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ABSTRACT

As with other illnesses, Acquired Immune Deficiency Syndrome (AIDS) is a socially constructed phenomenon, not simply a biological entity. Biologically, Human Immunodeficiency Virus (HIV) infection causes immunosuppression, which in turn causes a spectrum of disease states. The official definition of AIDS by the Centers for Disease Control requires the presence of certain marker conditions. Those whose illnesses do not have these markers, but may have equal or greater impairment, are categorized as "pre-AIDS" or "AIDS-related complex" (ARC). This study compared the experiences of both patients with AIDS and patients with non-AIDS symptomatic HIV illnesses. Subjects (N=104) responded to a survey instrument encompassing demographic characteristics, social supports, economic situations, and health services utilization. The extent to which the medical and socioeconomic needs of patients were being met was also assessed. Patients with ARC reported more unmet needs in most areas, often experiencing their situations as being in "limbo" or "the gray zone," and in many respects seemed to perceive their life situation more negatively than did those with AIDS. A reorientation is needed away from thinking about persons dying with AIDS towards persons living with HIV infection. (Author/ABL)

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Health Care and The Social Construction of AIDS: Impact of Disease Definitions on Psychosocial Adaptation and Economic Circumstances

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Health Care and the
Social Construction of AIDS

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Presented at the Annual Meeting of the American Sociological Association, San Francisco, August 1989.

As with other illnesses, "AIDS" is a socially constructed phenomenon, not simply a biological entity. Biologically, HIV infection causes immunosuppression which causes a spectrum of disease states. Socially, the experience of illness is shaped by officially sanctioned but medically arbitrary categorizations of clinical syndromes within this spectrum. Thus, "official" AIDS, as defined by the Centers for Disease Control, requires the presence of certain marker conditions. Persons "meeting criteria" for AIDS also are officially defined as "disabled", thus qualifying for various governmental health care and income benefits. Others, whose illness may cause impairment of equal or greater severity, are categorized as "pre-AIDS" or "AIDS-related complex" (ARC). Results of a San Diego study comparing the illness experience of 50 persons with AIDS and 55 with ARC indicate that the latter reported more unmet needs in most areas, often experienced their situation as being in "limbo" or "the gray zone", and in many respects seemed to perceive their life situation more negatively than those with AIDS.

Health Care and The Social Construction of AIDS: Impact of Disease Definitions on Psychosocial Adaptation and Economic Circumstances

An important theme in medical sociology has been that diseases are socially constructed entities, not simply biological phenomena. This perception is eminently true of AIDS; such constructs shape the societal response to the epidemic and therefore the experience of people with AIDS. Much of the discrimination and distancing they experience, for example, results from the perception of the disease as stigmatizing, as creating what Goffman referred to as a "spoiled identity". Another aspect of the social construction of AIDS which affects patients' experience involves medically arbitrary disease definitions. The effect of such definitions is particularly important in a political culture in which the provision and financing of health care is particularistic rather than universal, where access to benefits and care systems depends on such particular characteristics of the individual as employment, family, disability, or income status.

Biologically, HIV infection causes immunosuppression which causes a spectrum of disease states. Socially, the experience of illness is shaped by officially sanctioned but medically arbitrary categorizations of clinical syndromes within this spectrum. Thus, "official" AIDS, as defined by the Centers for Disease Control, requires the presence of certain marker conditions. Persons "meeting criteria" for AIDS are also officially defined as "disabled", thus qualifying for various governmental health care and income benefits. Others, whose illness may cause impairment of equal or greater severity, have been categorized as "pre-AIDS" or "AIDS-related complex" (ARC), and more recently have more typically been assigned to what is if anything an even more amorphous category, as persons with "associated opportunistic infections" or "HIV-related illness."

From the beginning of the epidemic, in terms of health care and social services needs, the focus was on CDC-defined AIDS. Indeed, this terminology is deeply embedded in the semantic referents we habitually employ. Our language incorporates a metaphorical figure of speech (formally known as synecdoche) in which the part is taken for the whole: the term AIDS has been habitually used when HIV disease is really meant. We tend to speak of the AIDS epidemic, AIDS health services, and so on; indeed, this session is entitled simply "AIDS". When we speak of England when referring to Great Britain, or Russia when referring to the Soviet Union, we may be led to think of these societies as less diverse than they really are. The consequences of the AIDS synecdoche are more significant. This sociolinguistic construction focuses our attention on the acute disease model of HIV illness; it leads the society to see AIDS as a devastating (and therefore highly stigmatizing) condition inevitably progressing to death over a relatively short period. Thus, it has kept the focus on persons dying of AIDS rather than on persons living with HIV. Our statistics, too, are shaped by the medically arbitrary disease definition; we think in terms of the approximately 100,000 reported cases of CDC-defined AIDS reported in the US to date rather than the larger number of individuals infected by the virus.

It is, however, in the area of health care and related services that the consequences of disease definitions are perhaps most concrete and most important. The present CDC AIDS definition[1] is based on the surveillance definition developed for epidemiological monitoring purposes early in the epidemic, even before the cause of the syndrome was known. In creating case definitions for epidemiological research on new and mystifying syndromes, it is more important that the definition be specific than sensitive. That is, the definition is drawn narrowly rather than inclusively; it is more important to assure that all the cases being studied represent the same thing than to be sure that all the possible cases are included, and "borderline" cases are excluded.

The original CDC definition has been expanded once, in September of 1987,[1] but it is still the case that many individuals die of HIV without ever having been diagnosed with full-blown AIDS, and the definition leaves out many individuals with health care needs. This is problematic at the aggregate, planning level, but even more so when the CDC definition is utilized, as it is, in eligibility determinations for health and income maintenance benefits.

