

Delays in Seeking HIV Care Due to Competing Caregiver Responsibilities

ABSTRACT

Objectives. This study sought to describe the characteristics of HIV-infected persons who delay medical care for themselves because they are caring for others.

Methods. HIV-infected adults ($n=2864$) enrolled in the HIV Cost and Services Utilization Study (1996–1997) were interviewed.

Results. The odds were 1.6 times greater for women than for men to put off care (95% confidence interval [CI]=1.2, 2.2); persons without insurance and with CD4 cell counts above 500 were also significantly more likely to put off care. Having a child in the household was associated with putting off care (odds ratio [OR]=1.8, 95% CI=1.4, 2.3).

Conclusions. Women or individuals with a child in the household should be offered services that might allow them to avoid delays in seeking their own medical care. (*Am J Public Health.* 2000;90:1138–1140)

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In the 1990s, women constituted one of the fastest-growing groups with newly diagnosed AIDS cases, and HIV disease remains the leading cause of death among women of reproductive age.^{1,2} Across studies, women have been less likely to receive antiretroviral therapy than men even after control for transmission risk group and race.^{3–5} One factor that may influence access to care is the caregiving role women often play.⁶ Women with AIDS (and less often men) may have children, HIV-infected relatives, or partners who require care. In this article, we describe the characteristics of HIV-infected persons who delay medical care for themselves because they are caring for others.

Methods

The HIV Cost and Services Utilization Study, which involved a multistage design, sampled geographical areas, medical providers, and patients 18 years or older with known HIV infection who made at least one visit for regular or ongoing care to a non-military, nonprison medical provider other than an emergency department. Computer-assisted personal interviewing instruments were used in conducting interviews, which took place between January 1996 and April 1997. Full details of the design have been published elsewhere.^{7–11}

The outcome in this analysis, delay in care due to caregiving, was a positive response to the following question: “In the last 6 months, have you ever put off going to the doctor for HIV care because taking care of someone else was more important to you?”

Independent variables included were sex, insurance, race, transmission risk group, education, and self-reported lowest CD4 cell count.¹² As a means of defining household composition, subjects were asked “Besides yourself, have any of the people in your household also been diagnosed with HIV or AIDS?” Subjects were also asked the ages of all children living with them.

Multiple logistic regression analyses were performed to determine independent associations between putting off care and sociodemographic, clinical, and household composition variables.

Results

Forty-five percent of women, in comparison with 6% of men, were living with children younger than 17 years (Table 1). Nearly equal proportions of men and women lived with another HIV-positive person.

Fourteen percent of women and 8% of men reported delaying care as a result of caregiving in the previous 6 months ($P=.001$). Those without private insurance and those with higher CD4 cell counts were more likely to report delaying care. Subjects with another HIV-positive person living in the household and those living with children younger than 17 years were more likely to report delaying care for themselves.

We used a series of logistic regression models to determine factors associated with putting off care as a result of caregiving (Table 2). In the first model, we found that the odds of putting off care were 1.7 times greater (95% confidence interval [CI]=1.1, 2.3) for women than for men. In addition, we found that the odds of putting off care were 2.2 times greater for subjects without insur-

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TABLE 1—Population Characteristics (n = 2864) and Percentages of Respondents Putting Off Care: HIV Cost and Services Utilization Study, 1996–1997

Characteristic	Sample, %	Putting Off Care, %
Sex		
Male	77	8*
Female	23	14
Race/ethnicity		
White	49	8*
Black	33	11
Hispanic	15	9
Other	3	16
Exposure/risk		
MSM	49	7
Injection drug use	24	12
Heterosexual	18	10
Other	9	12
Education		
High school	52	9
Some college or more	48	9
Insurance		
Private	32	5*
Public	48	11
None	20	11
CD4 cell count		
>500	10	14*
200–499	37	10
50–199	30	8
0–49	24	7
HIV-positive persons in household		
Yes	19	14*
No	81	8
Children younger than 17 years living in household		
Yes	15	16*
No	85	8

Note. The represented population was 231 400. For population sizes of subgroups, see Bozzette.¹⁷ MSM = men who have sex with men.

* $P < .01$.

ance and those with public insurance than for privately insured persons.

When we added disease stage (CD4 cell count), the sex effect remained (model 2). The odds were 2 times greater for persons with CD4 cell counts above 500 than for persons with CD4 cell counts below 50 to put off care. Subjects who did not complete high school were less likely than college-educated subjects to put off care.

When having an HIV-positive person in the household was included (model 3), the odds were 1.6 times greater for women than for men to report putting off care owing to caregiving. The odds of delaying care were 1.8 times greater for persons living with an HIV-positive person.

When we included having a child in the household (model 4), the odds were 1.3 times greater for women to report delaying care, but the sex effect was no longer statistically significant ($P = .32$). Other variables—lack of insurance, public insurance, education, and higher CD4 cell counts—remained significantly associated with putting

off care. Having a child in the household was significantly associated with putting off care; the odds ratio was 1.8.

