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**Sharing an Uncertain Future: Improved Survival and Stress Proliferation among  
Persons Living with HIV and their Caregivers**

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**Abstract:** This chapter examines how the historically time-altered trajectory of HIV/AIDS in the United States has influenced the lives of persons living with HIV (PLH) and their midlife and older female caregivers. Our theoretical model integrates the concepts of linked lives, stress proliferation, and future uncertainty. We report on a study of 135 PLH and their caregiving wives or mothers. We find that, net of other stress covariates, future uncertainty is positively associated with depressive symptoms among PLH but not among caregivers. We identify “cross-person” effects in that the caregiver’s perceptions of future uncertainty are positively associated with PLH depressive symptoms.

The course of HIV illness has changed dramatically over the past decade as a result of the introduction of anti-retroviral therapies (ART), often called treatment “cocktails,” which have led to substantial reductions in the incidence of opportunistic illness and in mortality. However beneficial these changes have been, they also have created uncertainty about the future for many persons living with HIV (PLH) who may have anticipated severe impairment or premature death. Uncertainty about the future may arise as well for family members, especially those who are engaged in providing care for the PLH. The extension of the HIV illness trajectory thus extends valued family relationships, but simultaneously extends the PLH’s illness and correspondingly the experience of caregiving and the stress that may accompany this role. In this chapter, we examine how the altered trajectory of HIV/AIDS has influenced the lives of adult PLH and their caregivers, especially with regard to their mental health and uncertainty about the future.

Our analysis is based largely on the principle of "linked lives," a paradigmatic component of life course theory outlined by Elder and associates (2003), which recognizes that individuals are often affected by macro-level social changes through the impact these changes have on their interpersonal relationships within more micro-level settings. This concept is especially germane to our analysis because we examine how future uncertainty is shaped by elements of the stress process for both PLH and their caregivers, focusing on the ways in which the experiences of the caregiver influence the PLH and vice versa.

We begin with a discussion of the current state of the HIV/AIDS epidemic in the United States (U.S.), as well as the evolution of AIDS caregiving. We then explore the historical specificity of HIV and how changes in disease prognosis have altered life expectancies over the past two decades. Next, we present a conceptual model that describes our life course approach to

examining linked lives and future uncertainty within a stress proliferation framework (Pearlin *et al* 1990; 1997). The remainder of the chapter focuses on empirical findings from a study of 135 caregiving dyads—midlife and older women caring for HIV-infected adult sons or husbands. We examine HIV-related stress among these dyads, as well as linkages between future uncertainty and mental health.

### ***HIV/AIDS and Informal Caregiving in the United States***

To date, over 1,100,000 persons have developed HIV/AIDS in the U.S., and over 530,000 persons have died (CDC, 2007). The case-fatality rate has dropped dramatically in this country since the introduction of ART, but still, over 16,000 persons died from AIDS in 2005 (CDC, 2007). Even though the death rate for HIV has dropped, the HIV incidence rate has continued to grow, and there are now more persons living with HIV than ever before—between 331,000 and 421,000 people in the U.S in 2005. In the U.S. alone, it is estimated that an additional 40,000 individuals are diagnosed each year. Fewer PLH are disabled or in need of support as compared to earlier in the epidemic, but HIV-related morbidity data clearly indicate that the potential need for AIDS caregiving is at an all-time high. Thus, HIV has evolved into a chronic condition in which some PLH require informal care that varies in intensity with the course of the illness itself, with periods of little or no need to times when assistance is critical. However, scant research has addressed the mental health impact of the PLH's extended survival on the interconnected lives of PLH and their caregivers.

As HIV has become both more prevalent and more chronic than in the past, the demographic profile of PLH has shifted as well, and along with it, the profiles of caregivers. Individuals of African American and Latino descent now account for 67% of new adult cases of

HIV infection (CDC, 2007). In Los Angeles, Latinos accounted for 51% of AIDS diagnoses in 2005, a figure up from 25% for the period of 1991-1992. Over the last 10 years the AIDS prevalence rate has increased precipitously among Latinos, increased somewhat among African Americans, and dropped dramatically among non-Hispanic Whites (City of Los Angeles, AIDS Coordinator's Office, 2007). Although men who have sex with men still predominate among PLH, it is increasingly becoming a disease associated with heterosexuals and with membership in an ethnic minority group. Given the shifting demographic profile of PLH, the caregivers most likely to be in increasing demand are the focus of the present study: midlife and older women, mostly wives and mothers.

Like other caregiving research, much of the early AIDS caregiving work focused primarily on examining care-related burden and how it negatively affected the health and well-being of caregivers (e.g., Folkman *et al* 1994; Land and Hudson 2002; LeBlanc *et al* 1995, 1997; Pearlman *et al* 1997; Turner and Catania 1997; Wight *et al* 1998, 2000). Given the high case fatality rate earlier in the epidemic, caregiving research also examined the effects of bereavement (e.g., Park and Folkman 1997; Richards *et al* 1999; Wight 2000). A unique aspect of AIDS caregiving also examined in earlier work was the concept of "precursive caregiving," a term attributed to AIDS caregivers who were themselves HIV-positive, with these persons generally reporting higher levels of stress and depressive symptoms than their HIV-negative counterparts (Wight 2000).

More recently, research has shifted to examining the dynamic relationship between caregivers and PLH as this relationship has been extended over time. For example, a recent study found that relationship quality was affected by factors associated with both the caregiver and the PLH—caregiver depression, PLH depression, physical impairment, and HIV medication

adherence—in addition to factors related to the burden of providing care (Miller *et al* 2007). Research on the sample analyzed in the current study revealed similar cross-person patterns. For example, characteristics of both the PLH and the caregiver affect each person’s perceptions of dyadic stigma, in addition to the caregiver also being infected with HIV (Wight *et al* 2006), and both caregiver and PLH characteristics influence PLH medication adherence (Beals *et al* 2006). Thus, research has focused increasingly on how the lives and experiences of caregivers and PLH are linked within the context of the caregiving dyad.

### ***Historical Specificity of HIV: Uncertainty about the Future***

Receiving an HIV diagnosis and/or an AIDS diagnosis is a traumatic life event that irrevocably alters a person’s life course. This trauma and resultant life course disruption also extends to family members, and may be especially disruptive for mothers caring for adult sons—a scenario that entails a return to mother-child dependencies associated with early life course activities (Wight *et al* 1998; 2007). For many diagnosed in the first waves of the epidemic, there was little time to consider the future, only the anticipation of rapidly approaching illness and death. Those who were able to manage the disease for longer not only struggled to defend the attack of HIV on their bodies and selves, they also faced stigmatization and discrimination from society at large (Schönnesson 2002).

