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## HIV serostatus and factors related to physical and mental well-being in Latina family AIDS caregivers

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### Abstract

In a survey of 154 Latina AIDS caregivers living in Los Angeles, we examined differences in the stress process for those who were HIV seropositive, seronegative, and those with an unknown serostatus. Most caregivers were monolingual, poor, suffered from chronic physical illness unrelated to HIV, and received few services. All three subsamples reached clinical cut-off levels for depression on the brief symptom inventory. In the sample as a whole and in all three groups we examined differences in primary and secondary stressors as predictors of mental and physical well-being; differences in background factors as they relate to mental and physical well-being; and differences in predictive value of various factors that may attenuate the relationship between stress and mental and physical well-being. Models predicting both mental and physical well-being differ across subsamples divided on the basis of serostatus. Based on these findings, we discuss implications for service provision designed to target these underserved Latina AIDS caregivers. © 2001 Elsevier Science Ltd. All rights reserved.

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Caregiving for a chronically ill loved one is often an emotionally intense and physically demanding experience, one that is characterized by persistent, stressful demands. To date, the large majority of caregiver studies have focused on those afflicted with Alzheimer's disease or similar progressive cognitive disorders (e.g. Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995; Wright, Clipp, & George, 1993; Yates, Tennstedt, & Chang, 1999; Zarit, Orr, & Zarit, 1985). Relatively few studies have investigated the lives of AIDS caregivers. Those published recently suggest that AIDS caregivers suffer a great deal of emotional distress as providers of informal care (Folkman, Chesney, & Christopher-Richards, 1994; Leblanc, London, & Aneshensel, 1997). The second decade of AIDS has ushered in a number of changes that may impact upon caregiving (Reynolds & Albonza, 1998). With the advent of new medications, AIDS is

frequently defined as a chronic disease, one that often requires vigilant and ongoing home care. As the AIDS epidemic continues, it is important that we learn how the increasingly lengthy and complicated process of providing care for a loved one with this disease affects the caregiver so that supportive service programs designed to alleviate stress in caregiving may be better informed.

In particular, information is lacking on how AIDS caregiving affects ethnolinguistic minorities. Such minorities, particularly women and children of Latin descent, account for a dynamic growth in the AIDS epidemic (Baker, Sudit, & Litwak, 1998; Centers for Disease Control and Prevention, 1997; Scott, Jorgensen, & Suarez, 1998). Very little is known of the lives of Latino caregivers, many of whom are women. The available information suggests that they may face challenges and problems that, in many respects, are different and more severe from those experienced by other caregivers (Cox & Monk, 1996; Flaskerud & Tabora, 1998; Kaplan, Marks, & Mertens, 1997; Land, 1994; Land & Hudson, 1997).

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In the Latin community, female AIDS caregivers constitute the backbone of family attendant care. In addition to providing care for HIV-infected children, partners or other loved ones, Latinas often assume a caregiving role for other family members. Caregiving tasks fall to these women because of strong cultural expectations, especially among the newly emigrated (Connel & Gibson, 1997; Fernandez, Luiz, & Bing, 1993; Lockerly, 1991; Medrano & Klopner, 1992; Mitzner, 1992). Studies reveal that female caregivers dedicate an enormous portion of their lives to the caregiving role, providing substantial assistance (Stetz & Brown, 1997; Wight, LeBlanc, & Aneshensel, 1998).

For a variety of reasons, these tasks may be more burdensome for Latina caregivers than others. Because of the complexity of the illness, people infected with HIV often require multiple services to promote disease management. Caregivers must understand the required services, and be familiar with the service systems and the individuals involved in care of the patient (Matheny, Mehr, & Brown, 1997). Latina caregivers are often coping with the concurrent stress of acculturation and accompanying isolation, and are not knowledgeable about AIDS services (Flaskerud & Nyamanthi, 1990; Land & Hudson, 1997; Marquis, 1998). Lack of knowledge can be an inhibiting factor in health maintenance, and ultimately in caregiving. Further, research suggests that Latinos are often reluctant to seek outside help or early care for their illness, perhaps for fear of disease stigma, fear of burdening their families, or due to the paucity of AIDS services that attend to the needs of Spanish speaking people with specific cultural values (Demi, Bakeman, Moneyham, Sowell, & Seals, 1997; Rogler, 1996; Salcido, 1990; Talamantes, Lawler, & Espino, 1995). Most Latina AIDS caregivers reside in very poor communities where health and social services are limited (Hackl, Somalai, Kelly, & Kalichman, 1997; Medrano & Klopner, 1992). Where outside resources do exist, family members may view them as unnecessary, insensitive to familial needs, or intrusive (O'Connor, 1995; Purdy & Arguello, 1992). Like other poor immigrant groups, Latinas may be at higher risk for chronic illnesses such as hypertension and heart disease (Rivera, Torres, & Carre, 1997; Sumaya, 1991). Because many are without documents, these caregivers often fail to qualify for physical and mental health benefits, child care, rent subsidies or other supportive services (Dennenberg, 1997; Land & Hudson, 1997).

