SELF-REPORTED LEGAL NEEDS OF WOMEN WITH OR AT RISK FOR HIV INFECTION

PAULA DISTABILE, MSN, JD, NANCY N. DUBLER, LLB,
LIZA SOLOMON, DRPH, AND ROBERT S. KLEIN, MD,
FOR THE HER STUDY GROUP*

ABSTRACT Women at risk for human immunodeficiency virus (HIV) infection are often poor and members of racial or ethnic minorities. In addition to legal concerns that might be common among persons with similar sociodemographic characteristics, HIV infection adds the potential of possible stigma and discrimination, as well as the prospect of illness and increased mortality. To determine women's perceptions of need for and access to legal services and whether such perceptions are affected by HIV infection, from November 1993 through September 1995 we interviewed 509 women with or at risk for HIV infection by virtue of injection drug use or high-risk sexual behaviors in New York and Baltimore, Maryland. A majority of women, regardless of HIV serostatus, reported current or future needs for legal assistance with government benefits. More than 25% reported needing current or future legal help with housing, debts, arrangements for care of children, a will, and advance directives. Substantial minorities of women reported other legal needs. HIV-positive women were significantly more likely to report anticipated future need for help with paternal custody or visitation, current need in making a will, and anticipated future assistance with advance directives. For most items, a majority of women thought they knew where to receive help. However, among women reporting a current need, only a minority actually were receiving legal assistance. This study suggests that the extent of legal needs among women with or at risk for HIV infection is substantial, and that few

*Members of the HER Study group are listed in the Appendix.

Drs. DiStabile and Klein and Ms. Dubler are from the Department of Epidemiology and Social Medicine, and Dr. Klein is from the Department of Medicine, Montefiore Medical Center and Albert Einstein College of Medicine, Bronx, New York; and Dr. Solomon is from the School of Hygiene and Public Health, Johns Hopkins University, Baltimore, Maryland.

Correspondence and reprints: Robert S. Klein, MD, Professor of Medicine, Montefiore Medical Center, 111 East 210th Street, Bronx, NY 10467. (E-mail: RKlein@montefiore.org)

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receive legal assistance. With few exceptions, at least for women early in the course of illness, HIV infection does not appear to alter the pattern or extent of legal needs. There are dramatic differences, regardless of HIV status, between expectation and reality in women's access to legal services.

KEY WORDS Demography, Drug Users, Knowledge, Legal, Women.

Serious illness may have legal implications, to the extent that it interferes with the ability to work, manage finances, and maintain health insurance and housing; it brings to the forefront needs related to advance directives, estate planning, and planning for the future care of dependents. Gender, poverty, and racism generate legal needs related to discrimination, denial or termination of government benefits and entitlements, finding or maintaining adequate housing, health care and substance abuse treatment, coping with divorce, domestic violence, child custody disputes, and involvement with the child welfare and foster care systems.^{1,2} Human immunodeficiency virus (HIV) infection casts a special overlay on these common legal issues. Although women with HIV infection share many of the legal problems confronting infected men, women shoulder different burdens related to their gender roles in society and in the family.³⁻⁵

Service providers have described the typical legal needs of individuals with HIV infection.⁵⁻¹⁹ However, little is known about the impact of HIV seropositivity on women's perceptions of their legal needs and their perceived access to legal services. The HIV Epidemiology Research Study (HERS), an ongoing study of a cohort of women with or at risk for HIV infection,²⁰ provided the opportunity to study the self-reported legal needs of such women. We report the results of a substudy designed to describe the pattern and scope of legal needs as identified by women with or at risk for HIV infection.

MATERIALS AND METHODS

HERS is a collaborative multicenter (New York City; Providence, RI; Baltimore, MD; Detroit, MI) study that enrolled 871 HIV-seropositive and 439 HIV-seronegative at-risk women in a prospective study of HIV infection. Women at risk through injection drug use (since 1985) or sex (with an at-risk male, in exchange for drugs or money, or with more than five partners within 5 years) were enrolled and evaluated every 6 months. Study design and characteristics of participants have been reported previously.²⁰ By design, approximately one-half of participants were at risk for HIV through drug use and one-half through sexual behaviors, and HIV-seropositive and HIV-seronegative women were enrolled at a ratio of 2:1. All subjects provided informed written consent, and the study was approved

by the Institutional Review Boards for the Protection of Human Subjects at each of the participating medical centers.

