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PERCEIVED NEEDS AND UNMET NEEDS FOR FORMAL SERVICES AMONG PEOPLE WITH HIV DISEASE

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ABSTRACT: This study presents estimates of the prevalence of perceived needs and unmet needs among people with HIV disease in the United States for six areas of community services: mental health, drug treatment, home care, housing, transportation, and entitlements. The prevalence of service needs and unmet needs within racial, gender, drug use history, and other subgroups was also examined. The study is based on a nonrandom cross-sectional sample of 907 people with HIV disease interviewed between November 1988 and May 1989 in nine major urban areas of the United States.

Respondents reported high levels of need and unmet need across a variety of service areas. One third or more of all respondents reported a need for mental health services (57%), housing (39%), entitlements (34%), and transportation (32%). Within each of the six service areas, 40% or more reported unmet need. Women, people of color, and injected drug users were more likely to report unmet service need in a number of areas. Given the limitations of the sampling and the focus on *current* needs, these estimates may represent a lower bound on the magnitude of service need and unmet need within this population.

INTRODUCTION

People with HIV disease require numerous social and medical supportive services. Crystal and Jackson[1] (p. 78) note that people with symptomatic HIV infection "must cope with severe and debilitating

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symptoms, must secure medical treatment, and also must deal with the various psychological, social, and economic sequelae of the physical illness." The growing emphasis on community-based care for these individuals heightens the need for creative solutions to long-standing problems of service delivery involving multiple providers. To effectively develop programs and allocate resources, information about the types of community services needed as well as the degree to which service needs remain unmet is critical; however, few studies have reported data addressing this issue.[1,2,3]

People with HIV infection come from a variety of racial and ethnic groups, and have varying levels of economic resources. While gay white males predominate in some areas, in others, people of color and injected drug users (IDUs) are the norm, with large and growing populations of infected women and children. Consequently global estimates of service need may mask important variations and lead to misguided program planning. The purpose of the current study was to estimate the prevalence of community-based service needs and unmet needs among people with HIV disease, and to identify particular subgroups of patients with especially prevalent difficulties.

METHODS

Sampling. All study participants were people with HIV disease interviewed between November 1988 and May 1989 as part of the evaluation of the Robert Wood Johnson AIDS Health Services program.[4] In-person interviews were conducted with program clients in nine sites: Newark and Jersey City, New Jersey (1986 respondents); Nassau County, New York (183); Atlanta, Georgia (182); Dallas, Texas (168); Fort Lauderdale and Miami, Florida (120); New Orleans, Louisiana (135); and Seattle, Washington (57).

Four hundred and ten respondents were recruited from the primary community-based organization providing social services to people with HIV infection in the site, and an additional 621 were recruited from outpatient clinics at the participating public hospital. In all sites, direct service providers (usually the client's case manager) made the initial request to participate in the study. Fleishman, Mor, Cwi, and Piette[5] discuss sampling procedures in greater detail. List-wise deletion of missing data reduced the sample for these analyses to 907.

Measuring Service Needs. Respondents were presented with a list of community services. For each service, the respondent indicated whether he or she needed the service in the previous three months. Those who reported a need were asked if they had received services from any agency or organization. Those who had received services were asked whether they were now getting as

much of the service as they needed. Respondents who either did not receive a needed service or received an insufficient amount were classified as having unmet need.

For the purposes of reducing the number of service areas in the analysis, three categories were constructed to combine information about similar services. "Home Care" was used as the summary category for home nursing, homemakers, and home meals. "Mental Health" was used to summarize information regarding need for support group and psychological counseling. "Housing" services represent help in locating housing and money to pay for housing. For each of these categories, the proportion of respondents with "No Need" was calculated as the proportion of all respondents reporting no service needs for any of the component services. The proportion of respondents with "Met Need" was calculated as the proportion of all respondents who reported a need in one or more of the component service areas, while reporting no unmet needs for any of the component services. The remaining respondents (i.e. those with "Unmet Need") were respondents reporting a need in one or more of the component service areas who also reported an unmet need in one or more of the component service areas.

