Caregiver Burden and Depression Among Informal Caregivers of HIV-infected Individuals

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BACKGROUND: Few studies have examined the factors associated with depression in informal caregivers of HIV-infected persons.

OBJECTIVE: To investigate the relationship between depression and caregiver burden among informal caregivers of HIV-infected individuals.

DESIGN: Cross-sectional study using baseline data from an ongoing randomized trial of a supportive telephone intervention.

PARTICIPANTS: One hundred seventy-six dyads of HIV patients and their informal caregiver.

MEASUREMENTS: Depression was defined as a Beck Depression Inventory >10. A Caregiver Strain Index >6 identified informal caregivers with a high caregiver burden. We used logistic regression to identify characteristics that were associated with depression in the informal caregiver.

RESULTS: Informal caregivers were 42 years old (SD, 13), 53% female, 59% nonwhite, and 30% had education beyond high school. Forty-seven percent of informal caregivers were the patient's partner, 18% a friend, and 35% a family member. Twenty-seven percent of informal caregivers had a high caregiver burden, and 50% were depressed. We found significantly greater odds of informal caregiver depression with high caregiver burden (OR, 6.08; 95% CI, 2.40 to 15.4), informal caregiver medical comorbidity besides HIV (OR, 2.32; 95% CI, 1.09 to 4.92), spending all day together (OR, 3.92; 95% CI, 1.59 to 9.69), having to help others besides the HIV patient (OR, 2.55; 95% CI, 1.14 to 5.74), and duration of the HIV patient's diagnosis (OR, 1.01 per month; 95% CI, 1.00 to 1.01).

CONCLUSIONS: High caregiver burden was strongly associated with depression among HIV-infected individuals' informal caregivers, who themselves had difficult life circumstances. Informal caregivers of HIV patients may be in need of both mental health services and assistance in caregiving.

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There has been increasing focus on the role of the caregiver of those with HIV.[1,2] However, relatively few studies have examined the factors associated with depression in the caregivers of HIV-infected persons. The description of depression among caregivers can help to identify a condition that is treatable and may also have repercussions with respect to the well-being of the HIV patient.

Previous work among caregivers for those with HIV or AIDS has illustrated that the burdens of caregiving are of great concern.[3] Caregiver burden, which is the negative impact of caregiving on the caregiver's life, has been associated with depressive symptoms[4,5] and suicidal ideation.[6] The work describing this relationship has focused on the caregiving provided by gay or bisexual men to gay or bisexual men, often with advanced HIV disease. We sought to expand these findings by investigating how the burden of caregiving relates to depression among the informal caregivers of HIV-infected individuals in an urban cohort that included men and women as well as heterosexuals and homosexuals. We hypothesized that caregiver burden would be related to depression in our heterogeneous population of informal caregivers of HIV-infected individuals.

METHODS

The source of data was an ongoing Institutional Review Board–approved randomized trial of a supportive psychoeducational telephone intervention for HIV-infected patients and their informal caregivers. Between February 2001 and January 2004, research staff approached consecutive patients awaiting their medical visit at the two Brown University AIDS Program clinical sites and informed them about a 12-month study for HIV patients and their families. During this initial screen, individuals were also asked to identify their "HIV-support person"; we will herein refer to this person as the HIV patient's informal caregiver. Interested individuals were screened to assess full eligibility for the study, which included: 18 years of age or older, English or Spanish speaking, regular access to a telephone, no plans to leave the area in the next 12 months, and competency to sign an informed consent form and participate in the research interview. If the patient qualified for the study, the patient and their informal caregiver were invited for individual face-to-face baseline interviews. During these interviews, after providing informed consent, participants were asked about HIV-related medical experiences, depression, family functioning, substance use, and social relationships. HIV patients and their informal caregivers were interviewed individually. Baseline data were used for this study.

Depression

The primary variable of interest was depression in the informal caregivers as measured by the Beck Depression Inventory (BDI).[7] The BDI is a 21-question survey that asks respondents

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to rate how they have felt over the preceding week. Scores can range from 0 to 63, with a higher score reflecting a greater burden and severity of symptoms. The BDI has been widely used, and its internal consistency and content validity are high.[8] Those with a BDI score of less than 10 are unlikely to have clinically diagnosed depression.[9] As our interest was in identifying features associated with depression, we applied this threshold to our sample. Herein, we refer to those with a BDI score of 10 or greater as depressed, using this term as a label for simplicity; we do not mean to imply it is a clinical diagnosis.

