with reference to her older sister, “and when I was tested positive the doctor asked me if she could be told. I agreed and she was called and the doctor told her that I am positive.”

A number of narratives indicated use of family members as intermediaries to inform other family members. The following family intermediations were mentioned: father asked to tell siblings, priest requested to inform wife, sister asked to inform mother, sister delegated to inform other siblings, wife requested to tell a brother, aunt charged with telling the pastor, brother asked to help inform a husband, brother asked to inform the rest of the family, cousin sent to tell a brother, brother requested to tell mother and sisters, uncle given duty of telling a mother, sister asked to inform aunt, daughter sent to inform mother-in-law, and father serving as intermediary to tell the mother. Friends were mentioned only twice as intermediaries, once to assist with telling a PLHA’s husband and once to intermediate disclosure to a religious leader. Although Hypothesis 8 (that disclosure to family members would be more strongly motivated by seeking intermediation than would disclosure to friends) was not supported in the statistical analysis, these data nevertheless indicate that intermediation was a function for which participants were inclined to turn to family members rather than friends.
Post Hoc Analyses: Motivation for testing and response to disclosure in HIV/AIDS disclosure narratives

Disclosure narratives collected for this study were an important source of information bearing on hypotheses and research questions regarding targets of disclosure, and even more so regarding methods of disclosure. However, some additional themes that had not been the subject of a priori research queries emerged as the narratives were examined. The following is a prototypical (though slightly longer than average) narrative in that it addresses not only disclosure technique reaction (here a combination of direct and indirect methods) but also (a) the reason the participant decided to be tested for HIV, and (b) the disclosee’s response:

When she was pregnant, she went to a city council clinic where they were told of the importance of getting tested for HIV so as to protect the unborn baby. They were given about three days to think about it and she went to talk to her husband about it. He asked her why she would do such a thing (go and get tested). He told her people get lied to by doctors about their HIV status. When she was tested and it came out positive she first told the husband jokingly about it. He told her that the tests are not straightforward and he promised her that he will get tested in a private laboratory. He then came and told her he was negative after they were tested. They then were advised to go to Kenyatta [Hospital] the two of them for tests and that was when she got to know that he was HIV positive also.

Given the prevalence of those emergent components of narrative as in this example, I conducted qualitative post hoc analyses of disclosure narratives on two other issues not addressed by hypotheses or research questions: motivations for testing and responses to disclosure.
Motivation for Being Tested

Reasons participants mentioned for being tested varied, but a very frequently cited motivation for being tested for HIV was the participant’s own symptomatic illness. Participants described experiencing skin rashes, tuberculosis, pneumonia, and a number of other lingering illnesses that either led them personally to go for testing or led others close to them to suggest they do so. Typical of these was the following description by a female PLHA:

When I got TB I realized I needed to be tested for HIV. The clinic said they could not give other drugs unless one was tested. So I was, and was positive. I was told I should start on ARVs. My CD4 count then was 100. I was sick in and out of the hospital. It was as if the hospital was my home area. . . .

In a number of cases, however, participants themselves were to all appearances healthy, but the illness or death of a child or sexual partner—usually not officially diagnosed as HIV-positive—led them to seek confirmation of their own condition. For example, one interviewer described the experience of a male PLHA:

His wife was sick on and off but had refused to be tested. Then he became sick (got a boil near the throat) and went to Aga Khan [Hospital] where he requested the doctor to test him. He was not surprised and went home and told the wife that was why she was always sick.

The remainder of respondents described being tested for reasons in some sense beyond their control. For instance, several pregnant women were subjects of routine HIV tests prior to delivery, as in the opening narrative in this section. Other people were tested along with their fiancés in line with church policies that individuals could not be married under the auspices of the church unless they knew each other’s HIV status beforehand. So far as I could determine, in
all of these pre-marital testing cases once one individual turned out to be HIV-positive, the marriage was called off. For example:

My interviewee was aspiring to marriage, so she and the boyfriend went for a test in a VCT center. The boyfriend and his sister-in-law used to work there. None of them had expected to be HIV-positive, hence it was a great shock to her when she realized her status. The boyfriend’s sister-in-law broke the sad news to her. They parted ways never to meet again. They did not discuss anything, support, comfort her, etc. The boyfriend was HIV-negative so he abandoned her.

Responses to Disclosure

A total of 374 responses to disclosure were mentioned by participants, sometimes two or more in a single narrative. Using a similar narrative elicitation procedures with 116 African American adolescents, Green and Faulkner (2002) identified five themes with respect to actual reactions to disclosure: negative emotional reaction, treated no differently, target told others, received support, and different treatment. Serovich (1998) derived six categories of reactions from interviews of 13 HIV-positive women: intellectual/cognitive/information based (e.g. asking questions about HIV, giving advice) physical/nonverbal (e.g. crying), spiritual (e.g. praying, advising PLHA to religiously), relational (e.g. questioning or alternatively affirming quality of relationship), instrumental (e.g. offering generic or specific support), emotional (blame, fear, pity, denial). Drawing upon these earlier category systems, I identified six major themes related to target responses to disclosure: shock versus equanimity, denial, anger/blame, rejection, acceptance, and provision of support.

Unquestionably among the participants interviewed for this study, as in similar studies in the U.S. (e.g. Cusick & Rhodes, 1999; Greene & Faulkner, 2002; Simoni et al., 1995; Stemptel et
al., 1995) and elsewhere in East Africa (Maman et al., 2003), disclosure of HIV serostatus was very often met with support and encouragement once the initial shock of the revelation wore off. A female participant explained the support provided by her close friend:

It was on a Wednesday I got sick. I sent my child to call [my friend]. She took me to the hospital. She saw I was very depressed and asked what sickness I was suffering from. I told her that I am HIV+. She became very sympathetic and helpful. She even fed my kids. She was very encouraging both financially and socially.

Also frequently noted were mirror image responses of disclosure targets being either shocked at the news or not shocked at all because they had expected it, as well as the generally positive response of acceptance. Typical of the “shock” responses was that of a female PLHA who reported her friend was initially taken aback by the participant’s disclosure, but later adjusted to it. She recalled:

We were chatting together. She gave me a story of a man who had sent off the wife for having been found to be HIV-positive. . . . I told her that I was also tested and found positive. Both me and my man. She was shocked. She would not believe me. She for a few days acted weird but later changed to accept my situation. We are still friends.

The non-shock or acceptance responses was generally ascribed to one of two reasons. First, the person in question already might have had reason to believe the participant was HIV-positive, as in the following quote: “I became very sick. I was admitted,” began a female participant. “I told my mother I am positive so that they can love me or hate me if they wanted. She wasn’t shocked because she had seen me suffer in sickness.” Many participants indicated significant persons in their lives suspected not because of any illness of the participant, but
because of the previous death of a spouse or small child. Other recipients of disclosure did not register shock because they themselves were HIV-positive, and even if they had not suspected the participant to be infected, the diagnosis itself was to them not so very threatening a happening.

Other commonly mentioned responses included denial, as in the following incident a participant narrated regarding disclosure to a friend:

I woke up one day feeling so depressed. I had kept my status to myself for three years. So I called and told my friend I think I am positive. She said, “It can’t be,” and I said I’d take her for a test. So I took her to VCT and told her the results directly afterward. . . We need to do a repeat test, she insisted. I said that was not necessary; I just know. She is still my friend but will never revisit the topic. That part of my life she completely ignores.

Denial by spouses and partners was especially frequent, as in the case of a woman who explained:

I went to pick up the results and so I just told [my husband] that night. He refused the claims and said that the blood had been switched in the lab. He told me to change clinics and continue with my prenatal clinic care since I was pregnant. He completely refused my claims that I was HIV-positive.

And that of another female PLHA:

He took me to the hospital then I was tested and confirmed positive. I didn’t tell him the truth there and then. At home I told him I want to go to be tested with him. He asked me for what? I told him HIV. He told me, ‘That is rubbish.’ Even today he has refused to be tested.
Acceptance, or, as it was often phrased, “s/he took it positively”, seemed to imply that the PLHA had anticipated a negative response from that individual and was relieved to discover a different reaction. For example, one participant described how she told her father of her condition, “We were so close and he used to hear that I was sick. So we were just eating and I decided to tell him that I am HIV positive. He took it normally and advised me to continue taking medicine and live normally.”

Anger and blame were mentioned by participants in association with locating the source of the infection between the partners in a couple. One man explained that after being tested himself he hid his condition from his wife but suggested she go to be tested herself, after which “she went and was confirmed positive. She was very furious because she thought it was him who infected her. She spent a month without talking to him.” A few spoke of the partner’s irritation at being labeled the cause of the problem, “When he went home he asked his wife why she infected him and why she was ‘moving’ infecting other people. [He accused her of] wanting to kill everyone. She was furious.” Anger and blame were in a few instances mentioned in the case of family members, as in the following account:

The [elder] brother had gone to visit her in the hospital. He demanded to know what was wrong. She told him the doctor’s diagnosis. He went in search of the doctor to get confirmation. He became angry and demanded she be discharged since were she to die in Nairobi, she would have been a burden. He wanted her to go upcountry [to the rural homestead to die].”

Outright rejection by the disclosee was mentioned in the same order of magnitude as denial, that is, with less prevalence than support and acceptance. Rejection in the case of spouses often took the form of abandonment. One male PLHA reported, “I got to tell her when we were
taking a walk. She was calm, cool, and understanding at the time but eventually she left me.”

Female participants told similar stories:

I got pregnant with my boyfriend’s child so during delivery I was tested for AIDS and the results were positive. I informed my boyfriend whose reaction was rather rude, ‘All this time you didn’t know I was HIV-positive?’ He disowned me and our child.

Several female respondents said they were beaten before being sent away. In the case of friends or relatives, the participants were rejected by being socially isolated and/or ignored. One PLHA recalled,

When my sister came back she told me you are going to die. You have AIDS. She started abusing me [verbally], how I’ve brought disgrace to the family. She stigmatized me. All my plates and spoons were thrown away because she said that I now brought death to the family that I would kill them all.

Some different patterns in responses across relationship categories were apparent. For instance, denial, anger/blame, and rejection commonly appeared in narratives about the responses of sexual partners and family members but rarely in narratives about friends or religious leaders. Family members as a group were likely to be cited as reacting with shock to the revelation of a participants’ HIV status. These two responses were often tied together; many respondents would state that a disclosure target was initially shocked but then became accustomed to the news and accepted it.

Finally, family members and religious leaders were notably represented as offering various types of support while this pattern was less evident among partners and friends. For example, a female participant explained regarding her pastor’s response,
After testing immediately we phoned him. I talked to him and told him I have tested positive. In the evening he came home and we talked further. The pastor is very concerned with his flock. . . . He encouraged me and told me I can stay for a long time so long as I live positively. He prayed for me. I felt very nice.

Other participants mentioned family members and pastors providing them with health food (fruits in particular), money for their children’s school fees and their house rent, emotional support and encouragement, and generally attending to any needs that arose in their lives as they struggled with their condition.

Giving advice was one particular aspect of supporting giving that was mentioned by some participants. A number of participants reported that when they revealed their serostatus to others in their lives the outcome was the offer of counsel on how to handle their situation. A female participant described how her sister offered guidance to her: “Her sister was encouraging. She told the respondent that she was lucky to have known early since she could now prepare the children for any eventuality. She also urged her to work harder for her children.”

Summary of Results of Hypothesis Testing and Research Questions

To summarize, six hypotheses were supported, one was partially supported, and four were not supported. Whereas the null hypothesis was rejected in both disclosure target hypotheses, and over half of motivation hypotheses were supported, in the area of disclosure method, no hypotheses were supported at all. Clearly this is an area of the study in which further exploration of the concepts investigated is warranted. Results are recapped in table 10 below. In addition, a brief summary of findings of the research questions is presented in table 11.
Table 10

Results of Hypothesis Testing

<table>
<thead>
<tr>
<th>Supported</th>
<th>Not Supported</th>
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<tbody>
<tr>
<td>Targets</td>
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</table>

H1: Family members will be more often among early disclosure targets than friends.

H11: Male PLHAs will be more likely than females to report a sexual partner among early targets.

Motivations

H2b: Disclosure to family members will be more strongly motivated by seeking material support than will disclosure to friends.

H2a: Disclosure to family will be more strongly motivated by seeking emotional support than will disclosure to friends.

H3: Disclosure to family will be less strongly motivated by knowledge that the target is HIV+ than will disclosure to friends.

H4: Nondisclosure to family will be more strongly motivated by fear of rejection than will nondisclosure to friends.

H5: Nondisclosure to family will be more strongly motivated by other-focused reasons than will nondisclosure to friends.

H8: Disclosure to family will be more strongly motivated by need for inter-mediation than will disclosure to friends.

H9: Nondisclosure will be more strongly motivation in males than in females by fear of rejection.

H10: Disclosure will be more strongly motivated among females than males by seeking material support.
H6: Persons of higher status than PLHAs, relative to persons of lower or equal status, will be more likely to be targets of (a) indirect and (b) intermediated disclosures.

H7a: A mathematical function of participants' reported closeness to their disclosure targets will discriminate disclosers who used indirect strategies from those who used direct communication when disclosing their serostatus to those targets. The function will reflect a positive relation between closeness and the disposition to disclose directly.

H7b: A mathematical function of participants' reported closeness to their disclosure targets will discriminate disclosers who used indirect strategies from those who used face-to-face communication when disclosing their serostatus to those targets. The function will reflect a positive relation between closeness and the disposition to disclose face-to-face.

Table 11

Summary of Findings on Research Questions

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Findings</th>
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<tbody>
<tr>
<td>RQ1:</td>
<td>Family members, followed by HIV-related, partners, and friends. Least often reported, religious leaders.</td>
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<tr>
<td></td>
<td>PLHAs most often report disclosing serostatus among early targets?</td>
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<tr>
<td>RQ2: Will motivations for disclosing predict whether a disclosure is indirect or intermediated?</td>
<td>No statistically significant relationships found.</td>
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<tr>
<td>RQ3: What types of disclosure strategies will be most characteristic of each relationship type?</td>
<td>Intermediation used more with partners than with other relationship types.</td>
</tr>
<tr>
<td>RQ4: How will female and male PLHAs differ in terms of disclosure method?</td>
<td>Females used direct methods more than males did.</td>
</tr>
</tbody>
</table>
CHAPTER 5

DISCUSSION

Chapter 1 indicated that this study had two major goals: (1) to elucidate methods and motivations for self-disclosure of a positive HIV diagnosis in the sub-Saharan context, specifically that of Nairobi, Kenya; and (2) to consider implications of those disclosure patterns for communication theory across cultures. Thus it seems natural to divide the discussion of results into two corresponding sections in this final chapter—applied and theoretical—even though there is extensive overlap between the two.

Implications of the Findings for Health Communication Practices

Results of this study have implications for counselor training, partner notification policies, and as we shall see below, church and FBO involvement in HIV/AIDS intervention. All of these remain critical aspects of the battle against HIV/AIDS on the African continent even in the midst of rejoicing over growing accessibility of treatment. To unpack those implications, this section will begin by comparing results from this study point by point to existing research, both from East Africa and the United States. It will then move on to highlight those findings that are least precedented, in the process to discuss application to HIV/AIDS research and practice.