Like other caregivers, Latina caregivers confront a higher rate of chronic illness and mortality than that expected for the normative life course. Many are bereaved of a partner or child as they continue to provide care for others. Further, it is important to note that in no other caregiving situation do caregivers so

often face the same fate as those for whom they are providing care (LeBlanc et al., 1997; Pakenham, Dadds, & Terry, 1995). In fact, Latinas are among the fastest growing group of those infected with HIV (Fernandez, 1995). Despite advances in disease containment, the percent of documented, advanced AIDS cases among Latin women in large urban areas has continued to climb over the last decade (Los Angeles County Department of Health Services, 1998). Many are at high risk for contracting HIV because of sociocultural sanctioning against the use of condoms (Deren, Schedlin, & Beardsley, 1996; Rosen & Black, 1992). Latina AIDS caregivers who are themselves HIV-positive may present with accelerated disease manifestations, even as they attend to others who require more extensive care (Black, Nair, & Harrington, 1994; Medrano & Klopner, 1992). These circumstances may evolve due to substantial misinformation concerning HIV coupled with a strong tendency to underestimate personal risk (Kalichman, Hunter, & Kelly, 1992; Marin, 1990; Weeks, Schensul, Williams, Singer, & Grier, 1995).

The multiple demands of AIDS caregiving coupled with limited resources may result in role strain and a powerful stress process that predictably pushes the boundaries of human physical and emotional capabilities (Demi et al., 1997; Stajduhar & Davies, 1998; Wardlaw, 1994). The negative effects of chronic stress and psychosocial risk factors on the immune system have already been documented (Kemeny et al., 1994; Kiecolt-Glaser, & Glaser, 1995; Littrell, 1996). For these reasons, Latina family AIDS caregivers constitute a growing, vulnerable group at risk for physical illness, the comorbid manifestations of AIDS, and the psychological sequelae of caregiving (Kaplan et al., 1997).

### Caregiver stress-health model

The purpose of this study was to examine stressors and their association with the physical and mental health of Latina AIDS caregivers, along with psychological mediators. We chose variables from the stress paradigm elaborated by Pearlin and colleagues (Pearlin, 1989; Pearlin, Aneshensel, & LeBlanc, 1997; Pearlin, Mullan, Aneshensel, Wardlaw, & Harrington, 1994). The model depicts the stress of caregiving as a process comprised of a number of interrelated conditions. These include (1) the sociodemographic characteristics of the caregiver; (2) primary stressors that are inherent in caregiving, such as the financial or psychosocial burdens stemming from the health and psychological needs of the patient; and (3) secondary stressors that evolve out of direct caregiving, including strain experienced in the roles and activities outside caregiving. These secondary

stressors may involve internal strains such as the diminishment of control or mastery over life, worries about one's own health status, and financial worries. All of these stressors are thought to result in negative outcomes for mental and physical well-being (Pearlin et al., 1997).

Psychological mediators may help to explain why not all individuals negotiating difficult circumstances go through the same stress process (Crystal, 1991; Hansell et al., 1998; Rait, 1991; White, Ritcher, & Fry, 1992). People may react differently to the caregiving role because of varying life circumstances or capacities for stress tolerance. For example, some studies have found that culture influences the appraisal of stressful events, the perception and use of support, as well as coping behaviors (Aranda & Knight, 1997; Horowitz & Reinhard, 1995). In addition, findings reveal variation in the range of caregiving responsibilities people are willing to assume and the kind of support they receive (Pearlin et al., 1997; Turner, Pearlin, & Mullan, 1998). Response differences may arise because caregivers are exposed to different constellations of stress and strain, as in the case of Latina AIDS caregivers. Importantly, caregivers may differ in their personal resources, such as self-esteem and coping efforts, and in their capacity to mobilize other resources such as social support or other supportive services (Turner & Catania, 1997).

Finally, AIDS caregivers may differ in their physical health status, with some being HIV infected and others not (Flaskerud & Tabora, 1998). Recent studies of Anglo AIDS caregivers reveal that caregivers with seropositive status shoulder an extra burden of stress (Folkman et al., 1994; LeBlanc et al., 1997). In fact, higher risk for depression, anxiety, hostility, and perceptions of caregiving burden has been found in HIV-positive gay male caregivers than in their HIV-negative counterparts (Blaney, Million, Morgan, Eisdorfer, & Szapocznik, 1990; Siegel, Raveis, & Kraus, 1997). Further, financial stress, and illness in friends and partners have been found to be strong predictors of depression in HIV-positive gay men (Thompson, Nani, & Levine, 1996). Such stressors and mental health differences reduce one's capacity to harness personal resources that buffer the stress process (Kileen, 1990; Nannis, Patterson, & Semple, 1997; Pearlin et al., 1994; Smith, Smith, & Toseland, 1991; Whitsett & Land, 1992b). Differences in primary and secondary stressors, and in background factors, as well as in these other mediating factors may explain why certain people fare better as HIV caregivers (Middel, 1991; Pearlin et al., 1997).