Evaluations consisted of an interview regarding sociodemographics; general medical and health history; obstetric, gynecologic, and contraceptive history; drug use and sexual behaviors; health care utilization; and psychosocial measures. General physical and pelvic examinations were performed, blood specimens were obtained for HIV antibody testing (enzyme immunoassay with confirmation by Western blot) and T-cell subsets, and other laboratory tests were done.

To determine participants' perceptions of their needs for legal services and their knowledge of how to access such services, a substudy was performed at the New York and Baltimore sites. Both of these sites had recruited from the community. At their second study visit, women were asked to participate in an additional interview module, which had been developed, piloted, and revised in consultation with nonparticipating women with or at risk for HIV infection and administered as part of the overall HERS interview. For each of 22 specific, simply phrased questions related to personal entitlements, relations with a sexual partner, children, or health issues, women were asked (in their choice of English or Spanish) whether they had a current need for legal assistance, anticipated a need in the future, were currently receiving help, and knew where to seek help. Open-ended questions about additional legal needs were included.

Categorical variables were analyzed using chi-square or Fisher exact test when appropriate; continuous variables were analyzed by analysis of variance or the Kruskal-Wallis test. Findings were considered significant statistically at the $P \leq .05$ level. All tests were two tailed. Odds ratios (ORs) and 95% confidence intervals (95% CIs) were calculated.

RESULTS

Of 568 women completing a second HERS visit at the New York or Baltimore sites, 509 women (90%) participated in the legal needs substudy from November 16, 1993, through September 12, 1995, with 248 (49%) from New York and 261 (51%) from Baltimore. The median age was 36 years. More than two-thirds of the women were African-American; about one-fifth were Latina. Slightly more than one-half had completed high school. Less than one-fifth were employed. Approximately one-half of the women drank alcohol, and a similar proportion had used cocaine or heroin in the 6 months prior to interview. One-half reported that they had inadequate money at some point in the last 6 months, and 15% had been homeless at some time in that period. Three-quarters of the women reported that they had someone close to them who had HIV infection, and more

than one-half had someone close die of acquired immunodeficiency syndrome (AIDS).

Despite some differences between the two sites in the characteristics of the women studied, HIV-seropositive and HIV-seronegative women at each site were similar in most demographic and behavioral characteristics. There were significant differences by HIV status in distribution of race ($P = .01$), with HIV-seropositive women having an over-representation of blacks (71% vs. 64% in seronegative women) and an under-representation of whites (5% vs. 13% of seronegative women) and in marital status ($P = .02$), due primarily to a higher prevalence of widows (9% vs. 2%) and divorces or annulments (9% vs. 6%) among seropositive women. HIV-seropositive women also were more likely to report having had both a sexual partner who had HIV infection or AIDS (OR 5.2, 95% CI 1.2–22.5) and someone close to them who had HIV or AIDS (OR 1.5, 95% CI 1.01–2.3). HIV-seronegative women were more likely to be employed (OR 1.8, 95% CI 1.1–3.0), to live alone (OR 2.1, 95% CI 1.1–4.1), and to use marijuana or hashish (OR 1.7, 95% CI 1.2–2.6).

The numbers and proportions of women reporting current and anticipated future legal needs are shown in Table I. The specific items that women were asked about have been shortened and categorized in the table for purposes of display. Need for current legal assistance regarding entitlements or other personal issues was reported by a majority of women and was anticipated by approximately one-third of those without current need regardless of HIV status. Current or future assistance regarding benefits or entitlements and help with housing were reported by a majority, and approximately one-third of the sample reported needing current or future legal help with debts. More than 40% of women also reported current or future need for assistance with issues related to children; one-quarter had current or anticipated need for assistance in making arrangements for care of children. Approximately one-third of women, both with and without HIV infection, reported current need with assistance relating to health issues. However, future need related to health issues was anticipated by significantly more HIV-seropositive women. Substantial minorities of women reported current or anticipated future need for most of the remaining items assessed, but there were few significant differences between HIV-seropositive and HIV-seronegative women, with the exception of health-related issues. HIV-seropositive women were significantly more likely to report anticipated future need for legal help with paternal custody or visitation issues (OR 2.6, 95% CI 1.1–5.9), current need in making a will (OR 1.7, 95% CI 1.1–2.6), and anticipated future assistance with a living will or health care proxy (OR 2.3, 95% CI 1.4–4.0). Women who were