Much has changed since the earliest days in the history of HIV and ART has provided reason for great optimism in the battle against HIV disease. With the introduction of ART, many long-term AIDS patients realized dramatic improvements in their health and more recently infected individuals have been able to strengthen their bodies’ capacities to keep opportunistic infections at bay indefinitely. Many PLH enjoy virtually normal lives and pursue personal and

work-related goals with a sense that the future, in many respects a bright one, awaits them. In short, over the past 10 to 15 years, HIV has been transformed from a certain “death sentence” to a chronic condition, manageable with proper self-care and vigilant adherence to the newest treatments.

Yet these real advances and the associated shifts in perspective, however hopeful, are not without complications. For example, ART requires strict adherence and is not always successful, sometimes due to the fact that some individuals develop treatment-resistant strains of the virus. There also is no claim that ART will lead to the complete eradication of HIV in PLH. Moreover, PLH are faced with complex treatment choices regarding a number of anti-HIV drugs, and combinations thereof, which include possible serious side effects that affect appearance and quality of life (Thompson 2003). The new treatments also do not take away the reality that PLH remain infectious, and they must therefore continue to negotiate their romantic desires and intimate relationships (Halkitis *et al* 2005).

In addition, although overt expressions of stigma, such as endorsing the idea of quarantine for PLH, have declined over time, inaccurate beliefs about the risks of casual social contact and the belief that PLH deserve their illness have increased (Herek *et al* 2002). Studies also show that HIV-related stigma and discrimination persist in a variety of settings (e.g., Sears 2006). Therefore, while much has changed, much remains the same, and in some respects PLH encounter some of the same challenges today as earlier in the epidemic.

A powerful and recurring theme in research on the experience of life with HIV is that of uncertainty, in particular uncertainty about the future.

In one early study, Weitz (1989) found that gay and bisexual men with HIV struggled to cope with the overwhelming uncertainty surrounding their health, articulating a range of



existential questions that demonstrated their inability to understand fully their circumstances or to predict their futures. In another early study, Seigel and Krauss (1991) described a number of adaptive strategies adopted by gay men to help them deal with such uncertainties, strategies such as maintaining appropriate vigilance about one's health and maintaining emotional equilibrium. Merriam and colleagues (2003) described HIV-related life course development using different dimensions of time. By interviewing PLH before and after the development of ART, they uncovered a relationship between improvements in HIV treatments, which happen in "historical time," and the ability of PLH to recapture their ability to see their lives in "social time." A return to social time, which is rooted in normal developmental patterns and ordering of events associated with adult life, afforded PLH a view of a future that just two years prior did not exist (Merriam *et al* 2001).

Thus, evolving anti-HIV treatments are offering many PLH and their loved ones the ability to envision a future. For PLH who have already experienced considerable illness, as those in our caregiving sample have, reconstructing their futures presents them with new uncertainties and the need for adaptive strategies to effectively manage these uncertainties. These PLH and their families are, in a sense, living "on the boundaries," for example the boundaries between terminal and chronic disease, between illness and health, between despair and hope, and ultimately, between death and existential concerns about their futures (Schönnesson 2002). They also are living on the border between needing care and living independently, a situation with clear ramifications for family members.

### ***Linked Lives and Stress Proliferation***

Our conceptual model integrates a core element of life course theory, that of linked lives, with a major component of the stress process, stress proliferation. The concept of linked lives unambiguously acknowledges that lives are lived interdependently (Elder *et al* 2003). When individuals share a close interpersonal relationship, each person is influenced by what transpires in the life of the other person. Nowhere is this principle more evident than within the family, where individuals are connected by relatively enduring, often life-long, bonds of kinship. Familial bonds typically engage the whole person, ideally providing a core component of identity, nourishing basic human needs for belonging and generating a sense of personal worth.

Family caregiving exemplifies these connections because one person's need for assistance is the catalyst for another person's reaction, providing care. In the current study, the progression of HIV infection to AIDS-related symptoms and impairments may overwhelm the person's ability to provide self-care, creating a state of dependency on others, in this instance reliance on wives and mothers. The transformation of mother-child and wife-husband relationships into ones that are defined by the provision and receipt of care bears testimony to the concept of linked lives.

The concept of linked lives is illustrated in Figure 1 by two circles, one representing the life of the PLH or care-recipient, the other representing that of the caregiver. The overlapping portion of the circles denotes the ways in which the lives of these two persons are intertwined. Note that this overlap is both substantial and incomplete. There are strong bonds, but each individual also lives a life that is separate from that of the other person. Their lives, therefore, comprise both common and unique components.

## FIGURE 1 ABOUT HERE

Closely aligned with the concept of linked lives is one meaning of stress proliferation, the contagion of stress from one person to another, usually within the context of close interpersonal relationships (Pearlin *et al* 2005). In essence, the hardships or stressors experienced by one person intrude upon the lives of others. The specific example of proliferation given by Pearlin and colleagues is that of prolonged caregiving to a loved one wherein the ongoing strains of providing care become problematic for others in the family, for example, when parents care for an elderly relation with Alzheimer's Disease, potentially depriving children of parental attention (Pearlin *et al* 2001). Our application of this concept varies slightly, emphasizing the proliferation of stress from caregiver to care-recipient and the reverse. This idea is captured in Figure 1 as bi-directional arrows that show stress flowing from the care-recipient to the caregiver, and the reverse.

A second meaning of stress proliferation refers to the ways in which one source of stress sets in motion a chain reaction of consequent stressors (Pearlin *et al* 1990; Pearlin *et al* 1997). This conceptualization of stress proliferation calls attention to the causal connections among stressors, to the idea that the seeds of subsequent hardships are to be found within an initial or primary stressor. Primary stressors are conceptualized as being directly caused by care-related needs. Primary stressors may be objective because they are observable, or subjective because they are interpretive experiences inherently embedded within a particular stress process (Pearlin *et al* 1997). Consequent stressors are referred to as secondary stressors because their origins lie within the original difficulty. As Pearlin and associates note, the term secondary does not imply that these stressors are of lesser magnitude or impact, merely that they derive from a primary

stressor. Secondary stressors are conceptualized as accounting for some of the association between primary stressors and health outcomes.<sup>1</sup>

The idea of stress proliferation is illustrated in the lower portion of Figure 1, which shows background characteristics (e.g., age), influencing the occurrence of primary stressors (e.g., daily living assistance needs), which subsequently engender secondary stressors (e.g., constriction of social activities) and influence mental health. The experience of each type of stressor, for both care-recipients and caregivers, is shared by these persons, but also is experienced in an individualized manner.