Respondent Descriptors. Sociodemographic variables measured include: gender, race (white non-Hispanic vs. other), and living arrangement (alone vs. with others). Clients reporting injected drug use (IDUs), including those who were gay/bisexual, were classified as IDUs. Respondents reported their current employment status and whether they had public, private or no medical insurance. Level of physical function was measured by asking about the degree of difficulty that the respondent encountered in performing six activities: shopping or doing small errands without help, doing cleaning or heavy housework, walking up ten steps without resting, lifting or carrying to full bags of groceries, walking a quarter mile, or getting around town. Respondents were trichotomized into those who reported no difficulties in any of the six areas, those who difficulties in one of the six tasks, and those who found two or more tasks difficult.

Analysis. For each service area, we constructed bivariate tables to determine differences in the distribution of respondents with no need, met need, and unmet need across sociodemographic and clinical groups. Chi-square statistics were used to assess the role of chance in determining the differences we observed. Finally, a matrix of service areas was used to determine the proportion of respondents with unmet need in each area who also reported an unmet need in each of the five remaining areas.

RESULTS

The sociodemographic characteristics of the sample are presented in Table 1. Unlike the low proportion of IDUs reported nationally who are white

TABLE 1

Sample Characteristics
N = 907

	Number	*(Percent)*
Gender		
Female	86	(9.5)
Male	821	(90.5)
Drug Use		
IDU	384	(33.5)
Non-IDU	603	(66.5)
Race		
Non-White	294	(32.5)
White	613	(67.5)
Living Arrangement		
Living Alone	249	(27.5)
Living with Others	658	(72.5)
Employment Status		
Employed	236	(26.0)
Unemployed	671	(74.0)
Insurance		
Public	408	(45.0)
Private	222	(24.5)
None	277	(30.5)
Physical Function		
Low	207	(22.8)
Medium	100	(11.0)
High	600	(66.2)

(29%),[6] 62% of the IDUs we interviewed were white (data not shown). More than a third of all respondents reported one or more emergency room visits in the previous three month period, and 30% reported one or more overnight hospital stays. Respondents reported a variety of symptoms of HIV infection including weakness or numbness in limbs (57%), night sweats (46%), dyspnea (53%), and diarrhea (49%). More than half of all respondents (57%) reported using ziduvodine at the time of interview, and an additional 17% reported some previous use. Forty-four percent reported a history of PCP, and 12% reported a history of Kaposi's sarcoma.

One-third of all respondents were interviewed within the year that they became aware of their HIV infection, and 71% were interviewed within two

years. Most respondents (88%) indicated that they had been diagnosed with AIDS or mentioned that they had been diagnosed with a specific AIDS-defining illness. More than 40% of all respondents reported that they were either married or in a long-term committed relationship. Among those not in a committed relationship, 81% reported some contact with family or friends several times per week or more; 48% reported some contact with family or friends on a daily basis.

Prevalence of Service Needs and Unmet Needs. More than eighty-one percent of all respondents reported a need in one or more service areas, and one-third reported a need for three or more services. The mean number of needed services was 2.4. Sixty-two percent reported one or more unmet needs. IDUs reported more needs on average than non-IDUs (2.3 vs. 1.9; $p<.001$) as well as more unmet service needs (1.4 vs. 1.1; $p=.001$). Unemployed respondents also reported more needs on average than those who were employed (2.3 vs. 1.1) and more unmet needs (1.4 vs. 0.6; both $p<.01$). On average, men, whites, and those living with others had fewer needs and unmet needs than their counterparts. However only the difference in needs between men and women (2.0 vs. 2.4 respectively) attained statistical significance (i.e. $p<.05$).

Mental health services were needed by more than half of all respondents, and more than one-third reported a need for housing, entitlement, and transportation (Table 2). The majority of the respondents who reported a need for housing or transportation also reported an unmet need. More than forty percent of those with a need in each of the other four areas reported unmet need.