TABLE 1 Reported Current and Anticipated Future Legal Needs

Reported Legal Needs	Number of women (%)					
	Current Need		Future Need*		Current or Future Need	
	HIV+	HIV-	HIV+	HIV-	HIV+	HIV-
Entitlements, personal issues	192/346 (55.5)	93/163 (57.1)	56/154 (36.4)	22/70 (31.4)	248/346 (71.7)	115/163 (70.6)
Benefits or entitlements	106/346 (30.6)	49/163 (30.1)	97/240 (40.4)	44/114 (38.6)	203/346 (58.7)	93/163 (57.1)
Housing	128/346 (37.0)	57/163 (35.0)	66/218 (30.3)	29/106 (27.4)	194/346 (56.1)	86/163 (52.8)
Work discrimination	10/346 (2.9)	5/163 (3.1)	24/336 (7.1)	21/158 (13.3)	34/346 (9.8)	26/163 (16.0)
Loans, debts, unpaid bills	71/346 (20.5)	41/163 (25.2)	44/274 (16.1)	15/122 (12.3)	115/346 (33.2)	56/163 (34.4)
Immigration	5/346 (1.4)	0/163	4/341 (1.2)	4/163 (2.5)	9/346 (2.6)	4/163 (2.5)
School discrimination, self	9/346 (2.6)	6/163 (3.7)	18/337 (5.3)	13/157 (8.3)	27/346 (7.8)	19/163 (11.7)
Issues related to partner	49/346 (14.2)	25/163 (15.3)	31/297 (10.4)	12/138 (8.7)	80/346 (23.1)	37/163 (22.7)
Abusive partner	16/346 (4.6)	10/163 (6.1)	24/329 (7.3)	12/153 (7.8)	40/346 (11.6)	22/163 (13.5)
Divorce or separation	29/346 (8.4)	14/163 (8.6)	15/317 (4.7)	6/149 (4.0)	44/346 (12.7)	20/163 (12.7)
Maintenance or alimony	18/346 (5.2)	11/163 (6.7)	14/328 (4.3)	8/152 (5.3)	32/346 (9.2)	19/163 (11.7)
Issues related to children	98/346 (28.3)	50/163 (30.7)	47/248 (19.0)	20/113 (17.7)	145/346 (41.9)	70/163 (42.9)
Child welfare agency	36/346 (10.4)	19/163 (11.7)	44/310 (14.2)	18/144 (12.5)	80/346 (23.1)	37/163 (22.7)
Foster care agency	26/346 (7.5)	5/163 (3.1)	19/320 (5.9)	9/157 (5.7)	45/346 (13.0)	14/163 (8.6)
Custody/visitation, father	16/346 (4.6)	13/163 (8.0)	37/330 (11.2)	7/150 (4.7)	53/346 (15.3)	20/163 (12.3)
Custody/visitation, other	29/346 (8.4)	12/162 (7.4)	28/317 (8.8)	12/151 (7.9)	57/346 (16.5)	24/163 (14.7)
Paternity	4/346 (1.2)	3/163 (1.8)	15/341 (4.4)	4/160 (2.5)	19/346 (5.5)	7/163 (4.3)
Order for child support	29/346 (8.4)	18/163 (11.0)	23/317 (7.3)	6/145 (4.1)	52/346 (15.0)	24/163 (14.7)
Collect child support	34/346 (9.8)	24/162 (14.8)	27/312 (8.7)	10/138 (7.2)	61/346 (17.6)	34/162 (21.0)
Care of children	55/346 (15.9)	23/163 (14.1)	37/291 (12.7)	17/140 (12.1)	92/346 (26.6)	40/163 (24.5)
Childs' school discrimination	2/346 (0.6)	3/163 (1.8)	27/344 (7.8)	11/160 (6.9)	29/346 (8.4)	14/163 (8.6)
Special education services	17/346 (4.9)	9/163 (5.5)	26/328 (7.9)	12/154 (7.8)	43/346 (12.4)	21/163 (12.9)
Health issues	131/346 (37.9)	54/163 (33.1)	84/215 (39.1)	30/109 (27.5) [†]	215/346 (62.1)	84/163 (51.5) [†]
Making a will	97/346 (28.0)	31/163 (19.0)	77/249 (31.9)	34/132 (25.8)	174/346 (50.3)	65/163 (39.9)
Living will/health care proxy	104/346 (30.1)	45/163 (27.6)	79/245 (32.5)	20/118 (16.9)	183/346 (52.9)	65/163 (39.9)
Health care discrimination	23/346 (6.6)	16/163 (9.8)	38/323 (11.8)	15/147 (10.2)	61/346 (17.6)	31/163 (19.0)