We conceptualize future uncertainty as a consequent stressor that arises out of background characteristics and primary stressors. That is, it is not inherently linked with the stress of care provision and care receipt, but rather, arises out of the subjective appraisals and reactions to other more primary forms of stress. For example, high daily living assistance needs that are prolonged may impel both caregivers and PLH to be pessimistic about the future, or to consider how they will continue to sustain themselves. These feelings about the future, however, are not the need for care, but rather are consequences of this need. As a secondary stressor, future uncertainty is expected to account for some of the association between primary stressors and mental health.

Stress proliferation is subject to constraints, however, to countervailing forces that hinder its progression. In other words, the occurrence of a major life stressor does not invariably lead to other stressors. The stress process model thus incorporates the concept of mediators, factors

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<sup>1</sup> In this instance, the idea of mediation is used as an analytic term connoting an empirical decrease in an association between two variables with the introduction of a third variable.

such as a personal sense of mastery, that dilute the otherwise damaging impact of stressful life events and circumstances (Pearlin 1999).<sup>2</sup>

Note in Figure 1 that mediators are influenced by the prior occurrence of stress. In the stress process model, stressors challenge resources that are called upon to counterbalance the aversive impact of the stressor. In other words, when stress activates a resource, the otherwise harmful impact of stress is attenuated because the increased resource is inversely associated with mental health outcomes. Stress may have a less benign effect, however, eroding resources, thereby illuminating one of the ways in which stress comes to be harmful (Wheaton 1985).

We extend the caregiving stress proliferation framework to include the concept of linked lives and, in doing so, to explicitly include the experiences of the care-recipient. We view the caregiving dyad as more than the sum of its two parts; it also captures how the caregiver and care-recipient stand in relation to one another. The PLH's experience of stress parallels that of the caregiver, but also crosses-over to influence the caregiver's experience, and vice versa. This cross-person stress contagion may be especially evident within dyads in which the caregiver is herself infected with HIV. The exact forms of stressors encountered may be distinct to the PLH or caregivers, but these stressors are intrinsically connected because of the relationship that exists between these persons. PLH stress and caregiver stress may intersect at various stages of the stress process. We emphasize how this intersection influences the emergence of uncertainty about the future and affects mental health, as shown in Figure 1. This emphasis on future uncertainty reflects our interest in the life course, that is, in how future uncertainty arises within a specific historical context.

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<sup>2</sup> Here the term mediator is used to identify a set of concepts that play a central role in interrupting the progression of stress proliferation. Often this set of mediators is conceptually positioned between stressors on the one hand and outcomes on the other.

Thus, we investigate how HIV care-related stress is experienced by individuals by examining the proliferation of stressors, the placement of future uncertainty within the stress proliferation process, how these stressors are associated with mental health, and whether mediators counterbalance their mental health impact. We also extend the individual-based analysis by examining how HIV care-related stress is linked between individuals by examining cross-person effects within caregiving dyads.

## **METHODS**

### ***Sample Selection and Characteristics***

To achieve the study's goals, a sample of caregiving dyads was recruited in the Los Angeles, California area. To be included in the study, participants had to be part of a dyad in which the primary caregiver was a midlife or older (at least 35 years of age) mother or wife/female partner<sup>3</sup> who provided practical assistance with activities of daily living (ADL) to a son or husband/male partner, respectively (over age 18 years), living with HIV and residing in the community. Physical or instrumental activity on the part of the caregiver was required; solely offering emotional support was not sufficient for inclusion in this research. Only informal caregivers were included in the study. If a caregiving wife disclosed that she was also HIV-positive, inclusion criteria stipulated that she provided more assistance to her husband than the reverse.<sup>4</sup>

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<sup>3</sup> Hereafter referred to as wife and husband for simplicity.

<sup>4</sup> To differentiate the caregiver and care-recipient role, we only refer to care-recipients as PLH, even though some wives are also infected with HIV.

Dyads with these characteristics are a select and distinctive subgroup of the larger population, making community-based probability sampling methods unfeasible. Instead, our recruitment strategy was based on outreach to the local HIV community, including maintaining a consistent presence at AIDS service organization meetings and functions. Participants in the study were obtained through a variety of community-based recruitment channels. Most responded to AIDS service organization mailings (46.7%), service provider referral (18.2%), posted flyers (16.2%), or word-of-mouth (6.8%) or unspecified means (12.1%). The sample, therefore, should be considered a self-selected convenience sample, characteristics that limit generalization.

A total of 477 persons were screened for participation. Of these, 184 caregivers were ineligible because of relationship status, gender, or age; 65 PLH were ineligible because of gender, lack of a caregiver, or cognitive impairment (N = 2). The remaining 293 people yielded 141 concordant dyadic interviews and nine unpaired interviewees. We limit our analysis to concordant dyads, dropping seven dyads because they declined to provide information on their relationship status. Background and personal characteristics of the 135 intact care-recipient-caregiver dyads used in the analysis appear in Table 1.

#### TABLE 1 ABOUT HERE

There are somewhat more wife/husband dyads in the sample than mother/son dyads. Age is highly variable: the range for caregivers is 35 to 93 years, and 20 to 63 years for PLH. The sample is ethnically diverse as well, with slightly over half self-identifying as Hispanic and a quarter as African American. Overall, these caregivers and PLH typically live in very low-

income households. Educational attainment similarly is limited and PLH have more years of education than caregivers. Nearly half of PLH identify themselves as gay or bisexual, just over one-quarter of caregivers also are HIV positive (all wives, none of the mothers are HIV positive), and three out of four caregivers live with the PLH. PLH have been sick with HIV for about six years, documenting the chronic course of HIV at the current time. Similarly, caregivers have been providing assistance for about five years, attesting to the long-term nature of HIV caregiving. Both caregivers and PLH rate their health to be between poor and good, on average (1 = very poor; 2 = poor; 3 = good; 4 = very good; 5 = excellent).