Targets of Disclosure

The identity of the first five disclosure targets listed by participants in this study was, as anticipated, different than target preferences typically expressed by PLHAs in the United States. However, findings on this subject are congruent with results of previous research in East Africa, while at the same time extending those findings. I will consider first family, friends, and partners
as targets of disclosure, and then focus on the two distinctive findings of the study regarding target identity: religious leaders and support groups.

Disclosure to Partners

As noted in Chapter 2, results regarding the proportion of PLHAs in sub-Saharan Africa who disclose their status to partners have varied widely. Percentages in the present cross-sectional study might be expected to be higher than in some longitudinal studies that terminate at six months or a year after diagnosis, as the mean year of diagnosis in this study was 2001 and the median 2003. Thus the mean of the years since diagnosis for participants was four, and the median two years. Indeed, the finding that 65.8% of participants who said they had had a sexual partner since they learned of their diagnosis had disclosed to that person is higher than results of a number of previous studies (Antelman et al., 2001; Issiaka et al., 2001; Lie & Biswalo, 1996; MacNeil, et al., 1999; Songok & Andayi, 2003; Temmerman et al., 1990, 1995) but can hardly be considered encouraging overall. Disclosure to partners among female PLHAs, was lower than among male PLHAs, even after accounting for the higher proportion of widowed women than men. Females in this sample were still somewhat more hesitant than males to undertake disclosure to lovers or spouses (59% as compared to 74% of those who had had a sexual partner since diagnosis).

Disclosure to Friends and Family

Unlike research among PLHAs in the U.S. context, which has consistently indicated that friends and primary partners are targets of disclosure more than family members (e.g. Greene et al., 2003; Greene & Serovich, 1996; Hays et al., 1993; Mansergh et al., 1995; Perry et al., 1990; Serovich & Greene, 2001; Stemptel et al., 1995; Wolitski et al., 1998), research in sub-Saharan Africa has found disclosure and intent to disclose more commonly direct toward family than
friends (Lie & Biswalo, 1996; Antelman et al., 2001; MacNeil, et al., 1999). This study confirmed that finding, with participants nearly twice as likely to list family members among the first five targets of disclosure compared with friends. Sisters were mentioned most frequently as family targets of disclosure, followed by mothers and brothers. Participants generally seemed more circumspect in their disclosure to friends, tending to confide in friends whom they believed to also be HIV-positive, and expressing concern that friends might not respect their confidentiality once informed. It appears that family more than friends should be considered by practitioners, and recommended by counselors, as the primary line of social support for PLHAs in this environment.

Disclosure to Religious Leaders

Little attention has been paid in either U.S. or sub-Saharan African research to how much disclosure takes place to religious leaders. However, nearly 90% of participants in this study indicated they had a religious leader in their lives, and around one-third of those had informed at least one such figure among the first five targets of disclosure. This suggests the role of religious institutions and religious leaders in the experience of many PLHAs is an important one.

In hindsight this appears obvious. In the sub-Saharan African context, religion plays such a critical role in personal and social life (Idowu, 1972; Long, 2000; Moemeka, 1996) that it must be considered one of the chief cultural factors governing all manner of behavior, including diagnosis disclosure. A recent BBC survey (Ferrett, 2005) found that when asked what was the most important factor in defining themselves, a majority of Africans put religion above any other factor, and three-quarters of survey participants indicated religious leaders were the group they most trusted. “Wherever the African is,” observed Mbiti (1970), “there is his religion; he carries it to the fields where he is sowing seeds or harvesting a new crop; he takes it with him to the beer
party or to attend a funeral ceremony” (p. 2). Originally this pervasive spirituality involved indigenous religious beliefs. However, since the achievement of independence by African nation-states in the 1960s and 1970s, Christianity has indigenized itself to become the dominant religious influence in the southern two-thirds of the continent; seventy to 80% of Kenyans at the turn of the Millennium belonged to a Christian denomination (Kenya, 2001).

With respect to HIV/AIDS, this prevalence is significant in two ways. First, today’s churches fill a central place in the social networks of many Kenyans. Especially in the urban environment where poverty makes them powerless and extended family systems are not available, churches provide a place where people can find acceptance, shed passivity, and entertain goals and ambitions in the context of a supportive community (Gifford, 1995; Hastings, 1995; Lonsdale, 2002). Second, the stable role of religious institutions as major provider of medical services in many sub-Saharan countries (Lee, 2003)—where government funded medical infrastructures may be sorely lacking—has already led a number of FBOs to assume responsibility for distributing medical, material, and social support to people affected by HIV/AIDS (Break the Silence, 2000; Byamugisha, Steinitz, Williams, & Zondi, 2002; Dortzbach, 1998; Dortzbach, Sasirye, Ngoga, Makuku, Mangin, & Calver, 2000; Foster, 2004; Kiiti, Ijumba, & Dortzbach, 1996; Rosenberg & Merson, 2003; Steinitz, 2000; UNICEF, 2004). As early as 1995, *The Kenya Church Growth Bulletin* (AIDS, 1995) was able to compile a list of exemplary HIV/AIDS projects by FBOs (see Mwithia, In press, for a more updated listing). In terms of sheer numbers, churches are very probably the most pervasive grassroots organizations in Kenya (Black, 1997; Long, 2000), and many PLHAs have naturally turned to them for assistance.
Given these realities, it is surprising that up to this point little research has been conducted from the perspective of PLHAs on the impact that religious leaders and institutions have on their experience of the disease (Gilmore & Somerville, 1994; Takyi, 2003). The issue is especially salient at this juncture, in part because a consensus is growing among some public health entities that partnership with and funding of interventions by faith-based organizations is one key to effectively addressing the HIV/AIDS catastrophe (President’s Emergency Plan, 2004; Social marketing, 2003; Tearfund, 2004; UNAIDS chief tells faith groups, 2004; Woldehanna, Ringheim, Murphy, Clerisme, Uttekar, et al., 2004).

Lack of scholarly and policy-oriented research on churches as care providers may in part be due to the fact that despite the impressive efforts mentioned above, many Christian churches have only recently awakened to the horrors of the AIDS pandemic. The turn toward active involvement in HIV/AIDS prevention and care by these churches and denominations has occasioned apologies from a number of African religious leaders for contributing to the stigma associated with HIV/AIDS (CCIH-AIDS, 2004; Crawley, 2003; Long, 2000; NCC-USA, 2003). In some cases this new activism represents a shift from a decade or more of condemnation or hopeless resignation (MAP, 2004; Nguru, 2003).

Results of the present study affirm the centrality of churches—for good or occasionally for ill—in the fight against HIV/AIDS in Kenya. Both structured interview and focus group data gave evidence of strong and polarized PLHA attitudes toward churches and church leadership. Some focus group members were effusive in their praise of churches that exhibited compassion and involvement; others narrated tales of gossip and discrimination by fellow congregants. Some group participants ran to their pastors to share their diagnosis before they spoke to their closest family members; others carefully guarded their secret from fellow church members and even left
the church when they sensed people suspected their condition. Participants in the individual
interviews were also divided. Whereas about 30% of interviewees who had religious leaders
trusted them so much that they made them early confidantes of a very threatening secret, 70%
did not.

Suffice it to say that the historic calling of religious institutions to be a refuge for those
who are suffering has rarely been more relevant than in the age of AIDS. Religious leaders have
a challenge before them not only to personally communicate an attitude of approachableness and
caring toward PLHAs, but also to exhort their congregations away from stigmatization and
toward compassion. The words of one focus group participant express this calling succinctly:

What I would say about the church is that I think the church is the best forum to spread this
“gospel” of HIV, because in church you find all different kind of people; we have men,
women, children, the youth. If you look at the churches they receive the highest number of
visitors. . . . .You go to a mosque you find the mosque is full; you go to churches and they
are filled. So if the churches take this initiative I think every body even in the remotest part
of the country will come to know about HIV. But if the church doesn’t accept it and take it
positively, I think we have a problem.

Disclosure to Support Groups

Results from this study strongly suggest that groups of like-status persons are a major
aspect of social support for PLHAs in Nairobi. Around half of participants in this study had
disclosed to at least one support group among their first five targets of disclosure, and over 10%
reported disclosing to a support group before disclosing to anyone else. Female focus group
participants were emphatic that developing new friendships with fellow HIV-positive persons
through contact in support groups often served in lieu of social support that might have been obtained through maintaining old friendships.

This idea, and even the role of support groups in general, has had next to no play in literature on HIV/AIDS in sub-Saharan Africa (for an exception see Kalichman, Sikkema, & Somlai, 1996), but has been examined to some degree in other contexts. HIV/AIDS support groups in Thailand have become, according to Lyttleton (1999), the primary means by which the experience of PLHAs is negotiated in Thai society, and PLHAs in Britain who are involved in support groups have been found to have stronger beliefs that they themselves have control over the course of the illness and fewer beliefs that chance factors determine their health (Fontaine, McKenna, & Cheskin, 1997).

More specifically to the point of this current investigation, in one U.S. study belonging to a support group was associated with differences in diagnosis disclosure patterns. Kalichman and associates (1996) found that members of HIV/AIDS support groups did not differ from nonmember PLHAs in terms of number of friends to whom they had disclosed their diagnoses. However, PLHAs who belonged to support groups did tend to disclose their status more to family members (with the exception of mothers) than did non-support group members. Apparently belonging to a support group made these people more comfortable with making their status known, at least to family members.

The possibility that rather than facilitating the development of, in CPM terms (Petronio, 1991), more permeable privacy boundaries, membership in a support groups actually acts as a substitute for other relationships and thereby decreases disclosure to friends has not been considered. On the other hand, any such subtractive effect of support group disclosure might be temporary, with support groups initially serving as a sort of cocoon into which members
withdraw to develop comfort with their status, and emerge after some time with greater
certainty to reveal their condition to others in their lives. At any rate, post hoc chi-square
analyses revealed no significant associations between listing a support group among the first five
disclosures and disclosure/nondisclosure to any of the other four relationship types (partners: $\chi^2$
(6) = 4.12, $p = .66$; friends: $\chi^2$ (6) – 7.50, $p = .28$; family members: $\chi^2$ (6) = 10.78, $p = .10$;
religious leaders: $\chi^2$ (6) = 7.22, $p = .30$). However, as many of the participants in this study were
drawn from existing support groups, even significant findings would be at most suggestive
because of the bias toward support group membership among such participants.

If support groups are performing vital functions in the lives of many PLHAs, a better
understanding of them is needed. The present sample was composed of persons from urban and
peri-urban areas— islands of relative alienation from extended family and tribal identities in a
more interdependent societal sea. For these people, it is possible that support groups may
substitute to some degree for extended family who live far away in the rural areas. Because the
scope of this study was limited to the capital city of Nairobi and environs, it can draw no
conclusions regarding functions support groups might serve in the lives of the large number of
Kenyan PLHAs who are rural residents. Would support groups perhaps be less important to
PLHAs who live in villages where the communal pattern of life provides a naturally occurring
group? No evidence currently speaks to that issue.

On the other hand, given the strong sanctions that African societies often impose on
members they view as errant (Long, 2000; Mbiti, 1992; Moemeka, 1996), it is also possible that
participants in this study sought out focus groups not so much as a substitute for the warmth of
absent family, but rather as a safe haven from castigation by the ingroup. It is tempting for those
of us hailing from individualistic societies like the U.S. to envision life in a collectivistic culture
as a warm, womb-like, if perhaps inefficient, existence. By definition, however, collectivistic societies must exercise discipline over their members for the good of the community, and stigmatization can be one means of exerting that control. If this second explanation were the case, support groups would be more essential to PLHAs in rural, as compared to urban, areas rather than less. Both explanations are possibilities in the context of the complex web of relational obligation that constitutes African collectivism. The importance of support groups in the lives of participants was an unanticipated finding of this study. Further research is needed so as to inform structuring of groups in both urban and rural situations toward effectively meeting PLHA needs.

In summary, findings in this study with reference to disclosure targets point toward a number of culture-typical patterns regarding PLHA selection of confidants, patterns that are notably different from those identified by existing research on the same subject in the United States. In contrast to U.S.-based results, Kenyan PLHAs in this sample were far more likely to share the secret of their diagnosis with family than friends. They were also likely to confide their status early on to support groups of other HIV-positive persons and to a lesser extent to number religious leaders among their first five disclosees. These latter two findings cannot be contrasted with results of similar research in the U.S. because they have evidently not even been investigated in that cultural context.

Reasons for Disclosure and Nondisclosure

Although reasons for disclosure of a positive diagnosis and particularly for nondisclosure have been studied in East Africa to some degree, the present study is innovative in that it pioneers research exploring motivations for disclosure to persons other than partners, and in that it employs a closed-ended instrument querying reasons for and against partner disclosure, thus
facilitating statistical analysis. It is also distinctive in introducing research on motivations for disclosure and nondisclosure to religious figures. In this section I will draw comparisons to existing research on disclosure and nondisclosure motivation in both the U.S. and sub-Saharan Africa, highlighting distinctions by target relationship and when applicable, by gender.

General Reasons for Disclosure

Reasons for disclosure among PLHAs in sub-Saharan Africa have been almost entirely studied with reference to disclosure to partners, so it is difficult to make comparisons based on existing literature about general reasons for disclosure. In U.S. based research, duty to educate and having a close relationship with the target (Derlega et al., 2000; Klitzman, 1999; Serovich, 2001; Simoni et al., 2000) as well as seeking emotional support (Serovich, 2001) have been found to be among the most frequently mentioned reasons for disclosure. This study found those to be strong motivations for disclosure among Kenyan PLHAs as well.

On the other hand, catharsis and testing a relationship, cited by several Western researchers (Derlega et al., 2000, 2003; Klitzman, 1999; Levy et al., 1999) as among the motivations most strongly impelling disclosure to others, were not included in the structured interview scales of this study at all because they were not mentioned even once in focus group discussion. The fact that testing relationship was also never mentioned in open-ended questions in the structured interviews, and that catharsis was spontaneously mentioned in only four out of 275 additional reasons offered by participants tends to support their noninclusion in the formal instrument. Whether these motivations were not experienced by participants in this study, or whether they were experienced but are not the sort of thing that one would mention is not known.

In contrast, several motivations that have been infrequently mentioned in U.S. research were quite common motivations among this sample: (1) preparing the target for what might
happen in the future, (2) seeking material support, (3) belief that the PLHA’s condition would be obvious to the target anyway, and (4) seeking advice. The first three are associated with the character of the sub-Saharan epidemic. Living in the developing world, where survival and health are balanced at times on a razor’s edge, and the plunge into poverty is just one paycheck away, participants were frank about their need for material support in a way PLHAs in U.S.-based studies have not been. They needed nutritional food, money for medication, resources to cover their children’s school fees, many of which they were unable to afford once their illness either cost them their jobs or their income. Few PLHAs in Kenya or the rest of the sub-Sahara have medical or life insurance, and the lives of many are financially uncertain at best. Participants could not assume that—diagnosed with a chronic and expensive, if not fatal, disease—they would be able to care for themselves or their families. Thus they disclosed to prepare for the future, and to assure that their children would be cared for. Only in the past year have anti-retroviral therapies become widely enough available in Kenya that numbers of PLHAs might live their lives asymptotically; most have had to assume that their deteriorating physical condition would reveal their status to those who knew them well anyway. Thus, with their condition so obvious, they could easily feel they might as well disclose to clear up misperceptions.