The analyses presented here were designed to examine differences in the stress process by serostatus, comparing three groups of women: those who report being seropositive, those who report being seronegative, and those who do not know their HIV serostatus. Our goals

were (1) to examine differences in primary and secondary stressors as predictors of mental and physical well-being, (2) to examine differences in background factors as they relate to mental and physical well-being and (3) to examine differences in predictive value of various factors that may attenuate the relationship between stress and mental and physical well-being, including social support, coping, self-esteem, and service use. Such information may be useful when designing programs that provide supportive services to persons with AIDS and their caregivers.

## Methods

### *Study sample*

The data presented below are based on a cross-sectional purposive sample of 154 Latina informal AIDS caregivers in the greater Los Angeles area. The sample was drawn between February 1995 and August 1996. Trained, bilingual, bicultural interviewers administered face-to-face interviews. Interviews were conducted in a setting agreed upon by the interviewer and the respondent; most took place in the caregiver's home. Respondents were paid \$25.00 for each interview. On average, interviews lasted about 2 h.

In order to participate in the study, caregivers had to meet a number of inclusion criteria: (1) caregiving had to be provided in the community rather than in institutional settings; (2) caregiving could not be provided in conjunction with employment as a health provider, such as nursing or attendant care; (3) assistance had to extend beyond offering emotional support to more instrumental types of caregiving and help with activities of daily living; (4) the caregiver had to be currently providing care and be the primary provider of assistance to a loved one with AIDS; (5) the caregiver had to be self-identified as Latina over 16 years of age.

We recruited 18 AIDS service organizations in the Los Angeles area to act as referral sources for our study. Respondents were referred from agencies and clinics, as well as through hospitals, media announcements, flyers, and by word of mouth. 193 women were referred to the study; seven refused to participate after initial contact with an interviewer; another 17 were ineligible, and 14 could not be contacted. Others may have been informed by service providers at participating organizations but refused referral to the study; however, we have no knowledge of how many women may have refused or what might have influenced their decision. Of the 154 women who agreed to participate, 50 were referred through AIDS service organizations, 100 through direct contact with prospective respondents at outpatient clinics, and the remainder through media announcements or from other respondents.

### Measures

English and Spanish language versions of the questionnaire were used in this study. Our aim was to achieve semantic as well as idiomatic and conceptual equivalence. The English language version was translated into Spanish, then back-translated by independent, bilingual, bicultural graduate students of Mexican descent. The back-translator was blind to the original English version of the instrument. Although the original English questionnaire and the back-translated version were highly comparable, a few subtle discrepancies were found. These differences were discussed with our bilingual, bicultural research team and addressed by forming a consensus translation. The following measures were included in both Spanish and English versions following pilot testing.

#### *Background characteristics*

We included questions on the respondents' income, educational level, age, marital status, language preference, country of origin, employment status, relationship to the person with AIDS, length of time caregiving, health insurance coverage, HIV status, their overall health status (including a measure of chronic illnesses such as asthma, high blood pressure, diabetes, and heart disease), and a general inventory of stressful life events (Pearlin, Mullan, Semple, & Skaff, 1990).

#### *Primary and secondary stressors*

We included five indicators of primary stressors, all of which used a four-point response continuum ranging from 1 (strongly disagree) to 4 (strongly agree) that had been validated in other studies of the stress process (Pearlin et al., 1997).

The first two scales are indirect measures of primary stress, based on the assumption that problem behaviors and cognitive difficulties of the patient are stressors for the caregivers. The first of these indicators measured stress associated with problem behaviors of the person with AIDS. The indicator is composed of an 18-item index addressing the extent to which the caregiver is involved in the control and surveillance of problem behaviors commonly observed at advanced stages of AIDS, including potentially dangerous acts, agitation and anger, and disruption of sleep ( $\alpha=0.83$ ). The second indicator of primary stress comprises nine items tapping the cognitive status of the person with AIDS, which can also decline with the progression of AIDS and have a serious adverse affect on the ease of communications and exchange. The items comprising this index inquire into such conditions as memory loss, hallucinatory behavior, the ability to follow conversation, and periods of confusion ( $\alpha=0.90$ ).

Three subjective measures assess how caregivers experience and appraise what they do: role overload,

role captivity, and feelings of loss of self. All three subjective stress measures are based on a four-point response continuum ranging from 1 (strongly disagree) to 4 (strongly agree). Our indicator of role overload is a four-item scale asking the extent to which the effort devoted to caregiving drains the energies and stamina of the caregiver. Specifically, this index inquires about the degree to which the caregiver has more to do than she can handle, is never able to finish what needs to be done, does not have enough time for herself, and is exhausted at bedtime ( $\alpha=0.82$ ). Role captivity is a three-item index measuring the sense of being captive in the caregiver role. This scale asks how strongly respondents wish they were free to lead a life of their own, feel trapped by the person's illness, and wish they could just run away ( $\alpha=0.81$ ). The loss-of-self measure is based on how strongly caregivers agree or disagree with questions regarding the extent to which they feel they are losing a sense of who they are, feel they are losing an important part of themselves, find it hard to think of themselves as anything but a caregiver, and feel that the person with AIDS seems like a stranger when they are together ( $\alpha=0.80$ ).