### ***Procedures***

This study used a mixed-methods design in which a small number of in-depth, open-ended qualitative interviews generated material for inclusions in a subsequent larger quantitative interview. The content of the standardized interviews primarily was derived from prior caregiving studies, carried out in part by our investigative team. In addition, because PLH are generally healthier than in the past, it was important to redesign protocols to appropriately capture the changing dynamics of HIV-caregiving dyads. Thus, our qualitative work with the same sample generated several new measures in addition to more standard caregiving stress and mental health measures. Instruments were pilot-tested. They also were translated into Spanish, and back-translated into English. In addition to the screener for eligibility criteria, described above, a psychological screener (the Short Portable Mental Status Questionnaire; Pfeiffer 1975) was used to screen for severe cognitive impairment.

Structured, computerized interviews were conducted between May 2002 and January 2004. Interviews were administered in either English (72%) or Spanish (28%), and lasted



approximately two hours. Seven interviewers (six females, one male) with various professional backgrounds underwent extensive training prior to fielding the survey instrument. All interviews were tape recorded for quality control purposes. Study participants were typically interviewed in their homes, with some interviewed at various other private locations of their choice. PLH and caregivers were interviewed separately. All materials and protocols were approved by the University of California, Los Angeles, Office for the Protection of Research Subjects. Informed consent was obtained prior to conducting the interviews. Each participant was paid \$25 upon completion of the interview.

### *Stress Measures*<sup>5</sup>

**Primary Objective Stressor.** ADL assistance need is pivotal within the caregiving stress proliferation framework because it is the dependency of the PLH on the caregiver that sets the stage for subsequent stressors. For our analyses, ADL were a count of 22 personal, instrumental, and management activities that PLH may need assistance with.

**Primary Subjective Stressor.** Perceived HIV also is a primary stressor because it is inherent to the HIV/AIDS caregiving experience. That is, it is not consequent to the level of ADL assistance needed, but rather is entrenched within the social context of living with HIV or having a family member who is infected with HIV. Unlike ADL, however, it is subjectively experienced. We assess perceived stigma with a measure adapted from Sowell and associates (Sowell *et al* 1997; Wight *et al* 2005), that includes nine items measuring perceptions of shame, rejection, and avoidance. Responses ranged from (1) not at all to (4) very much ( $\alpha$  caregiver =

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<sup>5</sup> Scale items can be found in the appendix.

0.84,  $\alpha$  PLH = 0.84), and items were summed and averaged to maintain the original response metric.

**Secondary Stressor.** Constriction of social activities is conceptualized as consequent to the primary stressors. ADL demands or needs may force caregivers and PLH to withdraw from other regular activities, and perceived stigma may inhibit their willingness to engage in such activities. Social constriction was a 14-item scale (adapted from Pearlin *et al* 1990) that reflects the extent to which caregivers and PLH have had to give up social and leisure activities due to caregiving requirements or needs. Responses ranged from (1) not at all to (4) completely ( $\alpha$  caregiver = 0.90,  $\alpha$  PLH = 0.89) and were summed and averaged to maintain the response metric.

**Mediator.** Mastery assesses individuals' understanding of their ability to control the forces that affect their lives, and is an important component of the stress proliferation process that has been shown to counterbalance the damaging health consequences of caregiving stress (e.g., Aneshensel *et al* 1995). Mastery was assessed ([1] strongly disagree to [4] strongly agree) with the 7-item Pearlin Mastery scale (Pearlin *et al* 1997;  $\alpha$  caregiver = 0.83;  $\alpha$  PLH = 0.80) and, as with previous measures, items were summed and averaged to maintain the response metric.

**Future Uncertainty.** Based on qualitative interviews (4 caregivers and 5 PLH), and pilot interviews (20 caregiving dyads), we developed a series of questions concerning uncertainty about the future. From these questions, we created a 4-item scale that captures feelings about the future and protracted survival with HIV. Principal components analyses indicated that each item had a factor loading  $\geq 0.50$ , and the factor structure of the 6-item scale was largely similar between caregivers and PLH. As with other measures, the items were summed and divided by

the number of items to maintain the response metric. Details of the individual items are presented in the results section.

**Mental Health.** Consistent with previous research cited above, the mental health outcome for this analysis is depressive symptoms, which were assessed with a modified 6-item subscale of the Hopkins Symptom Checklist (Derogatis *et al* 1974). Participants were asked how many days in the past week they had experienced an array of symptoms, with responses ranging from no days (1) to five or more days (4) ( $\alpha$  caregiver = 0.83;  $\alpha$  PLH = 0.86).

### ***Data Analysis***

Data are examined through descriptive statistical techniques, bivariate correlational analyses, and multivariate regression. The bivariate analysis investigates overall within-person and cross-person correlations among stress characteristics of the PLH and caregiver. This approach sheds light onto the concept of linked lives by assessing whether the stressful experience of one person are associated with those of the other person. Ordinary least squares (OLS) regression models using STATA Version 8.0 assess multivariate correlates of depressive symptoms; models were stratified between caregivers and PLH. In a preliminary model (not shown), depressive symptoms were regressed on the background characteristics, and only two variables that attained statistical significance for either the caregiver or PLH ( $p < 0.05$ , age and self-rated health) were retained in subsequent models to maintain parsimony for this small sample. The subsequent models were built by adding sequentially the two primary stressors, the secondary stressor, future uncertainty, and mastery, and by examining both their impact on other variables in the model and their associations with depressive symptoms. We then tested a model

that assessed cross-person effects (i.e., whether PLH stress and mental health affects caregiver mental health, and vice versa).

## **RESULTS**

### ***Stress Characteristics***

Mean scores for the stress proliferation measures are shown in Table 2.

#### TABLE 2 ABOUT HERE

In the primary stressor domain, caregivers provide assistance with nearly eight ADL. Similarly, PLH report needing assistance with approximately eight ADL. These are generally high levels of care. Perceived stigma is experienced “just a little” on average, with PLH reporting significantly higher stigma than caregivers. Turning to the secondary stressor, on average, “just a little” social constriction is reported among participants. In terms of the stress mediator, both caregivers and PLH report similarly high feelings of mastery, as evidenced by an average response code of “agree.” On average, depressive symptoms are experienced during one or two days in the previous week, with PLH scoring significantly higher than caregivers.

### ***Future Uncertainty***

Table 3 presents descriptive statistics for the items comprising the future uncertainty scale.

### TABLE 3 ABOUT HERE

The first item, “I didn’t expect (to/him to) live up to this point” (factor loading = 0.51) provides indication of existential concerns, and carries an implicit future orientation because it taps into the recognition that survival among PLH has been extended and death is not necessarily imminent. The second item, “I’m not sure how we’ll manage our money” (factor loading = 0.67) captures the financial strain that may be incumbent with extended survival. The third item, “It is difficult to think about the future” (factor loading = 0.68) shows how caregivers and PLH may struggle with maintaining a future orientation while dealing with the undeniable specter of severe illness or death. The fourth item, “Sometimes time seems endless” (factor loading = 0.50) is a general indicator of ambiguity about the future.