The fourth motivation, seeking advice, though unanticipated in the literature review makes sense as an outgrowth of a collectivistic mindset. Because PLHAs in Kenya live their lives embedded in groups, it is important from their perspective to seek advice on aspects of a situation that is at the same time devastating and completely novel. They disclose to obtain information on HIV/AIDS resources, to secure spiritual guidance, to access input on challenges of daily living. Persons offering counsel to PLHAs regarding selection of disclosure targets may
bear in mind these concerns and assist clients in thinking of individuals in their lives who might help address them.

*General Motivations for Nondisclosure*

Important reasons for not revealing one’s status among PLHAs both in the U.S. and sub-Saharan Africa have included fear of rejection, concerns about confidentiality, and protecting loved ones (Antelman et al., 2001; Gielen, et al., 1997; Issiaka et al., 2001; Maman et al., 2001; Moneyham et al., 1996; Serovich, 2002). In the present study these motivations were also reported often. Derlega and associates (2002) also found self-blame to be a frequently cited reasons for not sharing serostatus. However this latter issue, like catharsis, did not arise in the focus groups and were thus not included in the final instrument. Self-blame was also completely absent from answers to open-ended nondisclosure motivation questions. Instead, not knowing how to communicate about the situation was frequently indicated as a reason for nondisclosure. Once again, it is possible that these differences are connected to differences in collectivist vs. individualist orientations of Kenyan as opposed to U.S. societies. Because harmony is so important in Kenyan relationships, it may have been more difficult for PLHAs faced with a completely new and threatening situation to think of appropriate ways of revealing their secret without creating relational chaos. The concern for not knowing how to disclose may also be a function of the level of stigma in Kenyan society. The less stigmatized the disease becomes, the less sensitive the news of a positive diagnosis is likely to be, and the more readily individuals may begin to feel they can undertake the task of revealing their condition. In either case, one implication is that HIV/AIDS prevention efforts, particularly entertainment education efforts, can focus on modeling scripts for the disclosure task.
Relationship-specific Reasons for Disclosure and Nondisclosure

Results of this study strongly point toward disclosure decisions being made in the context of specific relationships. As in U.S.-based research, reasons for disclosure to family members and partners tended to differ from reasons to disclose to friends. Derlega and associates (1998; 2003) have suggested the stronger motivation of duty for disclosure to partners and family as opposed to friends supports the view that obligation underlies disclosure to parents and intimate partners. Those perceived obligations are based probably on loyalty to parents and concern for one’s sexual partner. In the present sample, disclosure to partners was similarly more highly motivated by duty than was disclosure to friends or religious leaders. On the other hand, concern not to cause worry or pain more strongly motivated nondisclosure to family members than nondisclosure to friends. This last result replicates findings in Western cultures (Derlega et al., 2004; Mason et al., 1995; Simoni, et al., 1995) and very likely represents the flip side of the same coin. Because one knows one has a mutual, unbreakable (or nearly so), obligation to family, one wants to protect them.

At the same time, the pragmatic goals of seeking material support and preparing for the future more strongly motivated disclosure to family and partners in this study than disclosure to friends and religious leaders. The pattern that emerged, then, would seem to indicate that the more involuntary, obligatory nature of partner and family relationships cuts both ways for Kenyan PLHAs; not only does one have a duty to keep these persons in one’s life informed, but they in turn have a duty to supply tangible assistance. When the reality is that PLHAs may be reduced by their illness to literal starvation or homelessness (as several participants in this study reported had been the case for them at various points in their past), family will be relied upon in
a way that is nearly inconceivable in a U.S. environment replete with social services agencies and other resources.

From several angles it is evident that disclosure to friends is fraught with specific concerns on the part of PLHAs that are not as much in evidence with respect to revealing serostatus to family members, thus the finding that participants were less concerned that family disclosure targets were HIV-positive than that friends were. In addition, unlike in U.S. based investigations, concern about lack of confidentiality was a stronger motivation for nondisclosure to friends than any other group. These quantitative findings echo concerns of focus group members that old friends were not trustworthy, and that one often had to resign oneself to leaving them behind. As focus group participants articulated the matter, the family (in most cases) cannot leave you; friends can.

The motivation of seeking advice figured more strongly in serostatus disclosure to religious leaders than to partners or family, reinforcing the point that training in counseling for HIV/AIDS may be an important investment if churches and pastors are to effectively assist their HIV-positive congregants. It is worth nothing that fear of rejection did not more strongly motivate nondisclosure to religious leaders than it did nondisclosure to any other group, a finding that might be viewed as in some measure discrediting the notion that churches are bastions of stigmatization (e.g. Nzioka, 1996; Patton, 1989; Susser & Stein, 2004; UNAIDS, 1999). Reasons for not sharing the news of a positive diagnosis with a religious leader were in most respects similar to those for not revealing serostatus to friends. On the other hand, it is less than encouraging that when religious institutions have historically seen themselves as called to succor the hurting and marginalized of society that they apparently had not communicated that distinctive to a large proportion of PLHAs in this sample. One clue to changing that perception
may lie in the finding that participants reported not having a close relationship was a stronger motivation for not disclosing to pastors than for any other group. This is not surprising; in an average sized church the pastor cannot know everyone well. But it does present a challenge to churches in the era of AIDS to strategize how they can distribute pastoral care so that all church members feel there is someone in leadership they are close enough to confide in.

*Gender Differences in Motivations for Disclosure and Nondisclosure*

Although gender differences in disclosure motivation did emerge in this sample, they were, as in U.S. investigations (e.g. Derlega et al., 2004), few. In fact, given differences in gender roles in sub-Saharan Africa, as well as the emphasis in literature on the particular challenges faced by female PLHAs in Kenyan society I had anticipated a larger effect. Females were more likely than males to disclose in order to obtain material support, and because they assumed the disclosure target to be HIV-positive. The effect sizes were very small, however. There may be several reasons for this finding. At best we might hope that as the epidemic has spread, marginalizing attitudes toward women have given way to a more gender-sensitive environment. However, it is also possible that because this study tapped women who had elected to disclose, at least to medical personnel and to research assistants in this study, the selection bias inherent in the method effectively screened out participants who would have been most likely to evidence such differences. Furthermore, this study was conducted in the urban environment. A sample drawn from the rural areas, where more traditional gender roles are enacted, might yield a larger effect.

To summarize this section, once again results of this study indicate that with respect to disclosure motivation, Kenyan participants differed in a number of ways from their U.S. counterparts. Motivations for disclosure that were frequently cited by members of this sample,
such as seeking advice, the realization that their status would be obvious to the other person, the need for material assistance, and a strong concern about preparing for the future, have rarely arisen in North American research. On the other hand, Kenyan PLHAs virtually never spoke of the common U.S. motivations of catharsis and testing a relationship. Although they emphasized not knowing how to reveal their status as a reason for nondisclosure, a motivation that has not been highlighted in U.S. research, not once did any of them mention avoiding disclosure because of self-blame, a reason that has appeared with regularity in U.S. investigations.

Both Kenyan PLHAs in this study and U.S. participants in previous research have reported a sense of duty toward informing family as well as concern for protecting family from pain and worry that are distinctive from their motivations for self-disclosure to friends. However, unlike PLHAs in the U.S., participants in this study expressed concerns about whether their friends would accept them if they knew the truth about their serostatus, and especially about the tendency of friends not to respect their confidences, displaying a relative hesitation about confiding in friends that has not emerged in parallel studies in North America.

Methods of Disclosure

In cultures with strong in-group boundaries and highly defined social hierarchies even more than in open, egalitarian ones, how information is communicated can be nearly as important as what is communicated (Moemeka, 1996). I have noted above that PLHAs face a situation that is completely new to them. The motivation for withholding disclosure of not knowing to tell significant others received a rather high level of endorsement. That is, PLHAs may simply need assistance in planning effective communication strategies for breaking their news to important people in their lives. Crucial as it is to find practical suggestions to assist PLHAs in disclosing their diagnosis, especially to partners, this issue has rarely been examined.
Implications for VCT Couples Services and Prevention

Key informant, focus group, and questionnaire data in this study all pointed to the importance of intermediation by VCT counselors and other clinic personnel as one means of facilitating diagnosis disclosure between partners, especially for male PLHAs. Not only did some participants go for testing with their partners and learn their status together, but some individuals who were already aware of their positive serostatus initiated couples testing in order to be sure their partners learned of their diagnosis when they were apparently reticent to break the news themselves. A few participants reported that clinic personnel explicitly encouraged them to use this route to inform their spouse or boyfriend/girlfriend. We cannot know, of course, how many participants who thought their partners found out their own status for the first time when they were tested together were actually on the receiving end of this same sort of mild deception.

Thus findings provide support for recent calls by several researchers for an increase in HIV prevention messages targeted at couples rather than individuals (Ndase, Thior, Wester, Stevens, Peter, et al., 2004), and by implication the need to increase the proportion of couples seeking VCT services (Ghosh, Kumbirai, Taruberekera, & Osewe, 2003). As Painter (2001) explained, “In effect, by providing high quality VCT and associated support for couples, HIV/AIDS prevention is returning full circle to the most typical and widespread sociocultural setting for heterosexual HIV/AIDS infections in Africa: couple relationships (italics in original; p. 1401). VCT interventions have in fact been found to be more effective when targeting couples (Sweat, Gregorich, Sanglwa, Furlonge, Balmer, et al., 2000) than when encouraging clients to send in or bring their partners later for separate testing (a longstanding feature of HIV/AIDS counseling that has been notably ineffective in sub-Saharan Africa, e.g. Ndase, et al., 2004). It has also been suggested that couple counseling can have a positive impact of prevention of
MTCT (De Paoli, Manongi, & Klepp, 2004; Painter, Diaby, Matia, Lin, Sibailly, et al., 2002; Siwale, et al., 2003).  

Other than findings from the present study, no estimate is available about the proportion of PLHAs choosing the above method to inform their partners of their diagnosis. However, there is information regarding what proportion of VCT counseling is conducted with couples as opposed to individuals. In the past five years the proportion of couples visiting VCTs together in Nairobi has steadily risen, from 3% in 2001 to 8% in 2002 and 12% in 2003, a rise that has not been shown to be an effect of the recent specifically couple-focused campaign running in the country, but is perhaps attributable to general VCT mass media campaigns of recent years (Marum, et al., 2004). Another study conducted in the major Kenyan cities of Mombasa, Kisumu, and Nairobi found that between 9 and 12% of VCT clients attended with a sexual partner (Odoyo, Hawken, Ng’ang’a, Kamau, Temmerman, et al., 2004). There is still room for progress in this aspect of Kenyan HIV/AIDS efforts; some interventions in neighboring Uganda had seen increases in the proportion of persons requesting VCT services as couples from 8% in 1992 to nearly one-third at the close of the millennium (Painter, 2001). Given that 40 to 50% of PLHAs who test positive in couples counseling have an HIV-negative partner (Alwano, Roels, Mwasalla, Ramosweu, Molosiwa, et al., 2004; Odoyo et al., 2004), such an increase has enormous implications for preventing the spread of infection.

Getting couples in together for counseling, however, is only part of the battle. Even among participants in this study there were those whose partners did not agree to share their results at the time of counseling. Furthermore, although couples counseling is viewed by counselors as more essential to HIV/AIDS interventions than individual counseling, it has also been reported to be more difficult (Grinstead, Van der Staten, & the Voluntary Counseling and
Testing Efficacy Study, 2000). There are also ethical implications to the minor deceptive role VCT personnel are regularly asked by positively diagnosed partner to assume, and I am not aware of any published study exploring them. Nevertheless, given the findings in this study that many individuals turned to VCTs to assist them with informing their partners and even family members of their status, it is important that capacity for VCT centers to provide intermediation for diagnosis disclosure be strengthened.

**Implications for Disclosure to Other Significant Persons**

Although quantitative analyses indicated sexual partners were the most likely group to be the recipients of intermediated disclosure, focus group discussion and open-ended narratives on the questionnaire brought to light a number of additional examples of intermediated disclosure by and to family members. Perhaps the frequency of intermediation in informing partners and family, is due to the involuntary, obligatory nature of those relationships. That is, it may be that a PLHA can simply decide to forego informing a friend if the process seems too difficult. However, with the obligations felt to both partners and family members, PLHAs who cannot bring themselves to inform family and or partners directly by face-to-face methods may be forced to consider other strategies. Intermediated methods, that is, finding a third person to carry the message, appear to be a top alternative. Other implications of the value of intermediated communication with and through family members could also be explored. For example, would it be helpful to develop policies of purposefully bring sisters, mothers, or other relatives into patient-provider discussions of treatment and medication from the beginning?

Before moving to the next issue, it must be admitted that there is discrepancy in results of this study with respect to intermediation. Even though qualitative data both from focus groups and open-ended questions pointed toward family members being used as intermediators to
inform other family members, intermediation as a motive for disclosure was no greater for family members than for other groups in the quantitative analyses. My suspicion is that incorporating intermediation into the motivations for disclosure scales was not an effective means for tapping that PLHA reason for disclosing. PLHAs may have been highly aware of other pressing needs that they chose to meet through disclosure, and that the decision to employ an intermediary likely came chronologically afterward as they wrestled with how to enact the disclosure itself.

Additional Considerations for Counseling and Care

A brief comment is in order on the outcomes of disclosure that were narrated by participants. In this study, as in others (e.g. Power, et al., 2004), a portion of participants who disclosed their diagnoses experienced negative consequences. These narratives underline the need for some clients to be warned about possible repercussions of disclosure and to be supported if need be in the aftermath. However, most stories of disclosure had positive endings. This prevalence of positive disclosure outcomes is congruent with data from a number of studies in East Africa in which response to disclosure was found to far more likely to be supportive than negative (Grinstead et al., 2001; Issiaka et al., 2001; Maman et al., 2003). In the U.S., too, most studies have found reception to diagnosis disclosure to be overall positive (e.g. Gielen, 1997; Greene & Faulkner, 2002; Hays et al., 1992; Klitzman, 1999; Serovich, 1998). Notwithstanding such consistent findings in previous research, in the face of ongoing concern about negative repercussions for women in particular who reveal their status, it seems useful to reiterate Maman and associate’s (2003) assertion that “Although concern is certainly warranted for all women who experience any negative outcomes as a result of disclosure, it is important not to lose sight
of the fact that for the majority of women HIV testing and disclosure is a positive experience” (p. 378).

To summarize this section on disclosure methods, then, participants in this study mentioned several culturally distinctive strategies for self-disclosure of their serostatus including going together with a partner to a VCT center for testing without telling him/her that they already knew themselves to be seropositive, and uses of intermediation to inform family members of their condition. U.S. research has been so little concerned with the issue of method that there is no current basis for comparison between the two cultures. But that in itself may well be a sign that decisions about disclosure technique are multi-faceted for Kenyan PLHAs in a way that they are not in North American interpersonal communication.

Recap of Data-Based Recommendations for HIV/AIDS Health Communication Practice

From the results of this study a number of tentative data-based recommendations for practitioners have been derived and mentioned in context. For convenience of reference they are reiterated below:

(1) Family more than friends should be recommended as the primary line of social support for PLHAs in this environment, particularly mothers, sisters, and brothers.