TABLE 2

Univariate Prevalence of Service Need and Unmet Need
N = 907

	% Need	*% of Need Unmet*[5]	*% All Unmet*[6]
Homecare[1]	27.9	53.4	14.9
Mental Health[2]	56.9	48.8	27.8
Drug Treatment	10.6	39.6	4.2
Housing[3]	38.9	81.3	31.6
Entitlements[4]	34.1	45.0	15.3
Transportation	32.4	70.7	22.9

[1] Includes Home Nurse, Home Meals, Homemaker
[2] Includes Psychological Counseling and Support Group
[3] Includes Money to Pay for Housing and Help in Finding a Place to Live
[4] Includes SSI and Medicaid
[5] Calculated as the proportion of all respondents reporting a need for that service who report either no service receipt or insufficient service receipt.
[6] Calculated as the proportion of all respondents reporting either no service receipt or insufficient service receipt.

TABLE 3

Prevalence of No Need, Met Need and Unmet Need for Mental Health and Drug Treatment Services within Respondent Subgroups
N = 907

	MENTAL HEALTH[1]			*DRUG TREATMENT*		
	No Need[2]	*Met Need*	*Unmet Need*	*No Need*[2]	*Met Need*	*Unmet Need*
Gender						
Male	43.8	27.6	28.5*	90.4	5.6	4.0*
Female	37.2	41.9	20.9	80.2	14.0	5.8
Drug Use						
IDU	42.1	30.9	27.0	79.6	13.2	7.2*
Non-IDU	43.8	28.0	28.2	94.4	3.0	2.7
Race						
White	37.4	33.0	29.7*	88.6	7.2	4.2
Nonwhite	55.4	20.7	23.8	91.2	4.8	4.1
Living Arrangements						
Living Alone	38.2	28.5	33.3*	91.2	4.8	4.0
Living w/Others	45.1	29.2	25.7	88.8	7.0	4.3
Employment Status						
Employed	48.7	24.6	26.7	92.4	5.5	2.1
Unemployed	41.3	30.6	28.2	88.4	6.7	4.9
Insurance						
Public	43.1	30.4	26.5*	85.8	9.3	4.9*
Private	36.0	29.7	34.2	92.8	4.1	3.2
None	49.1	26.4	24.5	92.1	4.0	4.0
Function						
Low	40.1	30.4	29.5	89.4	5.8	4.8
Medium	44.0	30.0	26.0	89.0	6.0	5.0
High	44.2	28.3	27.5	89.5	6.7	3.8

[1] Includes psychological counseling and support groups
[2] No need *in the past 3 months*
* $p < .05$ for the n × 3 crosstab of the independent variable by need status.

Among the 31 HIV+ respondents reporting no AIDS-related symptoms or diagnoses, a substantial proportion reported service needs and unmet needs (data not shown). Thirty-seven percent of the asymptomatics reported a need for mental health services, a third of these reporting an unmet need. Twenty-three percent reported a need for help with entitlements. For the six

TABLE 4

Prevalence of No Need, Met Need and Unmet Need for Home Care and Housing Services within Respondent Subgroups
N = 907

	HOME CARE[1]			*HOUSING*[2]		
	No Need[3]	*Met Need*	*Unmet Need*	*No Need*[3]	*Met Need*	*Unmet Need*
Gender						
Male	72.4	13.2	14.5	61.5	7.3	31.2
Female	70.9	10.5	18.6	57.0	7.0	36.0
Drug Use						
IDU	71.1	12.2	16.8	54.9	6.6	38.5*
Non-IDU	72.8	13.3	13.9	64.2	7.6	28.2
Race						
White	71.0	14.0	15.0	62.2	7.7	30.2
Nonwhite	74.8	10.5	14.6	58.8	6.5	34.7
Living Arrangements						
Living Alone	67.5	13.3	19.3	57.4	12.0	30.5*
Living w/Others	74.0	12.8	13.2	62.5	5.5	32.1
Employment Status						
Employed	90.3	3.8	5.9*	79.7	5.5	14.8*
Unemployed	65.9	16.1	18.0	54.5	7.9	37.6
Insurance						
Public	67.9	16.2	15.9	53.2	8.6	38.2*
Private	75.2	10.4	14.4	77.0	3.6	19.4
None	76.2	10.1	13.7	59.9	8.3	31.8
Function						
Low	51.7	18.4	30.3*	52.7	5.8	41.5*
Medium	62.0	19.0	19.0	50.0	8.0	42.0
High	81.0	10.0	9.0	65.8	7.7	26.5

[1] Includes home nurse, home meals and homemaker
[2] Includes money to pay for housing and help finding a place to live
[3] No need *in the past 3 months*
* $p < .05$ for the n × 3 crosstab of the independent variable by need status.

asymptomatic respondents reporting a need for housing assistance, five reported unmet need.