As can be seen, the scale demonstrates good reliability for both caregivers and PLH. Table 3 also shows that future uncertainty is somewhat high in this sample, with mean item scores representing an average response of “agree.” However, standard deviations are fairly large, indicating wide variation around these means. The range of responses extends to “strongly agree” for each item, indicating that some PLH and caregivers feel a high degree of uncertainty. For example: for item [A] “I didn’t expect (to/him to) live up to this point,” 36% of PLH and 17% of caregivers strongly agreed with this statement. PLH score significantly higher than caregivers on this item, but otherwise there is similarity within the dyads, on average.

#### ***Bivariate Cross-Person Associations***

As shown in Table 4, among both caregivers and PLH, depressive symptoms are highly correlated with each of the stressor variables, with the exception of ADL assistance, which is

only significantly associated with depressive symptoms among PLH. The positive and significant association between depressive symptoms and future uncertainty provides evidence that concerns about extended survival have an emotional impact. Perceived stigma is positively associated with social constriction and future uncertainty, and negatively associated with mastery for both parties. Social constriction is positively associated with future uncertainty among caregivers but not among PLH. Mastery is associated with each of the stress variables except ADL assistance.

#### TABLE 4 ABOUT HERE

Correlations *between* caregivers and PLH provide indication of cross-person associations at the bivariate level. These correlations are shown in the lower left quadrant of Table 4. As shown, the manifestation of most of the stress characteristics is individually experienced. However, caregiver depressive symptoms are positively associated with PLH reports of social constriction and PLH depressive symptoms are positively associated with the caregiver's reports of future uncertainty. Caregiver social constriction is positively associated with the PLH's report of ADL assistance needs. Caregiver mastery is negatively associated with the PLH's perceived stigma, and PLH mastery is negatively associated with the caregiver's reports of ADL assistance. Perceived stigma is significantly correlated between the two parties, as is ADL assistance. Thus, the caregiver's experience in some of these stress-related domains matters to the PLH, and vice versa.

### *Multivariate Associations*

Table 5 shows the regressions of depressive symptoms on care-related variables, run separately for caregivers and PLH. As discussed above, age and self-rated health are the only background characteristic to meet model-building criteria.

#### TABLE 5 ABOUT HERE

As shown in Model 1, the previously significant inverse association between age and depressive symptoms is attenuated once the primary stressors are controlled, and self-rated health is negatively associated with depressive symptoms for both caregivers and PLH. Overall, we see that caregivers and PLH seem to be influenced by somewhat different sources of stress. Among caregivers, perceived stigma is significantly associated with depressive symptoms whereas ADL assistance is not. Among PLH, both perceived stigma and ADL assistance needs are positively and significantly associated with depressive symptoms.

Model 2 adds constriction of social activities, a secondary stressor. Among caregivers, social constriction significantly improves the fit of the model and is positively associated with depressive symptoms, mediating some of the depressive effect of perceived stigma. Among PLH, social constriction is not associated with depressive symptoms and does not mediate the effect of either primary stressor.

Model 3 adds future uncertainty, which we have conceptualized as a secondary stressor. Among caregivers, future worry does not significantly add to the model, is not significantly associated with depressive symptoms, and does not mediate the depressive effects of either primary stressor. In contrast, among PLH, future uncertainty significantly improves the model,

is positively associated with depressive symptoms, and mediates the depressive effect of perceived stigma, but not of ADL assistance. Among PLH, age is now significant, meaning that its effect had previously been suppressed by not controlling for future uncertainty.

Model 4 adds mastery, a personal resource conceptualized as counterbalancing the damaging effect of stressors. Among caregivers, mastery does not improve the fit of the model and is not associated with depressive symptoms. However, there is some evidence of mediation in that the coefficient for perceived stigma shrinks and is no longer significant, and the coefficient for social constriction is slightly smaller. Among PLH, mastery significantly improves the model and is significantly and negatively associated with depressive symptoms, mediating a sizeable portion of the depressive effect of future uncertainty and a small amount of the negative effect of self-rated health.

### ***Multivariate Cross-Person Associations***

Table 6 shows the cross-person regressions of depressive symptoms on the care-related stress and background variables. Cross-person self-rated health effects are included because of their significant contribution to depressive symptoms in earlier models.

TABLE 6 ABOUT HERE

As shown, PLH social constriction is positively associated with caregiver depressive symptoms, independent of the other variables in the model. In contrast, caregiver social constriction is negatively associated with PLH depressive symptoms. Notably, caregiver future



uncertainty is positively associated with PLH depressive symptoms. Caregiver depressive symptoms are also significantly associated with PLH depressive symptoms, net of covariates.

## **DISCUSSION**

In this chapter, we intended to call attention to the phenomenon of “future uncertainty” within AIDS caregiving dyads, and how this construct is enmeshed within the stress proliferation process and associated with mental health. Our conceptual model included a core element of life course theory, that of linked lives, which acknowledges that individuals are influenced by what transpires in the life of others when they share a social relationship. We focused on caregivers who are midlife and older wives and mothers because these women maintain traditional family caretaker roles, and will increasingly be called upon to do so as HIV permeates mainstream society. Unlike most caregiving studies, we also took into consideration the experiences of the care-recipient, sons and husbands living with HIV, offering empirical evidence of both individually experienced and cross-person stress effects.

There is evidence at the bivariate level that future uncertainty is positively associated with depressive symptomatology among both caregivers and PLH. However, when other variables are controlled, this association is only significant among PLH, meaning that among caregivers its depressive effect is attenuated by self-rated health, perceived stigma, and social constriction. The caregiver’s feelings of future uncertainty manifest at the dyad-level because they cross-over to significantly affect the PLH’s depressive symptoms. Thus the overall “future uncertainty climate” within the dyad appears to be more consequential to the PLH than the caregiver. In addition, future uncertainty among PLH accounts for the significant association

between perceived stigma (a primary stressor) and depressive symptoms, providing evidence that its designation as a secondary stressor is appropriate, at least among PLH.

In terms of other individually experienced stress processes, the overall pattern of relationships is in the expected direction and is consistent with previous research. Of note, perceived stigma plays a powerful role in the emotional lives of caregivers and PLH, although its influence is only sustained among caregivers in the multivariate model. Mastery mediates associations between stressors and health for both parties, but particularly so among PLH. In both the bivariate and multivariate analyses, ADL assistance is associated with depressive symptoms among PLH but not caregivers, suggesting that it is more emotionally damaging to require assistance than to provide it.