(2) Counseling efforts should include strategizing a realistic approach to assisting PLHAs to balance concern for self and concern not to cause family members worry or pain.

(3) In addition to their role as spiritual nurturers, religious leaders in the lives of PLHAs should also be seen as major sources for obtaining advice, therefore continued and increasing focus on training of religious leaders in counseling PLHAs is critical.
(4) In light of the finding that not having a close relationship was a stronger motivation for not disclosing to pastors than to any other group in this study, churches must strategize how they can distribute pastoral care so that all church members feel there is someone in leadership they are close enough to confide in.

(5) Pastors and other religious leaders must work toward not only enhancing their own HIV counseling abilities but also toward reducing stigmatizing attitudes and actions within their congregations.

(6) The role of support groups in the lives of many PLHAs is central, as many PLHAs turn to support groups for support among their earliest confidants. A concerted effort to incorporate into support groups the meeting of relational needs normally accomplished by friendships is warranted, as well as strategies to enable members to gradually ease out of the group and back into previously existing relationships.

(7) It is crucial for counselors to be able to provide practical suggestions to assist PLHAs in disclosing their diagnosis to others, especially partners.

(8) HIV/AIDS prevention efforts, particularly entertainment education, can focus on modeling scripts for the disclosure task.

(9) One effective means of facilitating partner disclosure is intermediation by clinic personnel. Male PLHAs especially among this sample were inclined to initiate couples testing without telling their partners they already knew their status.

(10) This finding also lends support for calls for an increase in HIV prevention messages targeted at couples rather than individuals, because other methods of partner disclosure may prove difficult for many PLHAs.
(11) Counselors can recommend that PLHAs try using intermediated methods to disclose their status to particular family members.

(12) Purposeful incorporation of family members as intermediators into the loop of patient-provider communication from the beginning, may enhance that communication.

(13) Although most disclosure experiences reported were positive, negative consequences of disclosure experienced by a minority of participants emphasize the ongoing need to warn PLHAs about possible repercussions of disclosure and to be supported if need be in the aftermath.

Implications of Results for Theorizing About Interpersonal Communication

At the beginning of this report I stated with some qualifications that I was using Communication Privacy Management theory to provide the theoretical scaffolding for this investigation. In some respects it was a useful framework. It was convenient to use categories provided by CPM—gendered, motivational, and situational criteria for boundary rule formation—to make sense of the complicated process of self-disclosure. It was productive to be reminded throughout the investigation that disclosure of positive HIV serostatus is a dance between enormous costs and potentially devastating risks. It was helpful to be equipped with the very apt metaphor of self-disclosure as negotiation of boundaries when contemplating, for instance, the shared responsibility for controlling private information (boundary ownership) and the degree to which very sensitive information is shared at all (boundary permeability). However, by the end of the project I was concerned about the appropriateness of some aspects of the theory to self-disclosure of seropositivity in Nairobi. I was also in a position to comment on larger concerns about the appropriateness of U.S.-born self-disclosure theory to sub-Saharan cultures, and to suggest alternative foci for the context of the Kenyan HIV/AIDS epidemic. My
concerns about these issues will be divided in the discussion below into four areas: (1) the place of culture in self-disclosure theory, (2) implications of relationships for self-disclosure, (3) guarding autonomy of self or other, and (4) the importance of methods of self-disclosure.

The Place of Culture in Self-Disclosure Theory

Many theories of interpersonal communication include no mention at all of possible variation of the described phenomena from culture to culture. This may often be because the authors considered the cultures in which the theories were conceived to be the unstated parameters of their models of reality (Gudykunst & Lee, 2003). In some cases, of course, it may be a result of the ethnocentric assumption that if people act this way in my culture, they are bound to behave the same way in others. CPM, to its credit, explicitly recognizes the influence of culture on the domain of behavior it describes, and treats culture as a variable in the theory (Petronio, 1991, 2000). This cross-cultural approach, that is, the facilitation of comparison of the phenomenon across cultures, is important when considering disclosure in the context of HIV/AIDS, because the catastrophe has surged across cultural boundaries and has provoked massive international intervention efforts. It is critical to retain an awareness of how approaches in one cultural context should differ from those in another. Thus, at the end of this investigation I applaud the provision for cultural influence in this and some other (e.g. Derlega et al., 2004) disclosure theories. Nevertheless, I suggest reconceptualization of the place of that influence is needed.

The motivational component of this study was organized on the basis of the major types criteria identified by CPM as impacting boundary rule formation—cultural, gendered, motivational, and situational—all of which appear in the theory to operate at the same level of influence, functioning alongside one another in defining disclosure decisions. By implication, in
order to understand how disclosure rules worked in a specific situation, one might (were a
specific predictive element added to the theory) gather up all the separate cultural, gendered,
motivational, and situational factors, fill each one into its appointed slot in a regression equation,
and see what percent of variance in disclosure was accounted for. I suggest that is not an accurate
representation of the relationship between those factors.

Rather than being conceived of as one among several criteria for creating boundary
negotiation rules, culture should be viewed as infusing every level of the self-disclosure process,
defining the form all the other criteria take, and even what counts as disclosure. This all-
encompassing effect is illustrated in the differences between Kenyan and U.S. PLHA data that
have been highlighted throughout this chapter. The pervasive, rather than discrete, influence of
culture on boundary management is the reason why, when the hypotheses were reorganized at
the end of Chapter 2, I was able to mention hypotheses with relation to gendered and
motivational criteria, but found it impossible to create a separate category of hypotheses related
to cultural influences. Every question in this study—whether about gender, identity of disclosure
targets, even marital state (note the option of polygamous marriage on the questionnaire, page
1)—inquired into culture. To relegate it to one among several parallel contributing factors is to
far underestimate its reach.

In fact, intercultural communication researchers are accustomed to comparing dependent
variables across cultures. Hypotheses have been posed and tested regarding a wide variety of
interpersonal communication behaviors, from formats for requests to styles of argument to facial
expressions. But what about independent variables? Must they not, too, be nested within culture?
What defines maleness and femaleness, what constitutes a family, what place religious leaders
hold in the lives of a group of people, these are issues that are molded by the powerful hand of culture in the experiences of both researcher and participant.

To achieve this type of nested understanding of cultural influence for both independent and dependent variables, it may not be sufficient to locate the communicative artifacts that occur with the most frequency, or even that are exclusive to a given culture. An element present in one culture may be evident in another, yet carry an entirely different meaning; or a behavior may be exclusive to a culture but of only tangential importance. What is needed is a focus not on a single artifact, but on the holistic configuration of components, on the development of a kind of matrix of co-occurring elements. Comparison between cultures can then be accomplished by overlaying disparate matrices on one another and noting points of similarity. As a field, intercultural communication research has for too long assumed the generalizability of the constructs with which we are working. More appropriate would be a careful transfer of constructs between similar multi-dimensional matrices. Developing that kind of understanding will be a slow business, accomplished incrementally through the accumulated evidence of a multitude of studies, both qualitative and quantitative, but it will assure more valid and useful comparisons.

In making these suggestions I am not saying that there are no cultural commonalities in self-disclosure or other interpersonal communication processes. Just as Pepitone and Triandis (1987) have insisted that our common humanness means people from every culture share certain psychological patterns, there are no doubt features of revealing of private information about ourselves that transcend individual and societal differences, but they are probably fewer than we think. This is the intercultural reality that models of self-disclosure—models of any interpersonal communication process—must represent.
Implications of Relationships for Self-Disclosure

In support of the notion recently propounded by Derlega and associates (2004), results of this study indicate that motivations for disclosure operate in the context of specific relationships. Much of Western self-disclosure research has concentrated on personality traits as determinants of disclosure, or on gender of discloser and disclosee. In a collectivistic society like Kenya, however, more important than individual differences between disclosers may be the form of relational ties that bind the individuals to the persons they are contemplating as recipients of their secrets.

Effects on both motivations for disclosure and nondisclosure in this study were stronger for relationship type than for gender, as was also the case in Derlega and associates’ (2002, 2004) U.S.-based research. Methods of disclosure, too, were more strongly associated with relationship type than with other variables like social distance. Recall that in the quantitative portion of the study intermediation was distinctly preferred for partner diagnosis disclosure, and in the qualitative components of the study it emerged as a tool for informing family members. And yet it is gender, not relationship, that is included in the list of criteria for formulating boundary rules in the standard presentation of CPM (Petronio, 1991, 2000). The discrepancy between theory and empirical findings suggests alteration to the theory may be in order. A model of HIV diagnosis disclosure in the Kenyan environment must recognize that privacy boundaries are negotiated in part on the basis of the type of relationship that exists between the PLHA and the potential target of disclosure.

Guarding Autonomy and Vulnerability. . . of Whom?

Self-disclosure theorizing, like much theorizing in the behavioral sciences, has historically been predicated on the understanding of human relationships as preoccupied with
social exchange, i.e. as continuously assessing costs and benefits to the self to the neglect of selfless impulses and motivations. We understand from social penetration theory (Altman & Taylor, 1977) that people calculate the costs and benefits of disclosure in terms of increasing relational closeness before revealing private information, and from a plethora of empirical investigations that people in part disclose to get people to like them better (Dindia, 2000b). CPM explicitly reiterates this ego-oriented perspective in its basic assumptions that: 1) individuals erect boundaries to control their autonomy and vulnerability when disclosing and receiving private information, and 2) in a relational system people strategically regulate communication boundaries to control their autonomy and vulnerability (Petronio 2000). There is no mention of individuals strategically regulating communication boundaries to protect the autonomy and vulnerability of others.

But that is just what many PLHAs apparently do. If we are to believe the self-reported motivations for disclosure and nondisclosure of Kenyan PLHAs in this study, among strongest reasons for revealing and concealing a positive diagnosis are protecting others, having a duty to inform them, and wanting to prepare them for the future. Although other-focused reasons did emerge as a higher priority in this sample than in much U.S. research, collectivist cultures do not have a monopoly on concern for others as a determining factor in serostatus disclosure. North American PLHAs who are parents, for example, are regularly faced with deciding how much information their children can handle about their illness, and whether the balance of hurt and harm to the child will be better served by revelation or concealment (Greene & Faulkner, 2002; Rotheram-Borus, et al., 1997). Numerous U.S.-based studies make the point that many of the most common reasons for disclosure and nondisclosure among PLHAs—to a variety of significant persons in their lives—are other-focused (see for example Agne et al., 2000;

As a scion of dialectical theory, CPM has naturally focused on the dialectical tensions of openness-closedness and autonomy vs. relational intimacy as those most closely affiliated with self-disclosure (Petronio, 1991). Perhaps another dialectic should be introduced, labeled simply “self-other”. PLHAs in this sample clearly worked at balancing, for instance, the realization that they had a duty to warn their partners to take precautions with the fear of rejection or even extreme personal discomfort in the disclosure event; or in cases of nondisclosure, the knowledge that they might receive emotional support from family if their condition were known with concern that that same knowledge might devastate family members who looked to them for various reasons.

If I may lapse into the anecdotal for a moment, this latter is especially relevant in Kenyan society, where the idea that people have an absolute right to know about matters that intimately concern them does not have the force that it does in the United States. In my years of living in Kenya I have observed a number of instances (and been the recipient of one) when someone was the bearer of bad news regarding a family member of one of their friends or relatives, and withheld that news until they felt the most propitious time for revealing it had come. Sometimes that time was never. This is especially true in the case of deaths, where a person may be told something like, “your mother is not feeling well, you should probably go to see her”, or even less directly, “I’ve been told you need to go home to your mother’s place today”, when in fact she is already deceased. I have not located any scholarly literature on the subject at all, but there is no question it is a facet of the indirect communication that is frequently
employed in this context, and it requires a shift in the understanding of the other-self tensions inherent in nondisclosure.

Although the recognition of other-oriented disclosure (and non-disclosure) motivations has informed some research efforts on HIV serostatus disclosure (e.g. Agne, et al., 2000; Charbonneau, et al., 1999; Derlega, et al., 1998, 2003; Marks, Mason, & Simoni, 1995; Paxton, 2002; Simoni, et al., 1995; Serovich, 2001; Simoni et al., 1995), it has not yet managed to permeate many theoretical models of self-disclosure, and it is not present in the stated assumptions of CPM. The factor of motivational criteria in the theory should be expanded to explicitly embrace both self- and other-oriented considerations.

Methods of Disclosure

Although few disclosure theories take into account the means by which disclosure is effected, disclosure method is not a peripheral issue with respect to HIV serostatus disclosure. If, as participants in this study indicated, one of the main reasons a positive diagnosis is not communicated to partners and other significant persons in the lives of PLHAs is that they simply cannot find a manageable way to do so, it is important for counselors, clinicians, even pastors and lay leaders to be equipped with knowledge of techniques or scripts they can suggest to PLHAs. Thus a model explaining HIV status disclosure must include a component on disclosure method.

It is a strength of CPM that it is an exception to this trend, having proposed within the context of marital relationships associations between: (1) congruence of level of directness in disclosure vs. response messages and level of satisfaction with the disclosure event, and (2) disclosure method and (a) need for disclosure, (b) predicted outcomes of the exchange, (c) degree to which the information is considered private, and (d) emotional control the partners
exercise (Petronio, 1991). No tests of CPM’s predictions with respect to disclosure method have been published so far as I can determine, however; they were posited in the original micro-component of the theory and have been more or less dropped from later, macro-oriented, discussion (Petronio, 2000, 2002; Greene et al., 2003).

The present study was also macro-focused, and especially concerned with the impact of relationship type on disclosure method, a variable that is not incorporated into CPM’s disclosure method predictions. It therefore drew inspiration from politeness theory (Brown & Levinson, 1978, 1987), which does include independent variables at the relational level, and posited an association between relational closeness, relative social status, and disclosure method. Note, too, that the self-other tension I have recommended above as an additional component for CPM parallels the component in many face theories of concern for own face vs. concern for other face (e.g. Ting-Toomey & Oetzel, 2003).

Results of statistical analyses did not directly confirm the expected association between relative social status and disclosure method or between relational closeness and disclosure method, but the finding that persons disclosing for the purpose of obtaining material support are likely to use intermediated methods may be indicative of the operation of face concerns, as may the indication that women are more likely to use direct disclosure techniques than men. That is, people seeking physical assistance may feel their self-face is threatened by making such a request, and men may feel their more powerful role in relationships is jeopardized by revealing news of their serostatus. Other associations may yet appear when intermediation for other communicative purposes such as interpersonal conflict management is examined, or in a study that has sufficient statistical power with respect to disclosure within families to locate an effect. What did emerge from both qualitative and quantitative components of the study was a clear
indication that among Kenyan PLHAs, methods of disclosure, like motivations, are associated with relationship type.

**Intermediation as a Means of Communication Private Information**

In addition, it is apparent that indirectness is not the only quality that distinguishes disclosure method. Intermediation appeared to be a distinct means of communicating private information, especially useful for sharing news of a positive HIV serostatus to family or partners, and employed for the latter purpose more often by men than by women according to these data. Key informant interviews, and the author’s decade of participant observation in Kenyan life, indicate disclosure of other types of sensitive information, management of conflict, and expression of a range of relational issues appear to be not uncommonly undertaken through informal intermediation.