Two indicators of secondary stressors were selected for this study: loss of control or mastery over life, and worries about one's future health status. The first is a five-item scale based on the extent to which caregivers report that there is no way they can solve some of their problems, feel pushed around in life, have little control over things that happen to them, often feel helpless in dealing with the problems in life, and feel that there is little they can do to change many of the important things in their life ( $\alpha=0.77$ ). The scale measuring future health worries asks caregivers if they wonder, when not feeling well, if it could be a symptom of HIV infection, think about getting sick themselves, wonder who will take care of them when they are sick, and feel that they do not know enough about HIV to protect themselves as caregivers ( $\alpha=0.62$ ).

#### *Mediators*

Self-esteem was measured with the Rosenberg (1965) self esteem scale. The 10-item summative index employs a four-point response continuum ranging from 1 (strongly disagree) to 4 (strongly agree), and asks the extent to which respondents feel that they have a number of good qualities, on the whole are satisfied with themselves, feel that they are a person of worth, and are on an equal plane with others ( $\alpha=0.71$ ). Our coping scale ( $\alpha=0.77$ ) has been used in a number of studies and addresses the ways caregivers manage the vicissitudes of caregiving (e.g. Pearlin et al., 1997; Pearlin et al., 1990). Specifically, caregivers were queried as to how often they employ various coping efforts in order to negotiate the caregiving experience. Four coping questions address strategies for direct

management of the situation, such as trying to learn as much as they can about the illness, and being firm in directing the behavior of the person with AIDS. Thirteen coping items center on the management of the meaning of the situation in order to reduce its threat, such as focusing on the positive things in life, thinking about the present rather than the future, trying to make sense of the illness, and looking for things they always liked or admired in the person with AIDS. Fifteen coping items address potential methods of distress management, such as watching TV, turning to work or other activities, or seeking God's help. The summative index employs a four-point continuum ranging from "used very often" to "never used" ( $\alpha = 0.77$ ).<sup>1</sup>

#### *Mental and physical well-being*

For our analysis we considered two outcome variables of well-being: a global measure of mental well-being, the brief symptom inventory (BSI) (Derogatis, 1992), and a measure of physical well-being (Aneshensel et al., 1995; Pearlin et al., 1990). The BSI is a 53-item index of positive mental symptoms consisting of nine subscales, including measures of depression, anxiety, and other mental disorders. Respondents report the extent to which they experienced each symptom over the previous 7 days. The 5-point continuum ranges from 0 (not at all) to 4 (extremely). The BSI has well documented construct validity with a variety of ethnic groups including Latinos (Acosta, Nguyen, & Yamamoto, 1994) and evidences strong test-retest reliability, and high internal consistency in the present sample ( $\alpha = 0.91$ ). For our analyses we use the BSI's global measure of symptom distress, the global severity index (GSI), which is calculated as the grand mean of all reported symptoms.

Our measure of physical well-being is an eight-item index originally published by Pearlin and colleagues (Pearlin et al., 1990). These items ask respondents about physical conditions or symptoms of illness they experience including headaches, cold and chills, indigestion, backaches, constipation, sudden feeling of weakness or faintness, shortness of breath, and loss of appetite ( $\alpha = 0.80$ ). The five-point continuum ranges from 1 (never experienced), to 5 (experience more than once a week). While a self-report measure of health is less desirable than clinical readings, literature repeatedly indicates that self-report measures correlate highly with objective health outcomes (Kaplan, Barell, & Lusky, 1988).

<sup>1</sup> In addition to self-esteem and coping, we also examined in-home and out-of-home services, and emotional, instrumental, and general support. According to bivariate and multivariate analyses, only coping and self-esteem were related to our measures of well-being, the focus of this paper. Respondents used few services and reported low levels of support.

## Results

### *Respondent background characteristics*

Our sample of 154 was comprised primarily of low socioeconomic status, immigrant women: the mean income level reported by those who knew their income ( $n = 37$ ) was less than \$4000 per year, and 74% were foreign born. Of the 40 (26%) born in the United States, 31 identified themselves as of Mexican descent, 8 as Latina, and 1 as Mexican and Indian. Of those born outside of the United States, 69 (44.8%) were from Mexico; thus, 109 women were of Mexican heritage (71%). Of the 45 others, approximately half were from Honduras, a quarter from El Salvador, and the others were from Guatemala and Nicaragua. Of the total sample, 71% chose to be interviewed in Spanish. Only 16% were high school graduates, and nearly half of the respondents (44%) had completed 8 years or less of formal education. Regarding employment status, only 22% reported that they were holding a job at the time of the interview. Half reported that they had health insurance of some kind including Medicare or Medi-Cal (California's version of Medicaid). The median age of the participants was 33 years, ranging from 16 to 75 years. Most (62%) were married or living with a partner, while 9% were widowed, 14% divorced or separated, and 14% were never married.