*Among those not reporting current need.

[†]Significant difference between HIV-seropositive and HIV-seronegative women ($P \leq .05$).

HIV seronegative were more likely to anticipate future need for legal assistance with discrimination at work (OR 2.0, 95% CI 1.03–3.9). The few responses to open-ended questions about any additional legal needs generally duplicated items previously discussed; additional needs were reported rarely.

The number of women receiving legal assistance among those reporting a current need and the proportion of those anticipating a future need who knew where to obtain assistance are shown in Table II. For most items, a majority of women anticipating a need for future legal assistance thought that they knew where to obtain help. However, among women reporting a current need, for nearly all issues, only a minority actually were receiving help. We also assessed whether there were any differences by HIV status (data not shown). Only among women with current needs for legal assistance regarding arrangements for care of children and for a living will or health care proxy were there significant differences by HIV status in the proportion receiving such assistance; for both issues, HIV-seropositive women were more likely to be receiving help (Table II).

DISCUSSION

Women with or at risk for HIV infection reported a number of current or anticipated legal needs, but there were few significant differences between HIV-seropositive and HIV-seronegative women in the pattern or extent of these needs. This suggests that poor women of color struggle daily with problems that may engender legal concerns regardless of HIV status.²¹

Most women in the present study were unemployed. One-half had used cocaine or heroin, one-half reported having had inadequate money, and 15% had been homeless. The subjects' self-reported legal needs reflect these variables, especially in the areas of need for assistance with benefits/entitlements, housing, debt management, future care for children, and advance directives. The lack of an association between HIV serostatus and women's legal needs in these areas may reflect the reality that obtaining food, shelter, and seasonally adequate clothing are pressing priorities, followed by substance abuse treatment, regular work and housing, and child care. It may be that these needs must be met securely before women can focus on the impact of HIV.^{22,23}

Women with HIV infection were significantly more likely to report a future need for assistance in dealing with their children's father about custody or visitation. Seropositive women in the study were more likely to have an HIV-seropositive husband, partner, or lover. However, it is unknown how many of these were also the fathers of their children; some fathers may have been HIV negative or as yet undiagnosed. Women who feel stigmatized by an HIV diagnosis

TABLE II Receipt of Legal Assistance and Knowledge of How to Obtain Anticipated Future Legal Assistance in Women With or at Risk for HIV Infection*