Here intermediation should be distinguished from the concept of opinion leadership (Rogers, 2003). Opinion leaders are innovative, cosmopolitan, often better educated members of a community to whom others look for interpersonal guidance on various life issues and decisions, and who are considered key in the diffusion of innovations. On the other hand, intermediaries are specific to the situation and relationship at hand; rather than disseminating information generally within a community, intermediaries are entrusted by a sender with information for a particular target.

Although data from the structured interviews do not warrant extension of findings about intermediated communication to other topics besides HIV diagnosis disclosure, a narrative of intermediation related by one of my key informants (call her Carole) is one of many I could supply that suggest the possibility is worth exploring. Just two days prior to our meeting, another friend (call her Jane), came to Carole to get her assistance with some problems she was
having in her marriage. Together they decided the problems were serious enough that they needed to be mentioned to Jane’s mother. Jane could not tell her mother these things directly, however, so the two women decided that the best approach would be for Carole to go as an emissary to a young aunt of Jane’s who would then serve as a bridge between Jane and her mother. Jane called up her aunt, whom she knew to be getting her hair done at a local beauty parlor, and told her that Carole was in the neighborhood and wanted to stop by and say hi to her. This maneuver was designed to alert the aunt to the fact that there was an issue that needed to be discussed, which in fact it did. Carole then went alone to see the aunt. It was inappropriate for her to volunteer the information herself, so she spent some minutes discussing a wide range of general subjects until the aunt finally asked, “So, how is Jane’s husband these days?” Carole answered, “Well, you know there is something there. There is a problem.” At that point she unfolded the entire story. At the end of the conversation Carole and the aunt agreed abstractly that, “We must let the mother know.” From that comment the aunt correctly inferred that she herself was expected to broach the subject with the mother.

This story presents a fascinating combination of direct, indirect, and intermediated communication. Of the three, intermediated communication is a distinctly understudied area in intercultural communication. Lest we assume that it is a practice common only in collectivist sorts of societies, I urge the reader to recall a time in elementary or middle school when you sent or were sent to inquire of a pre-adolescent heart throb, “So-and-so likes you. Do you like her?” There is intermediation in U.S. life as well, and it does not entirely stop when we crossed the threshold into high school. This sort of communication in whatever cultural context involves intricate, subtly choreographed interpersonal maneuvering, and presents a fascinating topic for observation by communication researchers. Any sojourner in Kenya who hopes to be culturally
sensitive, any aid worker who intends to be culturally effective, must on occasion be either the sender or recipient of such third party communication.

To conclude this section I will mention a fifth factor that would be expected to impact disclosure patterns, that of situational characteristics, that is, circumstances at a specific point in time that advance or retard enactment of self-disclosure. Situational characteristics were not a focus of this investigation and therefore are not discussed above among major findings. However, Greene and colleagues (2003) speak of a similar concept when they describe contextual criteria for diagnosis disclosure, referring to anticipated timing and place of revealing personal information. Petronio (1991) and others (Greene et al., 2003) give details on a variety of situational factors that can impact the course of a disclosure event. In this study, focus group discussions and PLHA narratives on open-ended interview questions occasionally referred to times when PLHAs were either unable to bring themselves to disclose because the time or place did not seem right, or when suddenly they knew the circumstances were propitious for revealing their secret. In other words, the specific situation at critical moments in PLHA lives shaped the course of their disclosure decisions.

**Augmenting Models of Disclosure in Cultural Context**

The issues discussed above suggest that an appropriate model for HIV serostatus disclosure in Nairobi, Kenya, would view the expansion and constriction of privacy boundaries as contingent upon four general factors, the specifics of which would be defined by the cultural environment. These factors have been explicated above: (1) relationship structures and obligations, (2) motivations for disclosure, including both self- and other-oriented considerations, (3) disclosure method, and (4) situational characteristics. Each of the four posited factors will have a certain weight or priority in a given disclosure decision, and the simultaneous
calculus of those weights will determine the decision and the method for implementing that
decision. A PLHA might, for instance, have a goal of obtaining assistance with paying her rent
the following month, while at the same time entertaining the goal of not giving pain to her
family. She will examine her disclosive options in the light of the parameters her culture has
established for her with respect to relational structures and attendant obligations. After
evaluating pros and cons of various potential targets, she may consider that one way of obtaining
the needed funds would be to reveal her serostatus to her favorite aunt (a choice, by the way, that
would not generally be acceptable in the U.S. context), with whom she is very close and who she
is confident will accept her condition. However, she must at the same time determine whether it
is likely that her aunt will tell her mother, whom she knows will worry terribly about her.
Furthermore, she must plan a method of disclosure that she feels comfortable with. Even after
the disclosure decision is made, characteristics of the disclosure situation may cause her to
reformulate her disclosure method, hasten the disclosure process, or even to abort disclosure
plans entirely. Similar confluences of thought may occur at various times as she debates other
disclosure possibilities.

As I have described it thus far, this model is subject to a criticism that could readily be
made regarding the macro level of CPM: that it includes no predictive element. That element is
added to the model, however, when associations are posited between various factors. As detailed
above and in Chapter 4, results of this study have revealed effects for relationship type on goals,
motivations, and disclosure method in the urban Kenyan context. Future research will no doubt
supply additional information in that regard. For example, future investigations might explore to
what relationship types PLHAs will be most likely to turn to meet goals of informational support,
how belonging to
support groups impacts disclosure decisions toward other groups, and what characteristics of religious leaders contribute to PLHA willingness to disclose. Regarding disclosure method, the micro-level of CPM might be revisited and exploration conducted within the partner relationship as to whether, as the theory asserts, expected outcomes of disclosure and the emotional condition of the PLHA in the moment of disclosure predict disclosure method. Further investigation of cultural categories more theory-driven than just nationality is also needed. For example this study was situated in an urban environment, but urban Nairobi may reflect post-colonial globalization as much as it does traditional African communalism. Thus future research might address how the degree of identification with indigenous/rural versus urbanized/global/Westernized culture affects disclosure decisions in Kenya.

In summary, this formulation suggests boundary management is constituted by the four general factors of relational structures and obligations, disclosure motivation, disclosure method, and situational characteristics. In so doing it differs from the preponderance of disclosure models in three critical respects: (1) it expressly represents the pervasive impact of culture in setting parameters for every aspect of disclosure decision-making; (2) it includes a component for relationship type; and (3) it incorporates the choice of disclosure method. The first two of these are also distinctions from CPM. And whereas CPM already contains an explicit recognition of disclosure method in its original conceptualization (Petronio, 1991), this model augments CPM by adding the provision for both self- and other-focused motivations for disclosure.

Limitations of the Study

It was observed in Chapter 3 that a study of self-disclosure of a positive HIV diagnosis inherently utilizes a biased sample. Only individuals who have disclosed to some degree already
will be identifiable as potential participants. Individuals who then agree to reveal private information about their lives to a complete stranger are likely more disclosive still. Precautions were taken to make the purposive sample representative of a wide range of socio-economic statuses, urban to peri-urban residence, degrees and identity of religious affiliation, sex, and age, as detailed in Chapter 3. Nevertheless the sample is by no means representative of all PLHAs in Nairobi. It is even less representative of PLHAs in the rural areas of Kenya, whose experience with disease and disclosure is likely to differ substantially from that of their urban kin.

The decision to locate some of the participants through their membership in support groups also leads to potential for bias in the listing task for the first five disclosure targets. These individuals have obviously already disclosed to at least that category of target. On the other hand, in defense of this sampling procedure, membership in a support group does necessarily mean the group was one of the first five disclosees. The fact that support groups showed up as early disclosees speaks to their true salience.

The study is also limited by its single point of time design. In many respects longitudinal studies that trace disclosure over time are ideal, as they are not as subject to the whims of participant memory, especially in cases where years have passed since the earliest diagnosis disclosures were contemplated and subsequently made. Of course longitudinal studies are laced with a different set of constraints, such as the logistics of retaining a sufficient number of participants over time. In this project, time and financial limitations made a longitudinal design impossible.

Furthermore, this study was conducted not by a Kenyan, but by an outsider to Kenyan culture, albeit one who has resided for some years in Nairobi. There may be some advantages to the fresh perspective that an external observer brings to study of a particular culture, but there are
surely many more disadvantages. In recognition of that shortcoming, consultation was held at every stage of the research process with Kenyan cultural informants, and possible lack of perceived cultural solidarity between the investigator and the participants was mitigated by the used of Kenyans as primary data collectors. Even so, it is still possible and even likely that some cultural nuances slipped by unrecognized.

Finally and perhaps most importantly, this project was carried out in Nairobi, an environment considered by many Kenyans to be culturally halfway between the rural villages where two-thirds of Kenyans live and the alien atmosphere of New York City or London. In the cosmopolitan mix of the capital city, not only are extended families far away, but specific ethnic traditions and values are diluted. The responses of urban and peri-urban participants in this study cannot reliably be generalized to their rural cousins without confirmation of future research efforts.

Concluding Thoughts

Cross-Cultural Research: Not for the faint hearted

With my data all gathered, analyzed, and discussed, I find I cannot resist the temptation to insert a final comment on cross-cultural research methodology. I have already mentioned above adjustments I made to the design of the study in order to take into account concept, method, and item bias. Locating item bias, for instance finding out whether disclosure motivations of PLHAs in Kenya differed from those in the U.S. was relatively straightforward. Identifying construct bias was in a sense the whole purpose of my investigation. But my struggles with method bias revealed deep differences in thought process, cognitive structures, and values, and ultimately had enormous implications for the analysis of the data obtained.
In response to the cumulative impact of these cultural revelations, I now propose the cross-cultural “times two” principle. The principle states that any numbers involved in a cross-cultural research project should be multiplied—or divided, as the case may be—by no less than two before any proposal or report is set on paper. Thus, it will now be a rule of thumb for me in any research project outside of my own culture that pilot study samples be twice as large as those I would plan in my own culture, and carefully selected to represent a variety of demographic groups that might not appear in the home culture to differ substantially. Timelines should be figured by estimating the absolute longest a project should take to complete and then multiplying by two, because the plethora of issues both simple and complicated that assail the researcher before every deadline will inevitably generate delays. The length of time required for individual interviews may be halved or doubled, depending on whether the researcher, like me, meets with intolerance for lengthy instruments, or, on the other hand, finds s/he must fulfill all of the obligations of an honored guest before embarking on the interview proper. In my case, the result of the expectations for a short interview meant I had to trim far into the lean of my questionnaire, or so it felt at times, and the amount of spare data I carry away from this project to unpack at a later date in comparison to what I would likely have obtained in U.S. based research must be divided by much more than half. Bearing all this in mind, researchers like me must be twice as careful about contrasting results of our efforts to those conducted in the home culture, because after the Herculean effort of all this multiplying, we will be excruciatingly aware that cross-cultural comparison is an inexact and risky business.

The principle undoubtedly has many more applications. Fortunately it does have a positive side: the research can be doubly satisfying. For me the satisfaction came from encountering a fascinating variety of human communication behavior, from gathering piles of
tiny scraps of information and trying my best to piece them together into an orderly quilted pattern, from marveling at the subtle means by which humans across the globe communicate in their own cultural systems. And from learning yet another time that my cultural way of doing things isn’t, thank God, the only way. The process wasn’t pretty, but it was enjoyable even so.

A Reiteration of the Centrality of Self-Disclosure

In a number of ways interpersonal communication about HIV/AIDS may be more important in arresting the spread of the epidemic than the more traditional health communication foci of mass media and patient/provider communication (Cline, 2003). Findings in this study concerning the role of support groups in the lives of PLHAs, the potential of religious leaders for advising and assisting HIV-positive church members, the most common motivations for disclosure and nondisclosure, and the use of intermediation as a disclosure technique all have implications for HIV/AIDS prevention and care and should all be further validated in future research, including quasi-experimental intervention research. Implications of this study regarding the place of culture, the role of relationship type, the consideration of self vs. other, and the selection of disclosure method should be integrated into self-disclosure theory, especially with respect to disclosure of a positive diagnosis of HIV.

In the context of the sub-Saharan HIV/AIDS epidemic thoughtful and culturally grounded theorizing of interpersonal communication patterns is a life and death matter. It is in prevention that the ultimate key to arresting the spread of this currently incurable disease lies; it is in interpersonal disclosure of HIV test results that much of prevention is enacted.
REFERENCES


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APPENDIX A

CONSENT SCRIPT FOR FOCUS GROUPS

The study you are about to participate in is a research project being conducted by Ms. Ann N. Miller, a faculty member from Daystar University Communication Department who is currently working on a doctoral degree at the University of Georgia in the U.S.

The purpose of the research is to investigate why and how people with HIV/AIDS speak about their diagnosis to other people, especially how they would reveal their status to a partner or someone in their church, either a fellow member or a religious leader like a pastor. This sort of things has been studied in the U.S., but there has been little research on this conducted in Africa, especially about how people living with HIV/AIDS feel about their churches and pastors, although there has been research conducted on how people in churches feel about HIV/AIDS and how equipped they are to address either prevention or care issues. Our hope is to get information on these issues from the perspective of people living with HIV/AIDS.

Your part of the study will involve participating in a discussion of those issues as they relate to your life. Eight or ten people who are also clients at ______________________ (name of clinic/outreach) will be part of your discussion group. The total group discussion will take about one to one-and-a-half hours, and will be audio-tape recorded. We will not record your name and there will be no identification of you at any place in the research. If for any reason you decide that you wish to leave the discussion group, you may do so. If at any time you want to ask the discussion leader a question about the study, please feel free to do so. Also, if you want further information about the study please feel free to ask.

Eventually we will be conducting a large number of survey interviews looking at these same issues. In order to do so, we have to be sure that the questions on the surveys are culturally appropriate. Toward the end of the discussion we will show you some questionnaire questions and ask for your thoughts on whether they make sense in this cultural context, as well as any suggestions you have for changes that might make them more appropriate.

You may keep this information sheet for further reference and also get a copy of the results of the study as soon as they are available if you want. The discussion leader will remain after everyone is finished to answer any other questions. If you have any questions you may also feel free to contact Ms. Miller at Daystar University at 2723002/3/4 or via email at jamiller@nbi.ispkenya.com. Thank you for your participation.
APPENDIX B

FOCUS GROUP DISCUSSION GUIDE

1. First, I’m going to be asking you several questions about telling others when you found out you were HIV positive.

When you first found out you were positive, who if anyone did you want to know about your diagnosis?

What people did you NOT want to find out about your condition?

If you had people you wanted to know about your being HIV positive, why did you want them to know? In other words, what were your reasons for wanting them to be aware you had HIV?

The people that you wanted to know you were HIV positive, if anyone, how did you go about being sure that they knew? (prompt: did you tell them face-to-face? Did you ask someone else to tell them? Did you drop hints to them? Etc.)

NOTE: WE WILL WANT INFORMATION ON REVEALING TO PARTNERS/SPOUSES, FRIENDS, FAMILY, MEDICAL PROVIDERS, AND RELIGIOUS LEADERS. DEPENDING ON HOW MUCH IS OR IS NOT SAID ABOUT EACH OF THESE CATEGORIES, FOLLOW UP QUESTIONS BELOW:

2. What about your spouse or girlfriend at the time you found out? Did you want her or them if you had more than one, about your being HIV positive? What reasons did you have for and against telling her? Does he know about your condition? If so how did she find out? If she knows, how soon did she find out after you learned of your diagnosis?