Caregiver Burden

The burden of caregiving on the informal caregiver was assessed using the Caregiver Strain Index (CSI),[10] a 13-item instrument that measures the burden of caregiving. Scores can range from 0 to 13; a higher CSI score indicates a greater burden of caregiving. Among the items of the CSI are queries about whether caregiving disturbs sleep, is inconvenient, is confining, changes personal plans, and is a financial strain. The CSI was developed through interviews with patients and caregivers. The Cronbach's α for the CSI is 0.86, and its validity has been demonstrated.[10,11] We sought to identify those informal caregivers who reported a high degree of caregiving burden. We used a CSI of greater than 6 to denote a high degree of caregiving burden; this cutoff has been used previously among caregivers of stroke patients.[12,13]

Caregiver Characteristics

In addition to these measures, we examined the informal caregiver's age, gender, marital status, race/ethnicity, presence of any medical illness other than HIV, HIV status, binge alcohol and illicit substance abuse, and education. We dichotomized marital status into married/partnered or not. We categorized race into white, African American, or other. Self-reported illicit drug use included any use in the previous 6 months of marijuana or hash, inhaled nitrates, cocaine, amphetamines, hallucinogens, tranquilizers not prescribed by a physician, sedatives, ecstasy, heroin, or any other noninjectable drug used to get high. Binge alcohol use was defined as self-reported 1-day alcohol intake of 5 or more drinks in men or 3 or more in women within the previous 6 months. Education was dichotomized as through high school or greater than high school. While we did not collect data on income, we used as a proxy for poverty an affirmative response to the query as to whether "there was a time [in the past 6 months] when you did not have enough money to pay for things you needed to live, like food."

Relationship Between the HIV Patient and Informal Caregiver

We examined a number of characteristics of the relationship between the informal caregiver and HIV patient; these were categorized as follows. The type of relationship to the HIV patient was classified as partner, friend, or other. We divided the duration of the relationship into less than 5 years, 5 to 20 years, and greater than 20 years. The time per day spent together was divided into less than 6 hours a day, 6 to 18 hours a day, and all day. For the living situation of the HIV patient and their informal caregiver, we divided this into whether the patient and informal caregiver lived together at the time of participation in the study, and if they did, whether this predated the patient's HIV diagnosis or came after it. We also examined some elements directly related to caregiving as part of the relationship between the HIV patient and informal caregiver. This included whether the informal caregiver attended none, some, or all of the HIV patient's medical appointments and whether the informal caregiver reported having others besides the HIV patient who needed their help.

HIV Patient Characteristics

In addition to factors pertaining directly to the informal caregiver, HIV patient factors such as duration of HIV diagnosis, number of symptoms related to HIV, presence of any AIDS-defining condition, CD4 count (obtained from the patient's medical record with the patient's consent), frequent medical utilization (defined as more than 6 outpatient visits or more than 2 emergency room visits in the prior 6 months), and HIV patient depression ($\text{BDI} \geq 10$) were also considered. Other information about the HIV patient for analysis included age, gender, whether the patient had recently used illicit drugs or had binge alcohol use in the previous 6 months, education beyond high school, the presence of any other comorbid medical illness, and depression ($\text{BDI} \geq 10$); all of these were defined in the same fashion as described above for the informal caregiver.

Statistical Analysis

The unit of analysis was the dyad of HIV patient and informal caregiver. We employed χ^2 analysis and t tests to examine the relationship between informal caregiver depression and each characteristic of the informal caregiver, the relationship between informal caregiver and HIV patient, and that of the HIV patient. We then constructed a multiple logistic regression model to determine the adjusted odds of depression. The model included recognized risk factors for depression in the general population: female gender,[14,15] unmarried,[15] comorbid medical illness,[16] and substance abuse.[15,17] We also entered any factors found to be significant at $P<.05$ in the χ^2 or t test analyses. The one exception was the employment status of the HIV patient and of the informal caregiver due to the strong relationship of these to the amount of time the dyad spent together. We were interested in characteristics of the dyad, so we chose to exclude HIV patient and informal caregiver employment status in favor of time spent together. Because of the potential collinearity among the components of the model, we examined the variance inflation factor for each covariate as well as the condition index for all covariates.

All analyses were performed using SAS (SAS Institute, Cary, NC).

RESULTS

In total, 415 HIV patients were approached for participation. Eighty-six refused, 6 spoke languages other than English or Spanish, 35 did not have telephones, 89 could not identify an HIV support person, 6 had plans to move, and 17 were cognitively impaired, resulting in the 176 dyads included in this analysis. Study refusers were not significantly different from enrollees in ethnicity or gender.