Reported Legal Needs	Number of Women (%)	
	Receiving Help/ Currently in Need	Know Where to Obtain Help/ Anticipated Future Need†
Entitlements, personal issues		
Benefits or entitlements	68/154 (44.2)	113/141 (80.1)
Housing	49/185 (26.5)	73/95 (76.8)
Work discrimination	4/14 (28.6)	20/44 (45.5)
Loans, debts, unpaid bills	16/110 (14.5)	23/58 (39.7)
Immigration	3/5 (60.0)	3/8 (37.5)
School discrimination, self	3/15 (20.0)	20/31 (64.5)
Issues related to partner		
Abusive partner	5/26 (19.2)	24/36 (66.7)
Divorce or separation	1/8 (12.5)	10/21 (47.6)
Maintenance or alimony	1/29 (3.4)	13/22 (59.1)
Issues related to children		
Child welfare agency	16/55 (29.1)	47/62 (75.8)
Foster care agency	13/31 (41.9)	16/28 (57.1)
Custody/visitation, father	1/29 (3.4)	32/44 (72.7)
Custody/visitation, other	11/41 (26.8)	28/48 (58.3)
Paternity	1/7 (14.3)	14/19 (73.7)
Order for child support	5/47 (10.6)	19/29 (65.5)
Collect child support	3/58 (5.2)	27/37 (73.0)
Care of children	13/76 (17.1)‡	31/53 (58.5)
Childs' school discrimination	2/5 (40.0)	19/38 (50.0)
Special education services	7/26 (26.9)	23/38 (60.5)
Health issues		
Making a will	16/127 (12.6)	59/110 (53.6)
Living will/health care proxy	18/147 (12.2)§	53/99 (53.5)
Health care discrimination	12/39 (30.8)	31/53 (58.5)

*Independent confirmation and details of how some women successfully obtained or learned how to obtain help or why others did not successfully obtain or learn how to obtain help were not investigated.

†Among those not reporting current need.

‡13/55 (23.6%) HIV+, 0/21 HIV-; $P = .04$.

§17/103 (16.5%) HIV+, 1/44 (2.3%) HIV-; OR 8.5, 95% CI 1.1–66.0.

may feel that disclosure of their serostatus renders them particularly vulnerable in relation to their maternal roles.²⁴ They may fear that being HIV infected would have a negative impact on them in an adversarial custody or visitation matter, especially if their adversary is not known to be HIV infected.²⁵

Seropositive women were more likely to perceive a need for current legal help with making a will, but it is unlikely that the study group had substantial

assets to distribute. These women may have been expressing a recognition of impending death or a desire to exert control over their future with a tool that gives individuals the power to determine the distribution of their property, however meager, on death.⁵

It is also possible that the women believed, erroneously, that making a will would ensure posthumous implementation of their wishes for future care and custody of their children. Designating a guardian for children in a will is one of the available legal mechanisms for planning for the future care of children, but this statement of maternal desire is only advisory to a court. The standard of judgment remains that which is in the "best interest" of the child. The mother's choice, expressed in a will, may be challenged successfully after her death.⁸ The "standby guardianship" mechanism makes it possible for a parent to establish the future guardian and provides simple procedures for the transfer of guardianship at the time of incapacity or death or with parental consent.⁸ This option was relatively new in New York and Maryland at the time of data collection (effective in 1992 and 1994, respectively)^{26,27} and therefore may not have been well known to women.

That HIV-infected women were more likely to anticipate needing future help with a living will or health care proxy is most likely an acknowledgment that, at least at the time of the study, HIV infection often predicted the imminent onset of terminal illness. Seropositive women were more likely to report having had both a sexual partner and someone close to them who had HIV or AIDS, so they may have had more direct experience with or access to advance directives.

The lack of association between HIV serostatus and need for legal assistance to plan for the future care of children was unexpected. This result is difficult to reconcile with the advance directives and will items, as all three required the subject to acknowledge her mortality. There are several possible explanations for this finding. Some women may have confused making a will with planning for child guardianship. Women with a chronically heightened risk for premature death from violence and/or injection drug use may have found this question to be irrelevant.²⁸ It may signify the women's denial of what may be an intolerably painful aspect of HIV infection. Making decisions about medical care and disposal of property are easier than facing the prospect of leaving children motherless. It is also possible that the HIV-seropositive women's anticipated greater future need for assistance with paternal custody or visitation reflected beginning thoughts about future plans for their children if there would be no competitors for future custody beyond the children's fathers.