If you have had other sexual partners since then, do they know about your diagnosis? Why or why not? How did they find out?

3. And your friends? Did you want them to know your are HIV positive? What reasons did you think of for and against telling them? Do any of them know now? If so, how did they find out? How soon did they find out after you learned of your diagnosis?

4. What about your family. Did you want them to know about your being HIV positive? What reasons did you have for and against telling them? Do they know about your condition? How did they find out if they know? If they know, how soon did they find out after you learned of your diagnosis?
5. If you are a regular church attender, did you want your pastor or other church members to know about your being HIV positive? What reasons did you have for and against telling them? Do any of them know about your condition? If so, how did they find out? If they know, how soon did they find out after you learned of your diagnosis?

6. When you have told the people you have told about having HIV, if anyone, how have they responded to you?

Thank you very much for your time. If you have any questions I would be happy to answer them...
APPENDIX C

INFORMED CONSENT SCRIPT FOR STRUCTURED INTERVIEWS

To be read to participant prior to commencing interview:

The study you are about to participate in is a research project being conducted by Ms. Ann N. Miller, a faculty member from Daystar University Communication Department who is currently working on a doctoral degree at the University of Georgia in the U.S.

The purpose of the research is to find out why and how people with HIV/AIDS speak about their illness to other people. For example, do they talk about their disease to their wives or husbands or boyfriends or girlfriends? Do they ever tell about their condition to someone in their church, either a fellow member or pastor? This sort of things has been studied in the U.S., but there has been little research on this topic in Africa. Our hope is to find out about the true experiences of people living with HIV/AIDS in talking to different kinds of people about their sickness. We hope this research will eventually help in getting the right kinds of support to people who are living with the HIV/AIDS disease.

You will be answering a number of questions that I will read to you. It should take us about 30 to 45 minutes to get through all the questions. If at any time you have any concerns about this research, or if you need me to clarify something, please just stop me and ask for more explanation.

Some of the questions will be personal in nature. For example, I will be asking you about your family. I will also be asking you about your sexual partners. It is important that you answer all questions with complete honesty. Your name will never be mentioned in any report of this study. In fact, no record will be kept of your name after our conversation right now. No one will ever be able to tell what answers are yours and what answers came from someone else. So you do not need to worry about telling me the absolute truth.

You may keep this information sheet for further reference and also get a copy of the results of the study as soon as they are available if you want. If you have any questions you may also feel free to contact Ms. Miller at Daystar University at 2723002/3/4 or via email at jamiller@nbi.ispkenya.com. Thank you for your participation.

Do you want to continue with the survey?

_____ Yes  ______ No
APPENDIX D

QUESTIONNAIRE

NOTE TO INTERVIEWER. For questions with italicized answers, read QUESTIONS ONLY, then tick appropriate answer. Only read answers to participants if they get stuck or you are unsure how to categorize their answer.

Section One

First I need to get some general information from you, about yourself and then we’ll move on to talk about your experience with HIV/AIDS.

1. How old are you? ________ 2. Gender (M _____ F_____)  
   
3. What is your marital status?  
   (Interviewer tick from among the following:  
   _____ Married _____ Widowed _____ Divorced _____ Single  
   _____ Traditionally married _____ Polygamously married _____ Separated  
   
4. When did you receive you positive HIV diagnosis (year, month, day if possible)?
   ____________________________
   
5. Are you having physical symptoms of HIV, like infections, etc.?  
   (Interviewer tick one: _____ asymptomatic (no symptoms) _____ symptomatic)
   
6. Are you on ARV’s?  (_____ Yes _____ No)  
   
7. How do you think you were infected with HIV?  
   (Interviewer tick from among the following:  
   _____ sex with a woman/man who was NOT your husband/wife  
   _____ sex with your husband/wife  
   _____ sexual contact with someone of the same sex  
   _____ through tainted blood, medical procedure (e.g. transfusion)  
   _____ through tainted blood caring for another  
   _____ had AIDS since childhood (transmission from mother to child)  
   _____ injection drug use  
   _____ don’t know  
   _____ other ________________________________
Section Two

Now I want you to think back about the time you first learned that you were HIV positive. I’m going to ask you about several people whom you may or may not have told about your diagnosis. For each one I will ask you about reasons you had for telling or not telling them at the time, also what gender the person was, how close your relationship is to that person, and whether you would consider that person to be of a higher, lower, or equal social status than you. What we mean by social status is that there are some people whom we consider to be our equals, for example our agemates. Other people would be above us in terms of social standing and we have to treat them with more respect, such as an elder among certain tribal groups, your father’s oldest brother, a boss at work, etc. Finally, some people have lower social status than we do, such as children, people who work for us, and so on. If you did tell them your diagnosis, I’ll ask you how you went about doing it,

Spouse/boyfriend/girlfriend

Think of the first person with whom you started a romantic or marital or sexual relationship after you learned about the diagnosis or think about someone with whom you were already in a romantic or marital or sexual relationship when you first learned about your HIV diagnosis.

10. So is the person you are thinking of a spouse, boy/girlfriend?
   (Interviewer tick one: ____ Spouse ____ Boy/girlfriend)
   ____ N/A Participant has not had a spouse/lover since diagnosis. If this is the case, skip to question 19)

   (Substitute correct term, e.g. “Your husband” in remainder of section).

11. In terms of your feelings and commitment to your spouse/boyfriend/girlfriend, how emotionally close would you say you were to that person. Give me your answer on a scale of 1 to 5, with “1” being “not very close at all” and “5” being “extremely close”.
   
   1 2 3 4 5

12. Would you say your spouse/boyfriend/girlfriend was higher, the same, or lower social status than you? ____ Higher _____ Same _____ Lower

13. Does this person know that you are HIV positive? ___Yes ___No ___Unsure

   (IF NO, SKIP TO QUESTION 17)

14. Exactly when did s/he find out (month, day, year if possible)? ________________

15. Can you tell me briefly HOW this occurred? **For example did you tell your spouse/boyfriend/girlfriend straight out, did you drop hints, did you have someone else tell him/her? How did s/he respond?
   (GO BACK AND FILL IN DETAILS AFTER INTERVIEW. PLEASE GIVE AS MUCH DETAIL AS POSSIBLE)
(Interviewer, after writing out occurrence tick most appropriate option below. If unsure ask for clarification mentioning categories if need be:

___ a. I myself told my spouse/girlfriend/boyfriend straight out about my illness. either directly in a face-to-face conversation, on the phone, or in a letter.

___ b. I myself informed my spouse/girlfriend/boyfriend, but I did it indirectly through hints instead of saying straight out that I have HIV/AIDS.

___ c. I purposefully left clues about my condition (e.g. leaving out bottles of medicines or vitamins)

___ d. I asked my spouse/boyfriend/girlfriend to go with me to a VCT for testing but didn’t tell him/her I already knew I was HIV+.

___ e. We went together to VCT and found out at the same time

___ f. I approached a third party and directly asked them to inform my spouse/girlfriend/boyfriend of my condition.

___ g. I hinted to another person about my condition, hoping they would tell my spouse/girlfriend/boyfriend.

___ h. I informed a third party about my condition and trusted them to inform the people who needed to know.

___ i. Someone told my spouse/girlfriend/boyfriend that I had HIV/AIDS, even though I never wanted him/her to know. (IF PARTICIPANT GIVES THIS ANSWER, SKIP TO Q. 17)

___ j. My spouse/girlfriend/boyfriend figured out I had HIV/AIDS without anyone telling him/her (e.g. seeing symptoms, noticing visiting clinic, reading a medical chart, etc.) (IF PARTICIPANTS GIVES THIS ANSWER GO TO 16 OR 17 DEPENDING ON PARTICIPANT)

___ k. Other _______________________________________________________

16. Next I’m going to give you a list of reasons you might have had for wanting to tell your spouse/boyfriend/girlfriend about your being HIV positive. What we will do is to go through common reasons for telling someone one at a time and for each one I want to you to tell me as much as you can remember how important that reason was for you wanting to tell them about your condition. You will do this, again, on a five point scale with 1 = Not at all important; 2 = Slightly important; 3 = Moderately important; 4 = Very important; 5 = Extremely important. (NOTE TO INTERVIEWER: Be sure participant is clear about directions before proceeding. Circle correct number.)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not at all Important</th>
<th>Slightly Important</th>
<th>Moderately Important</th>
<th>Very Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I wanted to get advice from my spouse/boyfriend/girlfriend.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
b. We had a close relationship.  

c. I had a duty to tell my spouse/boyfriend/girlfriend so s/he could take precautions.  

d. My spouse/boyfriend/girlfriend would support me emotionally.  

e. I trusted my spouse/boyfriend/girlfriend not to tell anyone.  

f. My spouse/boyfriend/girlfriend would be able to help me with material support.  

g. I wanted to prepare my spouse/boyfriend/girlfriend for what might happen to me.  

h. I wanted my spouse/boyfriend/girlfriend to help me inform other people who needed to know.  

i. I knew s/he was HIV+  

j. My condition would be obvious to my spouse/boyfriend/girlfriend.  

k. Are there other reasons you had for wanting your spouse/girlfriend/boyfriend to know about your diagnosis that I haven’t mentioned? ____________________________________________  

____________________________________________________________________________  

**NOTE TO INTERVIEWER:** If participant disclosed to this person, skip to Q 18.  

17. Now I’m going to ask you to remember reasons why you might have thought about NOT telling your spouse/girlfriend/boyfriend about being HIV positive. Again, rate these on a scale of 1 to 5 with 1 being “not at all a reason for not telling” and 5 being “very much a reason for not telling.” **(NOTE TO INTERVIEWER: Be sure participant is clear about directions before proceeding)**  

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not at all Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I was afraid that my spouse/girlfriend/boyfriend would reject me.</td>
<td>1  2  3  4  5</td>
<td></td>
</tr>
<tr>
<td>b. They might go around telling people.</td>
<td>1  2  3  4  5</td>
<td></td>
</tr>
</tbody>
</table>
c. I didn’t want my spouse/girlfriend/boyfriend to experience pain over what I was going through. 1 2 3 4 5
d. We weren’t very close to one another. 1 2 3 4 5
e. I didn’t know how to tell my spouse/boyfriend/girlfriend. 1 2 3 4 5
f. I didn’t want my spouse/boyfriend/girlfriend to worry about me. 1 2 3 4 5
g. So far as I knew, my spouse/girlfriend/boyfriend was not HIV+. 1 2 3 4 5

h. Please mention any other reason you DIDN’T want to tell this person _____________

________________________________________________________________________

18. How many other sexual partners have you had since around the time of your diagnosis? ________.

Old Friend (someone you were already friends with when you received your diagnosis)

Now we’re going to stop talking about your spouse/girlfriend/boyfriend and I’m going to ask you to think of a friend of either sex whom you knew very well when you learned about your HIV diagnosis but with whom you were not romantically or sexually involved. This person should NOT be a member of your family. It can be someone who knows or doesn’t know about your having HIV/AIDS.

Please give me an initial to stand for the friend you are thinking of and we will use that throughout the rest of our discussion about the friend. (Initial: _____)

19. Was your friend male or female? _____M _____F

20. In terms of your feelings and commitment, how emotionally close would you say you were to _____? Give me your answer on a scale of 1 to 5, with “1” being “not very close at all” to “5” being “extremely close”.

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<th></th>
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<th>3</th>
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<th>5</th>
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</table>

21. Would you say _____ was higher, the same, or lower social status than you?

_____ Higher  _____ Same  _____ Lower

22. Does this person know you are HIV positive? ___Yes  ___No  ___Unsure

(If NO SKIP TO QUESTION 26)

23. Exactly when did s/he find out that you are HIV positive (month, day, year if possible)?  

_____________________


24. Can you tell me briefly HOW this occurred? **For example did you tell _____ straight out, did you drop hints, did you have someone else tell him/her? How did s/he respond? (AFTER INTERVIEW FILL IN DETAILS. PLEASE GIVE AS MUCH DETAIL AS POSSIBLE)

(Interviewer, after writing out occurrence tick most appropriate option below. If unsure ask for clarification mentioning categories if need be:

___ a. I myself told my friend straight out about my illness. I told him/her directly in a face-to-face conversation, on the phone, or in a letter.

___ b. I myself informed my friend, but I did it indirectly through hints instead of saying straight out that I have HIV/AIDS.

___ c. I purposefully left clues about my condition (e.g. leaving out bottles of medicines or vitamins)

___ d. I asked friend to go with me to a VCT for testing but didn’t tell him/her I already knew I was HIV+.

___ e. We went together to VCT and found out at the same time

___ f. I approached a third party and directly asked them to inform my friend of my condition.

___ g. I hinted to another person about my condition, hoping they would tell my friend.

___ h. I informed a third party about my condition and trusted them to inform the people who needed to know.

___ i. Someone told my friend that I had HIV/AIDS, even though I never wanted him/her to know. (IF PARTICIPANTS GIVES THIS ANSWER SKIP TO Q. 26)

___ j. My friend figured out I had HIV/AIDS without anyone telling him/her (e.g. seeing symptoms, noticing visiting clinic, reading a medical chart, etc.) (IF PARTICIPANTS GIVES THIS ANSWER GO TO Q. 25 OR 26 DEPENDING ON PARTICIPANT)

___ k. Other ___________________________________________________
25. Next I’m going to give you a list of reasons you might have had for wanting to tell your friend about your being HIV positive. You will do this, again, on a five point scale with 1 = Not at all important; 2 = Slightly important; 3 = Moderately important; 4 = Very important; 5 = Extremely important.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not at all Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I wanted to get advice from my friend.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>b. We had a close relationship</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>c. I had a duty to tell my friend.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>d. My friend would support me emotionally</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>e. I trusted my friend not to tell anyone.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>f. My friend would be able to help me with material support.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>g. I wanted to prepare my friend for what might happen to me.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>h. I wanted my friend to help me inform other people who needed to know</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>i. I knew my friend was HIV+.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>j. My condition would be obvious to my friend.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>k. Are there other reasons you had for wanting to tell your friend about your diagnosis that I haven’t mentioned? __________________________________________________________</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

INTERVIEWER: If participant disclosed to this person skip to Q 27.

26. Now I’m going to ask you to remember reasons why you might have thought about NOT telling your friend about being HIV positive. Again, rate these on a scale of 1 to 5 with 1 being “not at all a reason for not telling” and 5 being “very much a reason for not telling.”

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not at all Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I was afraid that my friend would reject me.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>b. My friend might go around telling people.</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
c. I didn’t want my friend to experience pain over what I was going through.  
   1 2 3 4 5

d. We weren’t very close to one another.  
   1 2 3 4 5

e. I didn’t know how to tell my friend.  
   1 2 3 4 5

f. I didn’t want my friend to worry about me.  
   1 2 3 4 5

g. So far as I knew my friend was not HIV+.  
   1 2 3 4 5

h. Please mention any other reason you DIDN’T want to tell your friend. ________________  
   ____________________________________________________________________________

Family member

Now we are going to move on to family. Think of a person within your close family at the time when you learned about your HIV diagnosis. It could be a parent, sister, brother, aunt, cousin. This person may or may not know that you are HIV positive. The person can be of either sex. This person should NOT be your spouse. Please answer the following questions with that person in mind.