Additional cross-person effects shed light on how the caregiver and PLH are linked within the dyad. First, caregiver depressive symptoms are positively and significantly associated with PLH depressive symptoms and vice versa, but only in the multivariate model. Thus, the cross-person association is complex, and it appears that the portion of poor mental health shared between the two parties may arise through the effects of other stress variables, such as social constriction or mastery. Second, the experience of social constriction significantly links the caregiver to the PLH, and vice versa, but in opposite directions. Caregiver social constriction is negatively associated with PLH depressive symptoms meaning that these symptoms are lower. The opposite is true for caregivers: Symptoms are higher among caregivers whose husband or son's social activities are constrained. It therefore appears that discordance in social constriction is emotionally harmful within caregiving dyads.

Although the nature of the caregiver and care-recipient roles differentiates the experiences of the two role partners, these persons nevertheless are linked precisely because they

are role partners. Among HIV-positive concordant romantic couples, the two roles also are distinguished by the need for care by only one person. There is experiential spillover, however, because in this instance, the caregiver is herself a PLH. In some instances, in fact, it is clear that the PLH infected the caregiver with HIV or vice versa. For example, one caregiving wife said the following at the end of the interview: “I know he gave it to me, but I love him anyway. I wish it were different, but I still love him.” This comment provides testimony to the strength of the bond between husband and wife, perhaps a form of “traumatic bonding” that is qualitatively unique to these HIV-positive couples.

In light of this bonding, it would seem that caregiver HIV status would be associated with depressive symptoms, consistent with previous research among gay partners on the concept of precursive AIDS caregiving (Wight 2000). Yet, we find no such evidence in our multivariate models, where the caregiver’s HIV status was statistically non-significant. In a supplemental analysis, we compared HIV-positive wives (N = 37) and HIV-negative wives (N = 39) in terms of their mean scores on both depressive symptoms (HIV-positive M = 2.03, SD = 0.71); HIV-negative M = 2.00, SD = 0.79) and the future uncertainty scale (HIV-positive M = 2.65, SD = 0.48; HIV-negative M = 2.73, SD = 0.56), finding no significant differences ( $p > 0.10$ ). We posit that the caregiving role may be so well-established for these women, that they are able to conceptually distance themselves and put aside, to some extent, the emotional impact of their own HIV-related health issues or their futures with HIV. For future uncertainty, the manner in which the questions were phrased may have contributed to this tendency in that we asked specifically about how the life of the care-recipient had changed as a result of medications.

In summary, we found that there are a range of future worries and concerns that accompany extended survival among PLH and that future uncertainty has mental health consequences. Some of these sentiments are best described by the study participants themselves.

For example, a caregiving wife described her feelings as follows:

I didn't think my husband was going to live, but he is and I cherish that. There are many people who had written him off, doctors included, thought he was gone, no coming back. It's amazing. But now that we realize he's going to live—he thought he was going to die, I thought he was going to die—so now I'm looking to see how I can re-start up my career. We have to think more about managing our money now.

When talking about her son's future, a caregiving mother said this:

Well, I know that he's worked up to a point where he's resistant to most of the treatments. He's tolerating one of the latest ones, and the doctor said his viral load had come down quite a bit, but then he gets an infection and it goes back up. So, it seems like there is always some major thing happening to drop him back down again. But the doctor implied that there were things out there that had never been tried on him so that's what we're hoping for.

Clearly, there is a mixture of feelings related to future worries, ranging from optimism to loss, and from preparing for death to planning for the future. Dealing with ART regimens in

more recent years, compared to early in the epidemic, speaks perhaps most distinctly to the historical specificity of the AIDS caregiving experience.

One of the PLH, a husband, said the following about ART regimens:

Compared to five or ten years ago, living with HIV today is a full time job. When I first got it, it was more just an “oh my god I’m gonna die” struggle, versus today with the balancing of the cocktails and side effects and pharmacies and agencies and doctor appointments, it’s actually harder today and gets harder and harder emotionally and physically. I have to fight hard to stay alive.

We have uncovered unique associations between future uncertainty and the AIDS caregiving stress process, but there are limitations to this study we wish to acknowledge. First, the sample of caregiving dyads was self-selected, meaning that study results should not be over-generalized. Second, as with all survey research, there is the possibility that unobserved confounding variables are responsible for significant effects. Third, the cross-sectional nature of the study limits us from firmly establishing causal directions of the observed associations. Fourth, a larger sample would have allowed for more extensive examinations of within-dyad processes (e.g., analyses stratified by dyad type). This latter limitation is important, given the absence of significant effects on depressive symptoms of most of the background personal characteristics (e.g., education, ethnicity, caregiver HIV status), characteristics whose mental health effects may have been unobserved due to a lack of statistical power.

Still, our analysis has shown that future uncertainty exists for many PLH and their caregivers, that its occurrence can be understood, at least in part, as an element in the stress proliferation process, and that it has mental health consequences. Our conceptualization highlights the ways in which the lives of caregivers and PLH are linked within this specific historical context. Further, it appears that future uncertainty is experienced individually by caregivers and PLH, but it also maintains shared components, as evidenced by cross-person associations. Researchers and interventionists should recognize that future uncertainty is a unique source of stress among PLH and their caregivers that may influence the health and social identity of these dyads.

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Table 1: Background Characteristics, *M (SD) or Proportion*

	CG (N = 135)	PLH (N = 135)
Age (years)	53.79(13.94)	42.14(7.53) <sup>a***</sup>
Education (years)	10.24(4.24)	11.26(3.22) <sup>a*</sup>
Household Income (thousands of dollars)	15.01(13.76)	12.80(11.74)
Ethnicity		
Non-Hispanic White	0.17	0.14
African American	0.27	0.28
Hispanic	0.52	0.51
Other	0.04	0.07
Mother/son dyad	0.44	0.44
PLH currently taking ARV	--	0.84
PLH gay or bisexual	--	0.43
CG lives with PLH	0.76	--
CG also HIV-positive <sup>(1)</sup>	0.27	--
Years PLH sick with HIV	--	6.31(4.09)
Years CG has been helping PLH	5.23(3.67)	--
Self-rated health (1-5)	2.63(1.10)	2.81(1.86)

*Note.* CG = Caregiver; PLH = Person Living with HIV (Care-recipient).

<sup>(1)</sup> No mothers reported being HIV-positive.