Other background factors reveal the health and life style considerations affecting these women. For example, 37% carried the dual status of caregiver and patient. Moreover, the majority, 67.3%, reported that they worry at least a little or more about the existence of HIV-related health issues. Importantly, 82% reported experiencing chronic illnesses such as asthma, high blood pressure and diabetes. In examining relationships with the persons for whom they provided care, we found that approximately a third were caring for their child (36%), and a third for their spouse or partner (32%). Others cared for a sibling (8%), parent (5%), friend (4%), or other relative (15%). Eight (5%) provided care for more than one person with AIDS. The length of time our participants had been AIDS caregivers ranged from 3 months to 14.5 years, with a median of 1 year and 3 months. Of the total, 62.1% endorsed experiencing stressful life events unrelated to caregiving. Most of these were "exit events" involving loss, such as a close friend moving away or separating from a partner.

Because we were interested in examining direct relationships between the two well-being measures and background characteristics, we conducted analyses of variance and correlations. We found no significant relation between the GSI and caregivers' age, education, income or marital status. Regarding physical symptoms, there was likewise no significant relation.

All respondents were asked if they had ever had an HIV antibody test, and if so, what were the results of their most recent test? Of the total, 57 women (37%) reported their most recent test to be positive, while 54 (35%) reported a negative outcome of the test. Forty-two women (27%) had never been tested and said they did not know their serostatus, and one had been tested but preferred not to say what the result was. There were multiple options for how to handle the group that had never been tested and thus did not know their serostatus, as there was a clear possibility that the group contained both seropositive and seronegative women. Preferring not to exclude them in the analyses, and thereby lose almost a third of our data, we decided to analyze this

group separately, and compare the three groups in our analyses.

#### *Differences among serostatus groups*

We conducted ANOVAs, Duncan's multiple range tests and chi-square analyses to examine differences between the three groups with regard to background characteristics, other major study variables and mental and physical well-being. With regard to background variables, some significant differences were found (see Table 1). The three groups were significantly different with regard to age; those caregivers with an unknown serostatus were oldest, followed by the seronegative

Table 1  
Demographic information according to caregiver serostatus

	HIV-negative ( <i>N</i> = 54)	HIV-positive ( <i>N</i> = 57)	Does not know HIV status ( <i>N</i> = 43)	$\chi^2$ , <i>p</i> -value
Mean caregiver age <sup>a</sup>	39.2 (A)	30.1 (B)	44.2 (C)	$p < 0.0001$
Employment status				$\chi^2(2) = 7.06, p < 0.05$
Employed part or full time	30%	11%	28%	
Education <sup>b</sup>				$F(2, 150) = 0.63, ns$
8th grade or less	50%	39%	45%	
9th–11th grade	28%	33%	21%	
High school graduate	13%	18%	19%	
Higher education	9%	11%	14%	
Annual income				$F(2, 133) = 3.76, ns$
Below \$4000	45%	47%	55%	
\$4000–\$7999	18%	22%	15%	
\$8000–11,999	12%	18%	19%	
\$12,000 and above	26%	13%	18%	
Marital status				$\chi^2(6) = 9.01, ns$
Married/live with partner	60%	70%	53%	
Widow	4%	12%	12%	
Divorced/separated	21%	9%	14%	
Never married	15%	9%	21%	
Relationship to PWA <sup>c</sup>				$\chi^2(6) = 35.05, p < 0.001$
Wife/partner	26%	54%	9%	
Mother	35%	35%	37%	
Sister	15%	2%	9%	
Other	24%	9%	44%	
Type of medical insurance				$\chi^2(8) = 33.11, p < 0.001$
None	54%	42%	58%	
Medi-Cal	24%	51%	9%	
Medicare	0%	2%	7%	
HMO	13%	4%	23%	
Other private	9%	2%	2%	
Mean years caring for PWA	2.8a	2.0ab	1.5b	$p < 0.05$

<sup>a</sup> Mean years of age and years caregiving compared using Duncan's multiple range test. Means with the same Duncan grouping (a, b, c) are not significantly different from each other at the  $p < 0.05$  level.

<sup>b</sup> Significant differences in level of education and income were tested using analysis of variance.