27. Who was the family member (e.g. father, sister, etc.) ________________

(Substitute correct word, e.g. “Your mother,” “Your cousin” in remainder of section)

28. In terms of your feelings and commitment, how emotionally close would you say you were to this family member? Give me your answer on a scale of 1 to 5, with “1” being “not very close at all” to “5” being “extremely close”.
   1 2 3 4 5

29. Would you say this family member was higher, the same, or lower social status than you?
   _____ Higher  _____ Same  _____ Lower

30. Was this family member male or female? _____M  _____F

31. Does this family member know that you are HIV+?  _____Yes  _____No  _____Unsure
   (IF NO, SKIP TO QUESTION 35)

32. If this family member knows your diagnosis, exactly when did s/he find out (month, day, year if possible)?  ________________________

33. Can you tell me briefly HOW this occurred?  **For example did you tell your family member straight out, did you drop hints, did you have someone else tell him/her?  How
did s/he respond? (AFTER INTERVIEW FILL IN DETAILS. PLEASE GIVE AS MUCH DETAIL AS POSSIBLE.)

(Interviewer, after writing out occurrence tick most appropriate option below. If unsure ask for clarification mentioning categories if need be:

____ a. I myself told my family member straight out about my illness. Either directly in a face-to-face conversation, on the phone, or in a letter.
____ b. I myself informed my family member, but I did it indirectly through hints instead of saying straight out that I have HIV/AIDS.
____ c. I purposefully left clues about my condition (e.g. leaving out bottles of medicines or vitamins)
____ d. I asked my family member to go with me to a VCT for testing but didn’t tell him/her I already knew I was HIV+.
____ e. We went together to VCT and found out at the same time
____ f. I approached a third party and directly asked them to inform my family member of my condition.
____ g. I hinted to another person about my condition, hoping they would tell my family member.
____ h. I informed a third party about my condition and trusted them to inform the people who needed to know.
____ i. Someone told my family member that I had HIV/AIDS, even though I never wanted him/her to know. (IF PARTICIPANTS GIVES THIS ANSWER SKIP TO Q. 35)
____ j. My family member figured out I had HIV/AIDS without anyone telling him/her (e.g. seeing symptoms, noticing visiting clinic, reading a medical chart, etc.)
____ k. Other ____________________________________________________
__________________________________________________
35. Next I’m going to give you a list of reasons you might have had for wanting to tell your family member about your being HIV positive. You will do this, again, on a five point scale with 1 = Not at all important; 2 = Slightly important; 3 = Moderately important; 4 = Very important; 5 = Extremely important.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not at all Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>I wanted to get advice from my family member.</td>
<td>1</td>
<td>4 5</td>
</tr>
<tr>
<td>We had a close relationship.</td>
<td>1</td>
<td>4 5</td>
</tr>
<tr>
<td>I had a duty to tell my family member.</td>
<td>1</td>
<td>4 5</td>
</tr>
<tr>
<td>My family member would support me emotionally.</td>
<td>1</td>
<td>4 5</td>
</tr>
<tr>
<td>I trusted my family member not to tell anyone.</td>
<td>1</td>
<td>4 5</td>
</tr>
<tr>
<td>My family member would be able to help me with material support.</td>
<td>1</td>
<td>4 5</td>
</tr>
<tr>
<td>I wanted to prepare my family member for what might happen to me.</td>
<td>1</td>
<td>4 5</td>
</tr>
<tr>
<td>I wanted my family member to help me inform other people who needed to know.</td>
<td>1</td>
<td>4 5</td>
</tr>
<tr>
<td>I knew my family member was HIV+.</td>
<td>1</td>
<td>4 5</td>
</tr>
<tr>
<td>My condition would be obvious to my family member.</td>
<td>1</td>
<td>4 5</td>
</tr>
</tbody>
</table>

k. Are there other reasons you had for wanting to tell your family member about your diagnosis that I haven’t mentioned? ____________________________________________________

________________________________________________________________________

INTERVIEWER: If participant disclosed to this person skip to Q 36.

35. Now I’m going to ask you to remember reasons why you might have thought about NOT telling your family member about being HIV positive. Again, rate these on a scale of 1 to 5 with 1 being “not at all a reason for not telling” and 5 being “very much a reason for not telling.”

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not at all Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was afraid that my family member would reject me.</td>
<td>1</td>
<td>4 5</td>
</tr>
</tbody>
</table>
b. My family member might go around telling people 1 2 3 4 5

c. I didn’t want my family member to experience pain over what I was going through. 1 2 3 4 5

d. We weren’t very close to one another. 1 2 3 4 5

e. I didn’t know how to tell my family member. 1 2 3 4 5

f. I didn’t want my family member to worry about me. 1 2 3 4 5

g. So far as I knew, my family member was not HIV+ 1 2 3 4 5

h. Please mention any other reason you DIDN’T want to tell your family member about your diagnosis. ____________________________________________________
______________________________________________________________________

Pastor/Religious Leader

Now we are going to move on to the last person I’ll ask you about. Think of a person who was a religious leader for you when you learned about your HIV diagnosis. It could be a pastor, evangelist, imam, women’s leader. This person may or may not know that you are HIV positive. The person can be of either sex. This person should NOT be your spouse. Please answer the following questions with that person in mind.

36. Who was the religious leader (e.g. pastor, ladies leader) ____________________

   No religious leader (N/A) __

   (Substitute correct word, e.g. “pastor” or “ladies leader” in remainder of section)

37. Was this religious leader male or female? _____M _____F

38. In terms of your feelings and commitment, how emotionally close would you say you were to this religious leader? Give me your answer on a scale of 1 to 5, with “1” being “not very close at all” to “5” being “extremely close”.

   1 2 3 4 5

39. Would you say this religious leader was higher, the same, or lower social status than you?

   _____ Higher _____ Same _____ Lower

40. Does this religious leader know that you are HIV+? _____Yes _____No _____ Unsure

   (IF NO, SKIP TO QUESTION 44)
41. If this religious leader knows your diagnosis, exactly when did s/he find out (month, day, year if possible)? ___________________

42. Can you tell me briefly HOW this occurred? **For example did you tell your religious leader straight out, did you drop hints, did you have someone else tell him/her? How did s/he respond? (AFTER INTERVIEW FILL IN DETAILS. PLEASE GIVE AS MUCH DETAIL AS POSSIBLE)

(Interviewer, after writing out occurrence tick most appropriate option below. If unsure ask for clarification mentioning categories if need be:

___ a. I myself told my religious leader straight out about my illness. Either directly in a face-to-face conversation, on the phone, or in a letter.

___ b. I myself informed my religious leader, but I did it indirectly through hints instead of saying straight out that I have HIV/AIDS.

___ c. I purposefully left clues about my condition (e.g. leaving out bottles of medicines or vitamins)

___ d. I asked my religious leader to go with me to a VCT for testing but didn’t tell him/her I already knew I was HIV+.

___ e. We went together to VCT and found out at the same time

___ f. I approached a third party and directly asked them to inform my religious leader of my condition.

___ g. I hinted to another person about my condition, hoping they would tell my religious leader.

___ h. I informed a third party about my condition and trusted them to inform the people who needed to know.

___ i. Someone told my religious leader that I had HIV/AIDS, even though I never wanted him/her to know. (IF PARTICIPANTS GIVES THIS ANSWER SKIP TO Q. 44)

___ j. My religious leader figured out I had HIV/AIDS without anyone telling him/her (e.g. seeing symptoms, noticing visiting clinic, reading a medical chart, etc.) (IF PARTICIPANTS GIVES THIS ANSWER GO TO Q. 43 OR 44 DEPENDING ON PARTICIPANT)

___ k. Other ____________________________________________________
__________________________________________________
43. Next I’m going to give you a list of reasons you might have had for wanting to tell your religious leader about your being HIV positive. You will do this, again, on a five point scale with 1 = Not at all important; 2 = Slightly important; 3 = Moderately important; 4 = Very important; 5 = Extremely important.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not at all Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I wanted to get advice from him/her</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>b. We had a close relationship</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>c. I had a duty to tell my religious leader.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>d. My religious leader would support me emotionally.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>e. I trusted my religious leader not to tell anyone.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>f. My religious leader would be able to help me with material support.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>g. I wanted to prepare my religious leader for what might happen to me.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>h. I wanted my religious leader to help me inform other people who needed to know.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>i. I knew my religious leader was HIV+.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>j. My condition would be obvious to my religious leader.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>k. Are there other reasons you had for wanting to tell your religious leader about your diagnosis that I haven’t mentioned?</td>
<td>______________________</td>
<td></td>
</tr>
</tbody>
</table>

INTERVIEWER: If the participant disclosed to this person skip to question 45

44. Now I’m going to ask you to remember reasons why you might have thought about NOT telling your religious leader about being HIV positive. Again, rate these on a scale of 1 to 5 with 1 being “not at all a reason for not telling” and 5 being “very much a reason for not telling.”

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not at all Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I was afraid that my religious leader would reject me.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>
b. My religious leader might go around telling people. 1 2 3 4 5

c. I didn’t want my religious leader to experience pain over what I was going through. 1 2 3 4 5

d. We weren’t very close to one another. 1 2 3 4 5

e. I didn’t know how to tell my religious leader. 1 2 3 4 5

f. I didn’t want my religious leader to worry about me. 1 2 3 4 5

g. So far as I knew, my religious leader was not HIV+. 1 2 3 4 5

h. Please mention any other reason you DIDN’T want to tell your religious leader about your diagnosis. ________________________________________________________
____________________________________________________________________

Section Three

45. Finally, I’m going to ask you to list the FIRST FIVE people who you told or who you made sure somehow (e.g. you had someone else tell them or you dropped hints to them) that you are HIV+. You don’t need to tell me their names, just the relationship to you (e.g. your sister, best friend). For each one I’ll also want to know their gender, when they found out that you are positive, and if you knew that person to be HIV+ also when you found a way to inform them.

<table>
<thead>
<tr>
<th>Person (group)</th>
<th>When informed</th>
<th>Gender</th>
<th>Did you know him/her to be HIV+ at the time you disclosed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. _____________</td>
<td>____________</td>
<td>M</td>
<td>F Y N Unsure</td>
</tr>
<tr>
<td>b. _____________</td>
<td>____________</td>
<td>M</td>
<td>F Y N Unsure</td>
</tr>
<tr>
<td>c. _____________</td>
<td>____________</td>
<td>M</td>
<td>F Y N Unsure</td>
</tr>
<tr>
<td>d. _____________</td>
<td>____________</td>
<td>M</td>
<td>F Y N Unsure</td>
</tr>
<tr>
<td>e. _____________</td>
<td>____________</td>
<td>M</td>
<td>F Y N Unsure</td>
</tr>
</tbody>
</table>
### APPENDIX E

**CORRELATION MATRICES**

Correlations Among Disclosure Motivations to Partners

<table>
<thead>
<tr>
<th></th>
<th>DISA***</th>
<th>DISB</th>
<th>DISC</th>
<th>DISD</th>
<th>DISF</th>
<th>DISG</th>
<th>DISH</th>
<th>DISI</th>
<th>DISJ</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DISA R</strong></td>
<td>1.00</td>
<td>.246**</td>
<td>-0.01</td>
<td>.464**</td>
<td>.085</td>
<td>.275**</td>
<td>.192*</td>
<td>.219**</td>
<td>.081</td>
</tr>
<tr>
<td><strong>p</strong></td>
<td>.001</td>
<td>.985</td>
<td>.000</td>
<td>.267</td>
<td>.000</td>
<td>.012</td>
<td>.004</td>
<td>.292</td>
<td>.289</td>
</tr>
<tr>
<td><strong>N</strong></td>
<td>174</td>
<td>174</td>
<td>172</td>
<td>174</td>
<td>171</td>
<td>170</td>
<td>174</td>
<td>172</td>
<td>172</td>
</tr>
<tr>
<td><strong>DISB R</strong></td>
<td>1.00</td>
<td>-0.011</td>
<td>.251**</td>
<td>-0.045</td>
<td>.045</td>
<td>.048</td>
<td>.060</td>
<td>.014</td>
<td>-0.074</td>
</tr>
<tr>
<td><strong>p</strong></td>
<td>.884</td>
<td>.001</td>
<td>.559</td>
<td>.558</td>
<td>.532</td>
<td>.434</td>
<td>.853</td>
<td>.332</td>
<td></td>
</tr>
<tr>
<td><strong>N</strong></td>
<td>174</td>
<td>172</td>
<td>174</td>
<td>174</td>
<td>170</td>
<td>170</td>
<td>174</td>
<td>172</td>
<td>172</td>
</tr>
<tr>
<td><strong>DISC R</strong></td>
<td>1.00</td>
<td>.207**</td>
<td>-0.026</td>
<td>.151*</td>
<td>.348**</td>
<td>.102</td>
<td>-0.042</td>
<td>.208**</td>
<td></td>
</tr>
<tr>
<td><strong>p</strong></td>
<td>.006</td>
<td>.731</td>
<td>.050</td>
<td>.000</td>
<td>.185</td>
<td>.589</td>
<td>.007</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>N</strong></td>
<td>172</td>
<td>172</td>
<td>172</td>
<td>170</td>
<td>168</td>
<td>172</td>
<td>170</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>DISD R</strong></td>
<td>1.00</td>
<td>.166*</td>
<td>.286**</td>
<td>.328**</td>
<td>.170*</td>
<td>.025</td>
<td>.011</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>p</strong></td>
<td>.028</td>
<td>.000</td>
<td>.000</td>
<td>.025</td>
<td>.742</td>
<td>.890</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>N</strong></td>
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<td>174</td>
<td>171</td>
<td>174</td>
<td>172</td>
<td>172</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>DISE R</strong></td>
<td>1.00</td>
<td>.463**</td>
<td>.192*</td>
<td>.002</td>
<td>-0.015</td>
<td>.115</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>p</strong></td>
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<td>.012</td>
<td>.979</td>
<td>.843</td>
<td>.131</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>N</strong></td>
<td>174</td>
<td>171</td>
<td>170</td>
<td>174</td>
<td>172</td>
<td>172</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Correlations Among Nondisclosure Motivations to Partners

<table>
<thead>
<tr>
<th>DISA</th>
<th>DISB</th>
<th>DISC</th>
<th>DISD</th>
<th>DISE</th>
<th>DISF</th>
<th>DISG</th>
<th>DISH</th>
<th>DISI</th>
<th>DISJ</th>
</tr>
</thead>
<tbody>
<tr>
<td>DISF</td>
<td>R</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>p</td>
<td></td>
<td>.000</td>
<td>.057</td>
<td>.344</td>
<td>.211</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>171</td>
<td>167</td>
<td>171</td>
<td>169</td>
<td>169</td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| DISG | R    |      |      |      |      |      |      |      |      |
| p    |      | .186* | .002 | .235** |
| N    | 170  | 168  | 168  | 168  |

| DISH | R    |      |      |      |      |      |      |      |      |
| p    |      | .186* | .159* |
| N    | 174  | 172  | 172  |

| DISI | R    |      |      |      |      |      |      |      |      |
| p    |      | .161* |
| N    | 174  | 172  | 172  |

| DISJ | R    |      |      |      |      |      |      |      |      |
| N    |      |      |      |      |      |      |      |      |