<sup>a</sup> CGs differ from PLH

\*  $p \leq .05$ ; \*\*  $p \leq .01$ ; \*\*\*  $p \leq .001$ .

Table 2: Stress Characteristics, *M (SD)*

	CG (N = 135)	PLH (N = 135)
<i>Primary Stressors</i>		
ADL assistance (count, 0 – 22)	7.83(5.08)	8.87(4.71)
Perceived stigma (1 – 4)	1.66(0.68)	2.11(0.75) <sup>a***</sup>
<i>Secondary Stressor</i>		
Social constriction (1 – 4)	1.62(0.65)	1.75(0.66)
<i>Mediator</i>		
Mastery (1 – 4)	2.73(0.51)	2.83(0.54)
<i>Mental Health</i>		
Depressive symptoms (1 – 4)	1.96(0.73)	2.19(0.79) <sup>a*</sup>

*Note.* CG = Caregiver; PLH = Person Living with HIV (Care-recipient); ADL=Activities of Daily Living.

<sup>a</sup> CGs differ from PLH

\*  $p \leq .05$ ; \*\*  $p \leq .01$ ; \*\*\*  $p \leq .001$ .

Table 3: Future Uncertainty Scale, *M (SD)*

Thinking about how people living with HIV's lives have changed with the new medications in the last few years, to what extent do you agree or disagree with the following statements:	CG (N = 135)	PLH (N = 135)
A. I didn't expect (to/him to) live up to this point	2.76(0.79)	3.01(0.92) <sup>a*</sup>
B. I'm not sure how we'll manage our money	2.67(0.71)	2.74(0.78)
D. It is difficult to think about the future	2.63(0.74)	2.69(0.80)
F. Sometimes time seems endless	2.63(0.73)	2.69(0.79)
Total Score	2.67(0.54)	2.78(0.59)
$\alpha$	0.70	0.70

*Note.* Response

categories: 1 = Strongly Disagree; 2 = Disagree; 3 = Agree; 4 = Strongly Agree;

CG = Caregiver; PLH = Person living with HIV (Care-recipient);

<sup>a</sup> CGs differ from PLH

\*  $p \leq .05$ .



Table 4: Linked Lives—Correlations Between Caregiver and Care-Recipient Stress Proliferation Variables

<i>CG:</i>	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. Depressive symptoms	---											
2. ADL assistance	0.13	---										
3. Perceived stigma	0.40***	0.12	---									
4. Social constriction	0.40***	0.47***	0.35***	---								
5. <b>Future uncertainty</b>	0.30***	0.10	0.38***	0.37***	---							
6. Mastery	-0.39***	-0.05	-0.51***	-0.32***	-0.35***	---						
<i>PLH:</i>												
7. Depressive symptoms	0.12	0.14	0.04	-0.04	0.19*	-0.07	---					
8. ADL assistance	0.07	0.59***	-0.09	0.33***	0.05	-0.04	0.30***	---				
9. Perceived stigma	-0.01	-0.05	0.20*	0.02	0.10	-0.17*	0.37***	0.03	---			
10. Social constriction	0.27**	0.10	0.13	-0.03	0.16	-0.05	0.25**	0.18*	0.25**	---		
11. <b>Future uncertainty</b>	-0.10	0.08	-0.01	0.02	0.10	-0.07	0.44***	0.18*	0.40***	0.16	---	
12. Mastery	0.05	-0.17*	-0.04	0.01	-0.13	0.11	-0.50***	-0.14	-0.40***	-0.18*	-0.49***	---

*Note:* CG=caregiver; PLH=person living with HIV (care recipient); ADL=activities of daily living.

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$ ; \*\*\*  $p \leq 0.001$

Table 5: Regression of Depressive Symptoms on Caregiving Stress Variables and Future Uncertainty

	Caregiver				PLH			
	Model 1	Model 2	Model 3	Model 4	Model 1	Model 2	Model 3	Model 4
	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)
<i>Background Characteristics</i>								
Age (years)	-0.01(0.00)	-0.00(0.00)	-0.00(0.00)	-0.00(0.00)	-0.01(0.01)	-0.01(0.01)	-0.02(0.01)*	-0.02(0.01)*
Self-rated health (1-5)	-0.15(0.06)**	-0.13(0.06)*	-0.13(0.06)*	-0.11(0.06)	-0.17(0.05)**	-0.17(0.05)**	-0.13(0.05)*	-0.09(0.05)
<i>Primary Stressors</i>								
ADL assistance (count, 0-22)	0.02(0.04)	-0.03(0.04)	-0.03(0.04)	-0.02(0.04)	0.13(0.04)**	0.12(0.04)**	0.10(0.04)*	0.10(0.04)*
Perceived stigma (1-4)	0.32(0.09)**	0.24(0.09)*	0.22(0.10)*	0.16(0.10)	0.29(0.08)**	0.26(0.09)**	0.15(0.09)	0.09(0.09)
<i>Secondary Stressors</i>								
Social constriction (1-4)		0.32(0.10)**	0.30(0.11)**	0.26(0.11)*		0.14(0.09)	0.14(0.09)	0.12(0.09)
<b>Future uncertainty (1-4)</b>			0.11(0.12)	0.08(0.12)			0.34(0.11)**	0.25(0.11)*
<i>Stress Mediator</i>								
Mastery (1-4)				-0.23(0.14)				-0.42(0.12)**
<i>R</i> <sup>2</sup>	0.18	0.23	0.23	0.24	0.26	0.27	0.32	0.37
<i>F</i>	8.54***	9.14***	7.75***	7.15***	12.85***	10.81***	11.63***	12.46***
( <i>df</i> )	(4,130)	(5,129)	(6,128)	(7,127)	(4,130)	(5,129)	(6,128)	(7,127)
<i>Incremental F</i>		9.34**	0.85	2.88		2.20	11.39**	11.61***
( <i>df</i> )		(1,129)	(1,128)	(1,127)		(1,129)	(1,128)	(1,127)

Note: CG=Caregiver; PLH=Person Living with HIV (Care-Recipient).