<sup>c</sup> PWA = person with AIDS.

group. The women in the seropositive group were significantly younger than those in the other two groups. In addition, HIV-negative caregivers and those with unknown serostatus were more likely to be employed. We also saw differences in the caregiver relationship to the person with AIDS. Just over a third of the women in all three groups were mothers caring for a child. More seropositive women were spouses caring for a husband or partner, while those with an unknown status were more likely to be related to the person with AIDS in some way other than as wife, mother or sister. The three groups also differed with regard to health insurance, with seronegative caregivers and those with an unknown status being slightly more likely to lack health insurance. Relative to the other groups, more of the seropositive caregivers (about half) reported having Medi-Cal. Finally, the groups differed in the length of time that they had been caring for a loved-one with AIDS. The seronegative women reported caregiving significantly longer than the women in the unknown status group (2.8 years versus 1.5 years); the mean for the seropositive women fell in the middle (2.0 years) and was not significantly different from either of the other two groups. The groups did not significantly differ with regard to income, education, marital status, the number of other chronic illnesses they suffered from, or frequency of major life events.

Concerning stressors and mediators, several significant differences were found between groups. For example, the scores reported by seropositive women on three of the stressor and mediating variables differed

significantly from the unknown serostatus group, while the seronegative women's scores were not significantly different from the other two. Specifically, the HIV-positive women reported greater cognitive difficulties concerning the person with AIDS and higher levels of role overload than those with unknown serostatus, as well as greater use of coping strategies. In addition, the seropositive women reported significantly higher levels of role captivity than either of the other groups, who did not differ from each other. The seropositive women did not differ significantly from either of the other groups on their reports of problem behaviors. In two instances, the unknown serostatus group had significantly lower scores than both the seropositive and the seronegative women; namely they reported less loss of self and fewer HIV-related health worries. In one case the seronegative women differed significantly from the women of unknown serostatus: seronegative women reported significantly higher levels of problem behaviors with the person with AIDS. The three groups did not differ from each other in sense of control/mastery or self-esteem.

In examining the levels of well-being among the three groups, several significant differences were found, most frequently between the seropositive and unknown status groups. The women who did not know their HIV status reported significantly less mental and physical symptomatology than the seropositive women, while the seronegative women's scores were not significantly different from either of the other groups (see Table 2). Based on a cut-off score of 0.87 for the GSI (equivalent to a *T*-score of 63), 31% of the women reached levels of

Table 2  
Mean differences<sup>a</sup> by caregivers' HIV status

Measure (theoretic range)	HIV-negative ( <i>N</i> = 54)	HIV-positive ( <i>N</i> = 57)	Does not know HIV status ( <i>N</i> = 43)	Overall <i>p</i> -value
<i>Independent variables</i>				
Other chronic illnesses (0–9)	1.57	1.89	1.84	Ns
Major life events/losses (0–10)	1.11	1.23	1.02	Ns
PWA problem behaviors (1–4)	2.02a	1.91ab	1.69b	<0.05
PWA cognitive difficulties (1–4)	1.61ab	1.65a	1.46b	<0.10
Role overload (1–4)	2.66ab	2.8a	2.51b	<0.10
Role captivity (1–4)	2.06b	2.66a	1.76b	<0.0001
Loss of self (1–4)	1.84a	1.80a	1.49b	<0.10
Sense of control (1–4)	2.48	2.57	2.44	Ns
HIV-related health worries (1–4)	2.35a	2.55a	1.80b	<0.0001
Self esteem (1–4)	3.06	3.07	2.98	Ns
Coping (1–4)	2.76ab	2.88a	2.71b	<0.05
<i>Dependent variables</i>				
BSI general severity index (0–4)	0.71ab	0.83a	0.56b	Ns
BSI depression subscale (0–4)	0.88	0.95	0.66	Ns
Physical symptomatology (1–5)	2.21ab	2.54a	2.08b	<0.05

<sup>a</sup> Means compared using Duncan's multiple range test. Means with the same Duncan grouping (a, b, c) are not significantly different from each other at the  $p < 0.05$  level.

potential psychiatric disorder. Group differences were non-significant

#### *Predictors of mental and physical well-being*

We then conducted a series of regression analyses between major study variables: background characteristics, stressors and mediators, and the two well-being measures. For the few occasions where missing values occurred for predictor variables, we assigned the subsample mean. We first examined the sample as a whole, and then stratified the sample by the caregivers' HIV status. First, bivariate analyses assessed the relationship of each study variable to each of the well-being indicators. For each outcome, all variables which were found to be significant at the  $p < 0.05$  level in the bivariate analyses were included in a multivariate stepwise regression model. Only variables that maintained significance at the  $p < 0.15$  level were retained in the stepwise model. Finally, we conducted simultaneous regression analyses of the models identified in the stepwise regressions; in these models, variables which failed to reach even marginal significance ( $p < 0.10$ ) were dropped. This process produced eight different models: two for the sample as a whole for each measure of well-being, and six subgroup models: one for each group of caregivers, for each indicator of well-being.