The responses detailing access to legal services may be among this study's

most important findings. While it is no surprise that poor women have limited access to legal services, the differences between expectation and reality were dramatic. A majority of women anticipating future legal needs thought they knew where to receive help for most issues. However, of the women with a current need for help with a particular legal problem, a minority actually were receiving help, except for the very few women currently in need of assistance with immigration. Of the self-reported categories of current legal need, receipt of assistance was most limited for paternal custody/visitation and collecting spousal alimony/maintenance.

Several limitations of this study suggest caution in generalizing the findings. Eligibility criteria for the HER study included documented HIV infection, a negative HIV test result within the previous 60 days, or consent to HIV testing as part of eligibility screening. Although severely immunodeficient women were eligible for enrollment, they were not eligible if they reported a history of selected AIDS-defining clinical conditions for which self-report was believed to be sufficiently reliable for screening purposes.²⁰ Of the HIV-seropositive women with CD4⁺ counts available at the time of the legal needs interview, 71%, a significant majority, had CD4⁺ cell counts above 200/mm³. Most of these women had not yet experienced HIV-related illnesses or hospitalizations. Women at more advanced stages of HIV infection may experience a different pattern of legal needs.

We did not study changes in perceived legal needs over time. Psychological state has been observed to influence the client's perception of her legal needs and her behavior in utilizing legal services.^{13,29} Several schemata of the "stages" of HIV infection have been proposed, with the emergence of particular psychosocial needs and corresponding needs for services at points along the continuum of adaptation to the diagnosis.^{22,30} Legal needs such as planning for future care of children, for example, may correspond to later stages of illness or of psychological adaptation to the HIV diagnosis.

Self-reported needs may not be equivalent to actual needs for legal assistance, and the absence of legal help for a current problem may not be due necessarily to lack of access. We did not ask subjects who reported current legal problems whether, how, or to what extent they had sought legal assistance. The number of women with any particular category of true legal need may have been small, and so the significance of the percentage receiving or not receiving legal assistance is uncertain. The pattern of unmet legal need, however, is interesting. Active legal assistance was almost nonexistent for women with a paternal custody or visitation dispute, spousal maintenance collection problem, and unresolved child support matters (3%, 3%, and 5%, respectively). These important and common

legal problems for women were the only situations in which legal assistance was being received by fewer than 10% of the women reporting a current need.

The findings in these cities may not be generalizable to all geographic locations or even to other large cities. Women may have greater access to legal services in these cities, including greater access to specialized legal services programs for people with HIV infection, than women elsewhere. Alternatively, local legal services in urban centers might be overtaxed and therefore less available. There may be local differences in access to court-appointed and paid counsel for various types of legal problems. The particulars of relevant state and municipal laws and variations in their enforcement also may influence women's perceptions of their need for and access to legal assistance.

Women who choose to participate in research may not be representative of all women. Some may enroll to take advantage of anticipated services and support. Others may be more altruistic and socially conscious.^{31,32} Our study sample may under-represent younger women with or at risk for HIV infection. Finally, the study was performed prior to the recognition of the improved prognosis associated with highly active antiretroviral therapies and prior to the enactment of national welfare reform legislation in 1996 that ended entitlement to Aid for Families with Dependent Children, permitted states to restrict benefits for certain immigrants³³ and for individuals with certain felony drug convictions,³⁴ and allowed states to test and to sanction beneficiaries who test positive for use of controlled substances.³⁵

With few exceptions, HIV serostatus does not appear to alter the pattern or extent of women's legal needs, at least for women who are early in the course of illness. The extent of reported legal needs among women with or at risk for HIV infection is substantial, however, and few receive legal assistance. Legal intervention may be crucial to securing even the most basic survival needs and may contribute significantly to health status, psychological and spiritual well-being, and quality of life. Effective legal services may conserve health care costs to the extent that they support women's access to and ability to comply with health care recommendations and to maintain adequate housing.³⁶ Research-based evidence of the pattern and extent of unmet legal needs, therefore, may add an important dimension to health care policy analysis, particularly in the arenas of women's health, maternal and child health, and HIV/AIDS. Taking into account the interplay of legal concerns with health status also might inform better the hard decisions and political debates surrounding public funding for legal services.

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APPENDIX

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