Women were more likely to report a need and an unmet need across all six service areas, with the differences for mental health, drug treatment, and transportation attaining the .05 level of statistical significance (Tables 3-5).

TABLE 5

Prevalence of No Need, Met Need and Unmet Service for Transportation Services and Help Applying for Entitlements within Respondent Subgroups
N = 907

	TRANSPORTATION			*ENTITLEMENTS*[1]		
	No Need[2]	*Met Need*	*Unmet Need*	*No Need*[2]	*Met Need*	*Unmet Need*
Gender						
Male	68.7	8.6	22.7*	66.4	19.1	14.5
Female	57.0	17.4	25.6*	61.6	15.1	23.3
Drug Use						
IDU	61.2	11.2	27.6	61.5	19.7	18.8
Non-IDU	70.8	8.6	20.6	68.2	18.2	13.6
Race						
White	68.7	8.8	22.5	68.0	19.1	12.9*
Nonwhite	65.3	10.9	23.8	61.6	18.0	20.4
Living Arrangements						
Living Alone	67.5	11.6	20.9	63.1	20.1	16.9
Living w/Others	67.6	8.7	23.7	67.0	18.2	14.7
Employment Status						
Employed	90.3	3.4	6.4*	86.0	8.5	5.5*
Unemployed	59.6	11.6	28.8	58.9	22.4	18.8
Insurance						
Public	58.1	13.0	28.9*	64.7	21.3	14.0*
Private	82.4	4.5	13.1	78.4	14.0	7.7
None	69.7	8.3	22.0	57.8	18.8	23.5
Function						
Low	45.9	15.5	38.6*	58.0	23.7	18.4*
Medium	51.0	12.0	37.0	61.0	17.0	22.0
High	77.8	7.0	15.2	69.5	17.3	13.2

[1] Help applying for either SSI or Medicaid
[2] No need *in the past 3 months*
* $p < .05$ for the n × 3 crosstab of the independent variable by need status.

IDUs were substantially more likely to report unmet need for entitlements, housing ($p<.05$), and drug treatment ($p<.05$). Those who were unemployed, had public insurance, or had poor physical functioning were more likely to report need and unmet need across all service areas.

Given the disproportionate number of white IDUs in the sample, the

relationship between race and service need was re-examined after stratifying the data by whether or not respondents were drug injectors (data not shown). In no service area did we observe a substantially different relationship than presented in Tables 3–5.

Across a number of service areas, a large proportion of the respondents with one unmet need reported an additional unmet need (Table 6). More than forty percent of those reporting an unmet need for homecare also reported an unmet need in the areas of mental health services, housing, and transportation. Among those reporting an unmet need for entitlements, sixty-two percent also reported an unmet need for housing services.

DISCUSSION

These data provide the first estimates to our knowledge of the level of needs and unmet needs for community services among people with HIV disease. The mechanisms mediating between sociodemographic factors and service needs include differences in individuals' level of social support, financial resources, health behaviors, and the way health care providers view people with HIV disease from different risk and racial groups.[7,8]

One third of all respondents reported a need for transportation,

TABLE 6

Proportion of Respondents with Unmet Needs for Two Services Simultaneously*

	Mental Health	*Drug TX*	*Housing*	*Home Care*	*Transportation*	*Entitlements*	*N*
Mental Health	—	7.1	41.7	23.8	33.3	19.0	252
Drug Tx	47.4	—	47.4	18.4	31.6	18.4	38
Housing	36.6	6.3	—	23.3	38.7	30.0	287
Homecare	44.4	5.2	49.6	—	51.9	27.4	135
Transportation	40.4	5.8	53.4	33.7	—	22.1	208
Entitlements	34.5	5.0	61.9	26.6	33.1	—	139

*Table entries represent the proportion of respondents reporting an unmet need within the service area of that row, who also reported unmet need within the service area of that column. The sample sizes in the last column denote the number of respondents reporting unmet need in that row. For example, 7.1% of the 252 respondents reporting an unmet need for mental health services, also reported an unmet need for drug treatment.

yet most of these (71%) were underserved or not served at all. Housing service was another common need (39%), and many respondents' needs were unmet (81%). The concomitant high level of need for help with entitlements (34%) underlines the importance of developing adequate services both to allocate funds to this population, and to assist patients in gaining access to these funds.