Nearly a quarter of all informal caregivers were themselves HIV positive, and nearly half had either used an illicit

Table 1. Characteristics of Informal Caregivers Divided by Those with BDI Less Than 10 Versus 10 or Greater

Characteristic	No Depression (BDI < 10) n=88	Depression (BDI ≥ 10) n=88	P Value
Mean age, y (± SD)	41.2 ± 13.9	43.0 ± 12.3	.35
Female, %	45.4	48.9	.65
Race, %			.93
White	39.8	42.1	
African-American	28.4	26.1	
Other	31.8	31.8	
Partnered/married, %	43.2	43.2	1.0
Post–high school education, %	31.8	28.4	.62
Reports not enough money, %	42.1	62.5	<.01
Any medical illness besides HIV, %	50.0	68.2	.01
HIV+, %	21.6	22.7	.86
Illicit drug use, %	25.0	40.9	.02
Binge alcohol use, %	20.4	33.0	.06
High caregiver burden (CSI > 6), %	10.2	43.2	<.001

BDI, Beck Depression Index; CSI, Caregiver Strain Index.

drug or engaged in binge alcohol drinking recently. The mean BDI score for informal caregivers was 11.4 (SD, 9.5). The characteristics of the informal caregivers categorized by the BDI threshold of 10 are displayed in Table 1. Of note, informal caregivers with a BDI score of 10 or greater reported significantly more frequent lack of money for necessities, medical illness (except HIV), and illicit drug use. Those with a BDI at or above the threshold of 10 also had an elevated caregiver burden (CSI >6).

Elements of the relationship between the informal caregiver and the HIV patient are shown in Table 2. Of all these characteristics, only 2 were significantly associated with informal caregiver depression. Informal caregivers with depression more commonly spent all day with the patient ($P<.01$), and more frequently reported having to help another person besides the HIV patient ($P<.01$).

The patient's HIV-specific disease characteristics illustrate the relatively low acuity of HIV disease among the HIV patients. The most recent CD4 count was 401 per cubic millimeter (SD, 328). One third of HIV patients reported having had an AIDS-defining illness. Frequent medical utilization was reported by 39.1% of HIV patients. Of the patient's HIV-specific disease characteristics, only the duration of the HIV patient's diagnosis was significantly associated with depression in the informal caregiver. Among informal caregivers without depression, the mean duration of the HIV patient's diagnosis was 92 months (SD, 76), while among informal caregivers with depression, it was 118 months (SD, 62) ($P<.05$).

HIV patients were 41 years old (SD, 8) and 46% were female. In the preceding 6 months, 48% had used an illicit drug and 24% had binge use of alcohol. Twenty-six percent had received education beyond high school. The presence of another comorbid medical illness besides HIV was reported in 66% of patients. Depression (BDI ≥10) was present in 69% of HIV patients. None of these was related to depression in the informal caregiver.

The final multiple logistic regression model included gender, marital status, presence of medical comorbidity, caregiver burden (CSI >6), illicit drug use, not enough money for ne-

Table 2. Characteristics of Relationship Between Informal Caregiver and HIV Patient

Characteristic	No Depression (BDI < 10) n=88	Depression (BDI ≥ 10) n=88	P Value
Informal caregiver is patient's, %			.36
Partner	42.0	52.5	
Friend	18.2	17.0	
All other	39.8	30.7	
Living situation, %			.22
Not together	44.7	32.2	
Predates patient's HIV	30.6	40.2	
After patient's HIV	24.7	27.6	
Duration of knowing each other, %			.58
>20 years	45.4	43.2	
5–20 years	27.3	34.1	
<5 years	27.3	22.7	
Time spent together per day, %			<.001
All day	23.9	53.4	
6–18 hours	34.1	23.9	
<6 hours	42.0	22.7	
Attends medical appointments, %			.20
All	29.5	29.5	
Some	27.3	38.6	
None	43.2	31.8	
Others need help besides HIV patient, %	28.4	46.6	.01

BDI, Beck Depression Index; CSI, Caregiver Strain Index.

Table 3. Adjusted Odds of Informal Caregiver BDI $\geq$ 10 for Final Logistic Model

Characteristic	Adjusted Odds Ratio	95% Confidence Interval
Female	0.84	0.38 to 1.82
Not partnered	0.88	0.42 to 1.90
Any medical illness besides HIV	2.32	1.09 to 4.92
High caregiver burden (CSI > 6)	6.08	2.40 to 15.4
Illicit drug use	2.34	0.99 to 5.52
Not enough money	1.34	0.64 to 2.83
All day together*	3.92	1.59 to 9.69
< 6 hours a day together*	1.17	0.48 to 2.90
Has others that need help	2.55	1.14 to 5.74
Months since HIV diagnosis (per month)	1.01	1.00 to 1.01

**Referent: 6 to 18 hours per day.*

BDI, Beck Depression Index; CSI, Caregiver Strain Index.

cessities, amount of time spent together per day, having others besides the HIV patient who need their help, and duration of the HIV patient's diagnosis. The results of this model are shown in Table 3. High caregiver burden, medical comorbidity besides HIV in the informal caregiver, spending all day together (compared to 6 to 18 hours a day), having others besides the HIV patient who need their help, and duration of the HIV patient's diagnosis were associated with significantly greater odds of depression in the informal caregiver. Of note, for duration of HIV patient's diagnosis, the adjusted odds of depression increased by 1% per month. The c-statistic for the logistic model was 0.81, which demonstrates good discrimination of the model.[18] The variance inflation factors for the model covariates ranged from 1.06 to 1.49 and the maximum condition index was 9.2, indicating that collinearity was not a concern. In addition, we found no significant interactions among the final model covariates.