Discussion

We found that being female and having a child in the household were both predictors of delaying care owing to caregiving; because women were more likely to have children in the household, however, the latter effect predominantly applies to them. Women, historically the providers of care at home for the elderly, constitute 70% to 75% of informal caregivers.⁶ Among American women with HIV or AIDS, more than half have children 16 years or younger for whom they are often the primary providers of economic and social support.^{13,14}

With the shift in locus of care from the hospital to the community, families and sexual partners have increasing responsibility for providing care to HIV-infected individuals. In extended families, HIV-infected

women may be caring for another HIV-infected adult or child. Men with HIV disease may also serve as primary caregivers, particularly for other HIV-infected men; in the HIV Cost and Services Utilization Study, 18% of men reported living with another HIV-positive person.¹⁵

We found that subjects living with an HIV-positive person were nearly twice as likely to put off their own care as subjects who did not live with another seropositive person. The extent to which partners and friends provide care may have been underestimated here; caregivers may also live apart from those for whom they care.^{16,17} Caregiving in the case of HIV disease is untraditional in several ways.¹⁵ For example, caregivers tend to be young. Also, caregivers may have the same disease as the care recipient, leading to psychological distress, strained relations, and financial difficulties.¹⁷

Subjects with high CD4 cell counts reported putting off care as a result of caregiving more often than subjects with low CD4 cell counts. We speculate that persons with early stage disease are less concerned about serious, acute HIV-related illness. Yet, the opportunity for timely initiation of antiretroviral therapy, preventing viral replication, could be lost if care is delayed.¹⁸

Subjects with private insurance were less likely to report putting off care than other subjects, perhaps owing to the economic ability of the privately insured to locate and hire other caregivers during those times when they need care themselves. Persons at higher education levels may delay seeking care because they are more confident in their self-care skills.

Our analysis was restricted to US adults receiving care. We tested 2 measures of caregiving, having an HIV-positive person in the household and having a child younger than 17 years in the household. There may be other measures, however, and we do not know the precise ages of children in the household, whether they were HIV infected, or the amount of time spent caregiving. Some persons in our cohort may have had both a child younger than 17 years in their household and one or several HIV-positive adults needing care. Also, having a child in the household does not necessarily imply that caregiving is taking place.

Furthermore, our data were based on self-report; men and women may differ in their interpretation of “putting off care.” Our outcome measure may be a convenient explanation for not seeking care as opposed to being a real barrier to care. Finally, we do not know whether this reported delay in seeking care translates to poorer health outcomes.

TABLE 2—Odds Ratios for Putting Off Care: HIV Cost and Services Utilization Study, 1996–1997

Characteristic	Odds Ratio (95% Confidence Interval)			
	Model 1	Model 2	Model 3	Model 4
Women	1.7 (1.2, 2.4)**	1.6 (1.2, 2.2)**	1.6 (1.2, 2.2)**	1.3 (0.8, 1.8)
No insurance	2.2 (1.3, 3.5)**	2.1 (1.3, 3.3)**	2.1 (1.3, 3.4)**	2.2 (1.3, 3.4)**
Public insurance ^a	2.2 (1.3, 3.7)**	2.4 (1.4, 4.1)**	2.4 (1.4, 4.2)**	2.3 (1.4, 3.9)**
Black ^b	1.0 (0.8, 1.4)	0.9 (0.7, 1.4)	1.0 (0.7, 1.4)	0.9 (0.7, 1.3)
Hispanic ^b	1.0 (0.7, 1.5)	1.0 (0.7, 1.5)	1.0 (0.7, 1.5)	0.9 (0.7, 1.5)
IDU ^c	1.0 (0.6, 1.7)	1.1 (0.6, 1.7)	1.1 (0.7, 1.8)	1.1 (0.7, 1.8)
High school or less ^d	0.7 (0.5, 1.0)	0.7 (0.5, 0.9)*	0.7 (0.5, 0.9)*	0.7 (0.5, 0.9)*
CD4 cell count >500 ^e	...	2.0 (1.3, 2.9)*	2.0 (1.4, 2.9)*	1.9 (1.3, 2.8)*
HIV positive persons in household	1.8 (1.4, 2.3)*	...
Child in household	1.8 (1.2, 2.6)**
Log-likelihood	−844	−839	−831	−834

Note. All variables included in each model are shown.

^aReference: private insurance.

^bReference: White.

^cReference: no history of injection drug use.

^dReference: college or more.

^eReference: CD4 cell count below 50.

* $P < .05$; ** $P < .01$.

Our findings emphasize the need for supportive services for HIV-infected women. The offer of free on-site child care in a medical setting resulted in a reduction in the number of missed visits for women in one study.¹⁹ Information about low-cost available child-care assistance services should be distributed by providers; the caregiving burden is likely to be moderated by the availability of resources for coping. Of course, women actively using illicit drugs may be reluctant to seek child-care assistance services for fear of losing custody of their children.²⁰

Persons living with AIDS often act as family caregivers. In medical and community-based settings, caregivers must be asked about their own needs and provided with services that allow them to avoid delay in seeking their own medical care. □

Contributors

All of the authors developed the instruments, reviewed the data, and wrote and edited the manuscript.

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