\* p ≤ 0.05; \*\* p ≤ 0.01; \*\*\* p ≤ 0.001

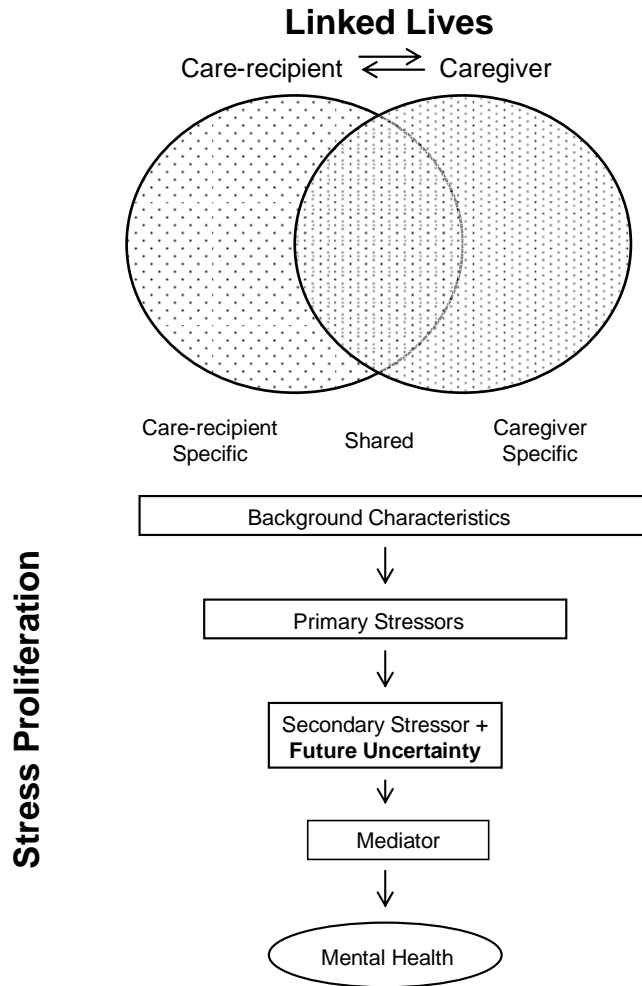
Table 6: Regression of Depressive Symptoms on Linked Lives Stress Variables

	Caregiver	PLH
	B (SE)	B (SE)
<i>Background Characteristics</i>		
Age (years)	-0.00(0.00)	-0.01(0.01)
CG Self-rated health (1-5)	-0.08(0.05)	-0.01(0.05)
PLH Self-rated health (1-5)	0.01(0.05)	-0.09(0.05)
<i>Primary Stressors</i>		
CG report of ADL assistance (count, 0-22)	-0.03(0.05)	-0.02(0.05)
PLH report of ADL assistance (count, 0-22)	-0.05(0.05)	0.15(0.05)**
CG Perceived stigma (1-4)	0.10(0.10)	-0.02(0.10)
PLH Perceived stigma (1-4)	-0.17(0.09)	0.14(0.09)
<i>Secondary Stressors</i>		
CG Social constriction (1-4)	0.35(0.11)**	-0.26(0.11)*
PLH Social constriction (1-4)	0.33(0.09)***	-0.01(0.09)
<b>CG Future uncertainty (1-4)</b>	-0.02(0.11)	0.22(0.11)*
<b>PLH Future uncertainty (1-4)</b>	-0.15(0.11)	0.25(0.11)*
<i>Stress Mediator</i>		
CG Mastery (1-4)	-0.33(0.13)*	0.15(0.13)
PLH Mastery (1-4)	0.17(0.13)	-0.41(0.12)**
<i>Linked Depressive Symptoms</i>		
CG Depressive symptoms		0.23(0.09)*
PLH Depressive symptoms	0.24(0.09)**	
$R^2$	0.35	0.41
$F$	6.12***	7.55***
(df)	(14,120)	(14,120)

Note: CG=Caregiver; PLH=Person Living with HIV (Care-Recipient).

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$ ; \*\*\*  $p \leq 0.001$

Figure 1. Stress Proliferation within Linked Lives: AIDS Caregiving



## APPENDIX

### *Scales Utilized:*

#### ADL Assistance

Now I'd like to ask about a number of ordinary daily activities with which (he/you) may need help with. In the past two to three weeks, (has he/have you) needed any help with:  
(If yes: How much of it [do you/does she] personally help with?)

(Response categories: 1=none of it; 2=some of it; 3=much of it; 4=all of it)

Items: Housework/housecleaning; Shopping for food; Cooking/preparing food; Laundry; Transportation; Picking up prescriptions; Eating; Bathing/showering/washing hair; Moving around/walking; Dressing/undressing; Brushing teeth/hair; Getting in/out of bed; Using the toilet; Managing financial affairs; Managing legal affairs; Coordinating help given by friends/family; Dealing with doctors/nurses/clinic staff; Keeping in touch with others; Finding work; Finding activities to occupy time; Finding housing; Paying bills.

#### Perceived Stigma

Here are some ways that people may feel about HIV and AIDS. Thinking about (your having/his having) HIV/AIDS, please tell me how you feel. How much do you \_\_\_\_\_. Would you say:

(Response categories: 1=not at all; 2=just a little; 3=somewhat; 4=very much)

Items: Feel blamed by others; Feel that you need to hide it; Feel ashamed; Think HIV is punishment for something; Think other people are uncomfortable being around you; Feel people avoid you; Fear you will lose your friends; Fear your family will reject you; Feel that people don't want you around their children.

#### Social Constriction

People sometimes give up certain activities as a result of (providing help to a family member/needing help from a family member). As a result of (providing help/needing help), to what extent have you had to give up:

(Response categories: 1=not at all; 2=just a little; 3=somewhat; 4=completely)

Items: Vacations/out of town trips; Getting together with friends/family; Regular exercise; Other leisure activities/hobbies; Close relationships with others; Eating out at restaurants; Going for health care check-ups; Your job/career; Pursuing more education; Attending religious/spiritual services; Spending time alone; Managing your own financial affairs; Managing your own legal affairs; Sexual relations.

### Mastery

I would like to ask some additional questions about how you see yourself as a person. How strongly do you agree or disagree with each of the following statements?

(Response categories: 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree)

Items: There is really no way I can solve some of the problems I have; Sometimes I feel I'm being pushed around in life; I have little control over the things that happen to me; I can do just about anything I really set my mind to do; I often feel helpless in dealing with the problems of life; What happens to me in the future mostly depends on me; There is little I can do to change many of the important things in my life.

### Depressive Symptoms

Now I'd like to ask how you've been feeling about things in the past week. On how many days in the past week did you:

(Response categories: 1=no days; 2=1 or 2 days; 3=3 or 4 days; 4=5 or more days)

Lack enthusiasm for doing anything; Feel bored or have little interest in doing anything; Cry easily or feel like crying; Feel downhearted or blue; Feel slowed down or low in energy; Feel that everything was an effort.