As in other chronically ill populations, the level of psychological morbidity among patients with HIV infection appears to be high.[9,10] Researchers and clinicians are just beginning to appreciate the extent of depression and other psychiatric morbidity associated with HIV.[11,12] These patients are often younger than most cancer patients, and many need counseling related to issues of homosexuality, discrimination, and chemical dependency.[13,14]

Women, people of color, and drug users were all more likely to report unmet service need in a number of areas. Other recent studies indicate that these groups may also have less access to antiviral therapy, prophylactic treatments, and preventive medical services.[15,16,17,18] Those who were unemployed at the time of interview were also more likely to report service needs and unmet needs.

Crystal and Jackson found that 30% of their sample of persons with symptomatic HIV infection reported a need for transportation or housing. Over 50% reported an unmet need for financial assistance, and over 25% reported unmet needs for transportation, housing, and psychological counseling. Consequently, although high, the proportions from the current study are consistent with previous estimates.

The calculation of unmet need in Tables 3-5 as a proportion of all respondents reduces the magnitude of the proportions by maximizing the denominator. An alternative way of conceiving of unmet need is as a percentage of the population needing that service (as in the second column of Table 2). This method of measurement provides a means of assessing the magnitude of unmet need controlling for the processes initially contributing to developing a need. Using the data from Tables 2-5, calculating the proportion of those with a need who have their need unmet illustrates that in many instances, a large proportion of those with HIV disease requiring services are currently unserved or underserved.

Limitations of the Estimates. Respondents were drawn from hospital clinics and community-based service organizations, and may have higher levels of need and unmet need than others with HIV disease who do not require the care of these agencies. Alternatively, since the sample was drawn from the population of individuals already connected

with medical providers and a case management program, individuals with poorly coordinated care are also underrepresented. Within the participating community-based organization, case managers may have been less likely to select respondents whose health status they felt might be adversely affected by the interview process. Consequently, the true level of need and unmet need within the participating communities may actually be higher than reported here.

These selection biases may be most operative among people of color. Since access to care is typically a greater problem in communities of color,[19] representatives of those communities in our sample who were connected with service providers are probably even more atypical than their white counterparts. If the selection of relatively well-off participants is differential across racial groups, the result would be to diminish the differences in levels of need and unmet need that would be observed if both groups were equally well represented. In our study, people of color reported greater need and unmet need in a number of areas. This differential should be interpreted as a lower-bound estimate of the differences existing in the source populations.

The true net result of the selection processes leading to study participation is ultimately unknown in the current study. More generalizable estimates can only come from future studies in which the sampling frame and processes leading to participation can be more clearly articulated.

Individuals' perceptions of their service needs are substantially influenced by subjective factors such as expectations, life experience, and knowledge of what services are available. The questions used as part of this survey specified service receipt "from [an] agency or organization." For many respondents, use of the word "service" itself may imply formal help rather than informal assistance from a friend or relative. Given that participants may not have reported need for services that they receive from their informal support network, the total amount of services needed may be underestimated.

The time period covered by these interview questions was only three months, and the proportion of individuals who develop a need at some time over the course of their illness may be much higher. Recent developments in antiviral therapy[20,21] and the expanded use of AZT among asymptomatic individuals[22] will mean increased prevalence of chronically ill persons in the community. Each of these compounds engenders substantial toxicities,[21,23] adding to the demands on the home health care system for services such as intravenous infusions. IDUs often have both greater HIV-related morbidity, and fewer social supports

than their counterparts in the gay community.[24] Shifts in the epidemiologic structure of the epidemic will mean that the number of people with fewer personal resources to cope with their illness will grow disproportionately. The proportion of HIV-infected patients with service needs is a function both of the incidence of newly diagnosed cases, and the duration of their illness; both factors are currently increasing. Policymakers and program planners need to view these data in light of the continuing rise in case prevalence throughout the country and the changing treatment pattern of HIV disease.

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