DISCUSSION

We found that the burden of caregiving was strongly and independently associated with depression in the informal caregiver of HIV-infected individuals. In addition, medical comorbidity besides HIV in the informal caregiver, illicit drug use by the informal caregiver, having others to help besides the HIV patient, spending all day together, and duration of the HIV patient's diagnosis were also associated with greater depression in the informal caregiver. Of all other characteristics of the informal caregiver, of the relationship between the informal caregiver and HIV patient, or of the HIV patient, none was independently associated with depression in the informal caregiver.

Previous work has reported that depression is common among caregivers of those with other diseases. For instance, among caregivers of demented patients, more hours spent on caregiving was associated with depression in the caregiver.[19] A study of the adult daughter caregivers of cancer patients found that sociodemographic variables and caregiver burden were associated with depressive symptomatology.[20] Another study of caregivers of cancer patients reported that poor quality of their relationship with the care receiver, initial depression, and loss of physical strength were related to depression.[21] While the association of depression with medical comorbidity and with illicit drug use has been described in the general population, these may represent aspects of the informal caregiver's life that complicate their caregiver role. Depression may also be the result of concrete aspects of care, which would be consistent with our finding that the amount of time spent with the HIV patient per day and caregiving responsibilities for those besides the HIV patient were associated with informal caregiver depression.

Our findings add to the body of literature regarding caregivers of those living with HIV, particularly toward extending the observation of an association of depression and caregiver burden to a population that also included women and heterosexuals. A study of HIV-positive homosexual men who were caregivers for an HIV-infected individual found that role overload, which the authors equated to care burden, was one of the baseline variables most strongly associated with depressive symptoms.[4] In contrast with other reports,[5,22] we did not find that the HIV status of the caregiver was associated with depression. However, our finding of the association between depression and caregiver burden was similar to the HIV-negative caregivers in both studies.[5,22] In a study that, in contrast to ours, focused on more severe psychopathology in a population caring for sicker patients, Rosengard and Folkman found that suicidal ideation was related to caregiving burden in partners of men with AIDS.[6]

The HIV patients in these previous studies of caregiver burden were generally more compromised than those in our cohort. We found that, with the exception of duration of HIV diagnosis, patient indices were not associated with the informal caregiver's depression. The addition of factors such as the duration of the HIV patient's diagnosis or whether the HIV patient had an AIDS-defining illness to the final multivariable model did not change the point estimate for caregiver burden, so that the relationship between depression and caregiver burden appears to be unaffected by HIV severity. The burden of care may be related to the medical comorbidity and social disadvantages common among HIV patients and their informal caregivers.

Limitations of our work should be acknowledged. Although higher BDI scores are strongly correlated with clinical depression,[9] it would have been ideal to have a clinical diagnosis of depression. We used a BDI score of 10 or greater to represent symptomatology consistent with depression, and we reiterate that the use of the term depression throughout was to represent this concept and did not reflect a clinical diagnosis of depression. We report on data collected at baseline from a randomized trial, so our information is cross-sectional. Therefore, we are unable to discern a causal relationship that suggests caregiver burden leads to depression or the converse. As the data are from a trial of a supportive telephone intervention, a selection bias may have occurred in that those who participated did so because of the possibility of receiving an intervention that they felt they needed. Much of the information in our study was self-reported, reflecting the experience of the informal caregiver, and therefore it would be difficult, if not impossible, to obtain this information through any other method. In addition, we did not know the informal caregiver's history of depression. Lastly, ours was not a random sample of HIV patients and their informal caregivers, but the study population is demographically similar to the full Brown AIDS Program population, and we feel it is therefore representative of HIV population of southern New England.

Knowing the factors associated with depression in an HIV patient's informal caregiver helps to identify a person who, in their caregiver role, may neglect self-care and would potentially benefit from treatment. It is also important to be aware of caregiver burden, as this is a concern of the caregiver that has implications for the well-being of the HIV patient. We did not assess the quality of the care the informal caregiver provided to the HIV patients. Therefore, we cannot conclude that the caregiving by informal caregivers with depression is of worse quality than by those without depression, but this is certainly plausible. The high rates of poverty, drug and alcohol use, HIV, and medical illness all may act to further erode the ability of the informal caregiver to act as a supportive caregiver and make them particularly susceptible to the burdens of care. Our finding that depression and caregiver burden are strongly related indicates that there is a distinct population that may be in need, both of mental health services and of assistance in caregiving.

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