Tables 3 and 4 present the results of the two stepwise multivariate regression analyses predicting mental well-being and physical well-being. The most important predictor for both outcome variables among the entire sample was the presence of other chronic illnesses. This variable was positively associated with BSI scores, indicating that women who reported experiencing more chronic illnesses also reported experiencing greater levels of mental symptomatology. Other positive predictors of BSI scores for the group as a whole (and thus predictors of poor mental well-being) were loss of self, poor self-esteem, role captivity, major life events or losses, a younger age, and person with AIDS problem behaviors. This model accounted for 49% of the variance in BSI scores. In addition to non-HIV-related chronic illnesses, predictors of physical symptomatology for the sample as a whole included role overload, a younger age, and loss of self. We noted that the latter two variables were also predictors of mental symptoms. This model accounted for 42% of the variance in physical symptoms.

Sub-sample regression analyses revealed important similarities and differences between caregivers with seropositive status, seronegative status, and those who did not know their serostatus in predictors of both mental and physical well-being (see Tables 3 and 4). For example, in the HIV-positive group, major life events and losses, other chronic illnesses, and person with AIDS cognitive difficulties formed the model in predicting mental symptomatology, accounting for 55% of the

Table 3  
Multivariate regression predicting mental wellbeing

	Standardized beta <i>p</i> -value	
<i>Entire sample (N = 151)</i>		
Other chronic illnesses	0.40	<0.0001
Loss of self	0.22	<0.01
Self esteem	-0.21	<0.001
Role captivity	0.14	<0.05
Major life events/losses	0.14	<0.05
Age	-0.13	<0.05
PWA problem behaviors	0.11	<0.10
$R^2 = 0.49, F(4) = 19.44, p < 0.0001$		
<i>HIV-positive (n = 56)</i>		
Major life events/losses	0.42	<0.0001
Other chronic illnesses	0.35	<0.01
PWA cognitive difficulties	0.20	<0.10
$R^2 = 0.55, F(3) = 21.39, p < 0.0001$		
<i>HIV-negative (n = 52)</i>		
Loss of self	0.34	<0.01
Self esteem	-0.32	<0.01
Other chronic illnesses	0.28	<0.05
PWA problem behaviors	0.25	<0.05
$R^2 = 0.54, F(4) = 13.62, p < 0.0001$		
<i>Does not know HIV status (n = 43)</i>		
Role captivity	0.60	<0.0001
Role overload	0.41	<0.001
Other chronic illnesses	0.35	<0.01
Coping	-0.36	<0.01
HIV-related health worries	0.27	<0.05
$R^2 = 0.64, F(5) = 12.96, p < 0.0001$		

variance. While some similar variables are present in the model predicting BSI scores for HIV-negative caregivers, loss of self and poor self-esteem were included first. Other chronic illnesses, and person with AIDS problem behaviors also enter; the total model accounted for 54% of the variance in BSI scores for seronegative caregivers. A quite different picture appeared for those caregivers who did not know their HIV status. In this group, variables predicting BSI scores included both role captivity and role overload, other chronic illnesses, less frequent coping efforts, and HIV-related health worries. The total model for this group accounted for 64% of the variance in BSI scores.

Turning to predictors of physical symptoms and we again saw both similarities and significant differences between groups. For example, for seropositive caregivers, the model included other chronic illnesses, loss of self, and role overload, accounting for 52% of the variance in physical symptomatology. For seronegative caregivers, only other chronic illnesses and person with AIDS cognitive difficulties comprised the model, the latter variable achieving only borderline significance.



Table 4  
Multivariate regression predicting physical wellbeing

	Standardized beta <i>p</i> -value	
<i>Entire sample (N = 154)</i>		
Other chronic illnesses	0.43	<0.0001
Role overload	0.28	<0.0001
Age	−0.20	<0.01
Loss of self	0.16	<0.05
$R^2 = 0.42, F(4) = 27.39, p < 0.0001$		
<i>HIV-positive (n = 57)</i>		
Other chronic illnesses	0.42	<0.001
Loss of self	0.27	<0.05
Role overload	0.25	<0.05
$R^2 = 0.52, F(3) = 19.19, p < 0.0001$		
<i>HIV-negative (n = 54)</i>		
Other chronic illnesses	0.44	<0.001
PWA cognitive difficulties	0.23	<0.10
$R^2 = 0.33, F(2) = 12.58, p < 0.0001$		
<i>Does not know HIV status (n = 43)</i>		
Role overload	0.52	<0.0001
Role captivity	0.38	<0.01
Other chronic illnesses	0.29	<0.05
HIV-related health worries	−0.24	<0.10
$R^2 = 0.49, F(4) = 9.19, p < 0.0001$		

For those caregivers who did not know their serostatus, we again saw the importance of role strains as predictors; the model comprising role overload, role captivity, other chronic illnesses, and fewer HIV-related health worries accounted for 49% of the variance in physical symptoms.

## Discussion

This study highlights the similarities and differences in predictors of mental and physical well-being for Latina AIDS caregivers of different HIV status. The findings are significant for the design of HIV/AIDS service delivery for this highly underserved group, for they shed light on the daily plight of a highly vulnerable group of low SES women experiencing substantial stress in their role as AIDS caregivers. As well as giving care, many are ill themselves, yet they receive little formal or informal support. As substantiated in the literature, our findings suggest that those who are widowed may be particularly at risk for a poorer health status (Prigerson et al., 1997).