### Correlations Among Nondisclosure Motivations to Partners

<table>
<thead>
<tr>
<th>NONA</th>
<th>NONB</th>
<th>NONC</th>
<th>NOND</th>
<th>NONE</th>
<th>NONF</th>
<th>NONG</th>
</tr>
</thead>
<tbody>
<tr>
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| p    | .038 | .003 | .935 | .145 | .260 |
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| **DISF** R | 1.00 | .179* | .098 | .023 | .067 |
| p    | .011 | .167 | .745 | .351 |
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| **DISG** R | 1.00 | .088 | -.004 | .193** |
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| **DISH** R | 1.00 | .127 | .159* |
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Summary of Correlations Among Disclosure Motivations Across Relationship Types

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Summary of Correlations Among Nondisclosure Motivations Across Relationship Types

(Note: this table is provided only as a summarization strategy for the convenience of the reader. Because some individuals by nature of the analysis conducted will participate in the correlation more than once, it should not be read as a set of legitimate correlations)

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*correlation is significant at the .05 level (two-tailed)  **correlation is significant at the .01 level (two-tailed)
***Disclosure Motivation Abbreviations

DISA = Seeking Advice  
DISB = Close Relationship  
DISC = Duty to Inform or Educate  
DISD = Seeking Emotional Support  
DISE = Assured of Confidentiality  
DISF = Seeking Material Support  
DISG = Prepare for the Future  
DISH = Seeking Intermediation  
DISI = Target also HIV+  
DISJ = Condition would be Obvious

Nondisclosure Motivation Abbreviations

NONA = Fear of Rejection  
NONB = Gossip  
NONC = Don’t want to Cause Pain  
NOND = Relationship not Close  
NONE = Didn’t Know how to Tell  
NONF = Didn’t want to Cause Worry  
NONG = Target not HIV+  
NONH = Too Much Risk
APPENDIX F

RESULTS OF HOMOGENEITY OF VARIANCE TESTS ON MULTIVARIATE ANALYSES

Effect of Relationship Type on Motivations for Disclosure

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Effect of Relationship Type on Motivations for Nondisclosure

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**Effect of Gender on Motivations for Disclosure**

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**Effect of Gender on Motivations for Nondisclosure**

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APPENDIX G

COMPARISON OF RESULTS OF PARAMETRIC AND NON-PARAMETRIC TESTS ON UNIVARIATE ANALYSES WHERE HOMOGENEITY OF VARIANCE COULD NOT BE ASSUMED*

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<td>p = .001**, η² = .028</td>
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<td>t (356.723) = 1.695,</td>
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<td>partner vs. religious leader</td>
<td>t (258.016) = 5.057,</td>
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<td>friend vs. religious leader</td>
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<td>( t(147.292) = 5.668, ) ( p = .000 )</td>
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<tr>
<td>Duty to Tell</td>
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<td>Seeking Emotional Support</td>
<td>( F(3, 605) = 1.888, ) ( p = 1.00, \eta^2 = .009 )</td>
<td>( \chi^2 (3) = 11.940, ) ( p = .024 )</td>
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<td>Prepare for the Future</td>
<td>( F(3, 597) = 7.035, ) ( p = .000, \eta^2 = .034 )</td>
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<td>partner vs. religious leader</td>
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<td>Parametric Test</td>
<td>Non-parametric Test (Kruskal-Wallis)</td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>family vs. religious leader</td>
<td>$t(143.737) = 4.492, p = .000$</td>
<td>$U = 6486.00, p = .000$</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeking Intermediation</td>
<td>$F(3, 605) = 3.207, \chi^2 (3) = 12.981, p = .230, \eta^2 = .016$</td>
<td>$p = .015$</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$p = .000, \eta^2 = .157$</td>
<td>$p = .000$</td>
<td></td>
</tr>
<tr>
<td>Target HIV+</td>
<td>$F(3, 597) = 37.05, \chi^2 (3) = 115.787$</td>
<td>$p = .000$</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$p = .000, \eta^2 = .157$</td>
<td>$p = .000$</td>
<td></td>
</tr>
<tr>
<td>partner vs. friend</td>
<td>$t(334.415) = 5.060, p = .000$</td>
<td>$U = 10244.50, p = .000$</td>
<td></td>
</tr>
<tr>
<td>partner vs. family</td>
<td>$t(266.820) = 9.710, p = .000$</td>
<td>$U = 9352.00, p = .000$</td>
<td></td>
</tr>
<tr>
<td>partner vs. religious leader</td>
<td>$t(255.430) = 10.624, p = .000$</td>
<td>$U = 4029.00, p = .000$</td>
<td></td>
</tr>
<tr>
<td>friend vs. family</td>
<td>$t(279.347) = 3.928, p = .000$</td>
<td>$U = 13982.00, p = .000$</td>
<td></td>
</tr>
<tr>
<td>friend vs. religious leader</td>
<td>$t(254.233) = 5.033, p = .000$</td>
<td>$U = 6232.50, p = .000$</td>
<td></td>
</tr>
<tr>
<td>family vs. religious leader</td>
<td>$t(237.566) = 1.634, p = .312$</td>
<td>$U = 8958.00, p = .444$</td>
<td></td>
</tr>
</tbody>
</table>

Effect of Relationship Type on Motivations for Nondisclosure

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Parametric Test</th>
<th>Non-parametric Test (Kruskal-Wallis)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear Breach of Confidentiality</td>
<td>$F(3, 412) = 8.371, \chi^2 (3) = 36.893, p = .000, \eta^2 = .057$</td>
<td>$p = .000$</td>
</tr>
<tr>
<td>partner vs. friend</td>
<td>$t(75.366) = 5.092, p = .000$</td>
<td>$U = 1698.00, p = .000$</td>
</tr>
<tr>
<td>Dependent Variable</td>
<td>Parametric Test</td>
<td>Non-parametric Test (Kruskal-Wallis)</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-----------------</td>
<td>-------------------------------------</td>
</tr>
<tr>
<td>friend vs. family</td>
<td>$t (183.830) = 4.729$, $p = .000$</td>
<td>$U = 4976.50$, $p = .000$</td>
</tr>
<tr>
<td>friend vs. religious leader</td>
<td>$t (283.608) = 3.73$, $p = .000$</td>
<td>$U = 7702.00$, $p = .000$</td>
</tr>
<tr>
<td>family vs. religious leader</td>
<td>$t (194.600) = .806$, $p = 1.00$</td>
<td>$U = 7227.50$, $p = .405$</td>
</tr>
<tr>
<td>Didn’t Want to Cause Pain</td>
<td>$F (3, 412) = 10.999$, $p = .000$, $\eta^2 = .074$</td>
<td>$\chi^2 (3) = 45.506$, $p = .000$</td>
</tr>
<tr>
<td>partner vs. family</td>
<td>$t (77.943) = 3.617$, $p = .003$</td>
<td>$U = 1598.00$, $p = .000$</td>
</tr>
<tr>
<td>friend vs. family</td>
<td>$t (219.383) = 4.064$, $p = .000$</td>
<td>$U = 4264.00$, $p = .000$</td>
</tr>
<tr>
<td>family vs. religious leader</td>
<td>$t (231.623) = 7.069$, $p = .000$</td>
<td>$U = 4320.50$, $p = .000$</td>
</tr>
<tr>
<td>Didn’t Know How to Tell</td>
<td>$F (3, 412) = 1.486$, $p = .654$, $\eta^2 = .011$</td>
<td>$\chi^2 (3) = 3.809$, $p = .849$</td>
</tr>
<tr>
<td>Didn’t Want to Cause Worry</td>
<td>$F (3, 412) = 11.733$, $p = .000$, $\eta^2 = .079$</td>
<td>$\chi^2 (3) = 42.282$, $p = .000$</td>
</tr>
<tr>
<td>partner vs. family</td>
<td>$t (74.217) = 3.648$, $p = .000$</td>
<td>$U = 1624.50$, $p = .003$</td>
</tr>
<tr>
<td>friend vs. family</td>
<td>$t (220.843) = 3.895$, $p = .000$</td>
<td>$U = 4405.50$, $p = .000$</td>
</tr>
<tr>
<td>family vs. religious leader</td>
<td>$t (245.147) = 7.269$, $p = .000$</td>
<td>$U = 4301.50$, $p = .000$</td>
</tr>
<tr>
<td>Target not HIV+</td>
<td>$F (3, 419) = 2.092$, $p = .101$, $\eta^2 = .015$</td>
<td>$\chi^2 (3) = 6.962$, $p = .219$</td>
</tr>
</tbody>
</table>
### Effect of Gender on Motivations for Disclosure

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Parametric Test</th>
<th>Non-parametric Test (Mann-Whitney U)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeking Advice</td>
<td>$F (1, 603) = 7.468, p = .018, \eta^2 = .012$</td>
<td>$U = 35183.50, p = .027$</td>
</tr>
<tr>
<td>Duty to Tell</td>
<td>$F (1, 603) = 2.060, p = .456, \eta^2 = .003$</td>
<td>$U = 38922.00, p = 1.00$</td>
</tr>
<tr>
<td>Prepare for the Future</td>
<td>$F (1, 603) = 2.742, p = .294, \eta^2 = .005$</td>
<td>$U = 37798.00, p = .285$</td>
</tr>
<tr>
<td>Seeking Intermediation</td>
<td>$F (1, 603) = 3.687, p = .165, \eta^2 = .006$</td>
<td>$U = 35792.00, p = .042$</td>
</tr>
<tr>
<td>Target HIV+</td>
<td>$F (1, 603) = 2.155, p = .429, \eta^2 = .004$</td>
<td>$U = 38523, p = 1.00$</td>
</tr>
<tr>
<td>Condition Obvious</td>
<td>$F (1, 603) = .309, p = .579, \eta^2 = .001$</td>
<td>$U = 37317.50, p = 1.00$</td>
</tr>
</tbody>
</table>

### Effect of Gender on Motivations for Nondisclosure

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Parametric Test</th>
<th>Non-parametric Test (Mann-Whitney U)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Didn’t Want to Cause Pain</td>
<td>$F (1, 418) = 2.565, p = .330$</td>
<td>$U = 18322.50, p = .174$</td>
</tr>
<tr>
<td>Didn’t Want to Cause Worry</td>
<td>$F (1, 418) = .829, p = 1.00$</td>
<td>$U = 18509.50, p = .333$</td>
</tr>
<tr>
<td>Target not HIV+</td>
<td>$t (1, 418) = 5.119, p = .072$</td>
<td>$U = 18112.50, p = .096$</td>
</tr>
</tbody>
</table>
*The only analyses listed are those for which Levene’s Test indicated that equal variance could not be assumed. In some cases even though equal variance could not be assumed for the omnibus test, the homogeneity of variance assumption was not violated for certain paired comparisons. Those comparisons are also not listed in the table.

**p** values adjusted as per Bonferroni rationale to adjust for multiple tests.

***paired comparisons are included only for statistically significant omnibus tests.

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1 In the original formulation of the theory (Petronio, 1991) strategies for disclosure initiators were labeled as explicit and implicit, whereas strategies for disclosure recipients were labeled as direct and indirect. The categories were presented as parallel in virtually every respect and at one point specifically equated (p. 324). The author was unable to locate any explanation as to why two different sets of terms were used for the two interaction partners. Although an argument can be made that the terms should not be considered synonymous, because literature on conversational patterns that will be discussed below adopts the labels of directness and indirectness this paper will use those terms from this point to encompass both sets of terms.

2 Kenya counts some 30 to 40 distinct vernacular languages within its borders (Abdulaziz, M. H., 1982; Whiteley, 1974). The outcome of all of this linguistic diversity is that, as in many African states, multilingualism is the norm rather than the exception (Myers-Scotton, 1993). Swahili, spoken by approximately 75% of rural residents (Whiteley, 1974) and nearly 100% of urban residents (Parkin, 1974a, b; Myers-Scotton, 1982) is referred to as the “national” language, an indication of its symbolism of cultural pride and national identity (Schmied, 1991a, b; Sure, 1991). It is also the language of small trade and more recently the pop music scene (Kihara, 2004). As long as thirty years ago English was spoken with some degree of competence by over half of the urban population (Whiteley, 1974; Parkin, 1974b; Myers-Scotton, 1982) and the percentage is certainly higher now. It is considered to be the “official” language of Kenya, a term normally applied in Africa to the local European language and indicating its predominance in education and government. Persons preferring English to Swahili tend to more educated, more likely to hold white-collar jobs, and have higher incomes (Parkin, 1974a). Persons preferring Swahili to English tend to be lower income, less educated, and hold jobs in the blue-collar or “jua kali” (entrepreneurial) sector. Thus if the final phase of the project ends out being carried out in clinics that service primarily lower SES clients, interviews are likely to be mostly conducted in Swahili.

3 To further confirm the precedent for such an approach I spoke by phone to Mary Amuyuzu, Director of African Institute for Health and Development, who has extensive experience conducting research on sexuality-related issues across the continent, and has just completed a nation-wide survey regarding HIV-related knowledge, attitudes, and practice among youth, married men and women, and clergy. This project, in which Britain’s DFID, Kenya’s National AIDS Control Council and National AIDS/STD Control Program among others were partners, employed a consent procedure in which the interviewer read a consent script aloud and then asking the participant if s/he was willing to be interviewed. If the participant responded in the affirmative, the “yes” box was checked and the interview proceeded. If the participant answered “no”, the appropriate box was checked and the interviewed came to an end at that
point. Her rationale for the waiving of written consent in this case was that even in literature populations, the topic of a questionnaire may dictate that informed consent is most effectively obtained orally. In designing my questionnaire I have followed her convention.

4 For all statistical analyses conducted it was deemed important to ensure that there was no influence on results by interview site, language, or interviewer. However, as all of these variables were categorical, it was impossible to enter them into statistical analyses as covariates. It was also unrealistic to code 45 interviewers and six sites as dummy variables. Nevertheless to ensure that these factors did not influence outcomes, separate analyses were run for all dependent variables to check for main effects of site, language, or interviewer. No main effects for site or language emerged on any analysis. A main effect for language was found with respect to motivations for disclosure and non-disclosure. However, when post hoc analyses were conducted to locate the effects, it was found that one interviewer who had conducted just two interviewers had significantly differed from 13 others on a single question, and another interviewer who had conducted seven interviewers had differed from four others on another single question. As the source of these effects was thus so isolated, results from all interviewers were retained for all analyses.

5 However, univariate analysis indicated that female participants reported fear of rejection as a stronger motivation for nondisclosure than did males ($F$$(1, 418) = 4.23, p = .04, \eta^2 = .01$). Therefore hypothesis 9 was supported.

6 This study was not designed to test the value of VCT as an HIV/AIDS intervention, an issue that has been the subject of debate, particularly regarding cost-effectiveness. Recent analysis does seem suggest VCT is an efficient (Sweat et al., 2000; Voluntary Counseling and Testing Efficacy Study Group, 2000; WHO, 2002) and practical (Pronyk, Kim, Makhubele, Hargreaves, Mohlala, et al., 2002) prevention approach, and as non-hospital based VCT centres have proliferated in Nairobi in the past several years it seems appropriate to apply results of this study to those existing efforts.