Further, because findings for all three groups reveal the important relationship of other chronic illnesses in predicting both mental and physical symptoms, AIDS service organizations may need to rethink their role in attending to primary health care issues for ethnolinguis-

tic minority caregivers. In our study, 126 of the 154 women reported the presence of other chronic illnesses, with the mean for the entire sample being 1.3 and the range 0–6 illnesses. Of note, there were no significant differences in the number of reported chronic illnesses by HIV status. Clearly, physical symptomatology due to chronic illness other than HIV impacts on caregiving for all of these caregivers. Several of the illnesses such as high blood pressure, heart disease, colitis, and diabetes can be quite debilitating and responsive to stress conditions.

For seropositive caregivers, predictors of mental symptoms depict a depleted caregiving scenario: the presence of major life events, particularly exit events, other chronic illnesses, and patients' cognitive difficulties. For those living with HIV/AIDS, life events and exit events are common, social life is constricted, relationships with partners end, employment becomes more difficult, and there are changes in living arrangements. Further, we infer that a positive serostatus may leave the caregiver more vulnerable to other chronic illnesses that compound an already aggravated health scene. Such a vulnerable caregiving status may make coping with the cognitive difficulties of the person with AIDS particularly stressful.

For seronegative caregivers, the data indicate a need to address the psychological issues of loss of self stemming from the caregiving role, and poor self-esteem, often associated with and compounded by poor mental health. Again, we see the presence of other chronic illnesses in predicting poorer mental health, and the negative impact of handling patient's problem behaviors.

Those caregivers with an unknown serostatus present a slightly different scenario perhaps because this subgroup is somewhat older, and has been caregiving for fewer years than the other two groups. Moreover, nearly half were caregiving for someone other than an immediate family member. While this group appears to have fewer problems, we note that they had similar problems with chronic illnesses, loss, sense of control and self-esteem.

When we turn to the physical well-being of these caregivers, we again find both similarities and differences between groups. While other chronic illnesses predict physical well-being for all groups, it is the strongest predictor where HIV serostatus is known, be it positive or negative. In addition to chronic illness, health-related HIV worries may also influence physical well-being for those with an unknown serostatus. Subjective stressors such as loss of self, and role strains may be important factors in predicting physical symptoms for seropositive caregivers and those with an unknown serostatus. Such findings give credence to stress theory which points to the interaction between the more subjective readings of caregiving stressors and physical sequelae. Distinctly

objective stressors, such as living with a patient's cognitive difficulties, may influence physical symptoms, particularly in seronegative caregivers. Clearly, problems embedded in the caregiving role are implicated in the physical well-being of these caregivers.

Our findings strongly suggest the need for both physical and mental health services, coupled with respite care and other support services for all caregivers. Adequately addressing these needs may prove to be a challenge for some service providers, as poor use of health and social services by Latin groups has been noted (Hu & Snowden, 1992; Land & Hudson, 1997; Talamantes et al., 1995). These low utilization patterns may persist because of lack of knowledge of services, lack of access to them, lack of health insurance, and lack of Spanish-speaking service providers. Importantly, many AIDS service programs lack an adequate understanding of Latino cultural values, community customs, and consequent help-seeking behaviors. While not measured directly in our study, other literature suggests that specific cultural customs, beliefs and attitudes make substantial contributions to decisions to seek help (Cox & Monk, 1993, 1996). The inclusion of these values in care provision may very well increase service use and adherence (Lockerly, 1991; Talamantes et al., 1995).

The challenge of meeting the service needs of the HIV-infected and their caregivers has changed dramatically over the past decade. Yet often, models of service delivery attendant to social and mental health needs fail to take into account the changing face of AIDS. Now seen more frequently in Latin groups, AIDS is no longer considered a death sentence. Rather, AIDS is increasingly defined as a chronic illness requiring in-home care, management of, and adherence to the complex regimen associated with combination therapies. These data present an alarming picture of the stresses experienced by low income, Latina women who shoulder the burden of providing this care. Services designed with gender and cultural sensitivity to Latin groups are greatly needed in order to curtail the predictable stress process experienced by the growing body of Latina AIDS caregivers. Furthermore, programs and services must meet the needs of the HIV-infected, many of whom are themselves caregivers.

There are several considerations which may limit the conclusions that can be drawn from these results. All variables were created from self-report measures. The data are cross-sectional, and therefore, the direction of causality we propose is inferred but not demonstrated. The sample size is fairly modest, which limits the statistical power of some analyses. Finally, the sample was drawn from a group who, as previously noted, had already accessed at least some services. These were all women of Latin descent, primarily low income immigrants, living in a major metropolitan area in the United States. The results thus may not be generalizable to

males or to women of other ethnic groups or backgrounds. In spite of these limitations, the data and the critical situation they document are compelling.

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