Persons with HIV illness who have not attained the CDC criterion receive separate and unequal treatment in qualifying for public health care and financial benefits. Unlike those with AIDS, they are not presumed to be disabled for purposes of benefits determination, but are subject to a lengthy case-by-case determination of disability, a process which sometimes last longer than the benefit applicant. Benefits like Social Security Disability Insurance payments (SSDI), Supplemental Security Income (SSI), and Medicaid are crucial for persons who are suffering from the debilitating and disabling effects of the infection. At the end of the labyrinth, those with HIV illness but not AIDS may or may not ultimately succeed in gaining access to these basic survival benefits, even though, as the data I will present suggest, they are often unable to work and are certainly likely to need costly medical care.

Thus, with HIV as with other types of illness, our unique American approach to health care financing in this country creates separate classes of ill people. One such class has access to publicly financed benefits without respect to means testing, through Medicare. This class includes the elderly and also the disabled, but the latter are subject to a two-year waiting period, barring most persons with HIV infection from eligibility. Another class, presumptively disabled, can qualify either for income benefits through Social Security disability or means-tested health benefits through Medicaid. A third category is likely to have difficulty accessing even means-tested benefits. Attributions of deservingness are clearly implied in these official classifications.

Experience with the health care system of persons with HIV infection but not AIDS is shaped by these definitions and by the concomitant fact that many of their most disabling symptoms are non-specific ones. A specific condition such as Kaposi's Sarcoma establishes clear-cut eligibility for benefits, but may not in itself be particularly impairing. By contrast, the symptoms that most impair the functional capabilities of PWARCs include chronic and debilitating fatigue, night sweats, diarrhea, headaches, sleep loss, and inability to concentrate. Such conditions can be chronic, recurring, and thoroughly incapacitating, but are likely to be unpersuasive to a disability examiner.

In part, the utilization of the CDC AIDS definition in benefit eligibility reflects an assumption that because patients with ARC are at an earlier stage, medically, of the progression of the HIV infection, the disabling effects of the disease and the care needs created by it are less severe. In order to evaluate this assumption and, more generally, to compare the experience of persons with AIDS and with non-AIDS symptomatic HIV illness, we included both persons with AIDS and with what at that time was generally referred to as Aids-Related Complex, or ARC, in a needs assessment conducted in San Diego County between October 1986 and February 1987. The purpose of the survey was to ascertain medical, social, economic, and other needs and the way in which these needs were being met. We were concerned to include persons with ARC as well as persons with AIDS since the number of such patients is larger, while less attention has been paid to their needs. We wanted to know if the assumption was substantiated in the patients' experiences that a diagnosis of ARC represents an illness with less severe impact, and whether needs for services (including health care financing) were less among PWARCs than among PWAs.

METHODS

The survey instrument was designed to encompass a range of issues including demographic characteristics, social supports, economic situation, and health services utilization. A series of five-point Likert type scales were developed to assess the extent to which medical and socioeconomic needs of patients were being met in a number of areas including income, access to outpatient and inpatient care, social services assistance, relief for persons providing care, psychological counseling, household help, and others. Additional series of scales assessed social support, the response of persons in the patient's social network to the illness, and satisfaction with various aspects of available medical care. Patients were also asked about the social and economic sequelae of their illness, and about the medical symptoms they had experienced.

Data were collected on 104 subjects. Subjects were eligible for the study who reported that they had been diagnosed with AIDS or ARC; respondents were asked to give dates of diagnoses. Fifty respondents identified themselves as having AIDS, fifty-four as having ARC. Questionnaires were administered in two waves to secure as representative a sample of cases as possible. Initially, data were collected through questionnaires distributed to the major health care providers in San Diego County and to the San Diego AIDS Project. Key persons at each location distributed questionnaires to persons known to meet criteria for a diagnosis of AIDS or ARC. From October through December of 1986, 48 questionnaires were completed, representing patients who received their principal medical care from sources covering the spectrum of providers in the County. Since most questionnaires obtained in this period were completed at the time the individual was seeking medical care, additional respondents were solicited early in 1987 at support groups and social events for PWAs/PWARCs at the San Diego AIDS Project. This provided an opportunity to include persons who may not have required or utilized medical care during the period in which they were contacted. An additional 29 questionnaires were completed by participants in these events, for a total of 77.

To expand the sample and as a check on any possible bias introduced by self-selection in the initial wave, a second wave of data were collected at an outpatient clinic at the University of California, San Diego School of Medicine. UCSD's Owen Clinic is a clinic dedicated primarily to persons with HIV infection, with emphasis on AIDS and ARC, and is the largest single provider of outpatient medical care for AIDS and ARC patients in the County. Patients meeting criteria for AIDS or ARC who had not previously completed the questionnaire were referred to a medical student interviewer at clinic sessions, and were interviewed using the study questionnaire during January and February, 1987. In this wave, the response rate was determinable: 30 eligible patients were asked to participate in the study and 27 agreed to participate, for a response rate of 90 percent. The proportion of PWARCs in this group (63 percent) was somewhat higher than the proportion in the earlier group (48 percent).

Data were coded, entered, and error checked prior to analysis using the Statistical Package for the Social Sciences (SPSS). Questionnaires were anonymous; however, respondents were offered the opportunity to identify themselves if they wished to permit contact for clarification of any ambiguous or missing responses. Over 75% of respondents provided their names and indicated willingness for followup, and where necessary they were contacted to resolve any questions in the data coding process.

The sample included patients from across the county, but with the modal group (63 percent) living in zip code areas of San Diego that include the central city and the Hillcrest neighborhood, identified by many as the center of San Diego's gay community. UCSD Medical Center and the San Diego AIDS Project are also located in this area of San Diego. Among 308 cases of AIDS reported in San Diego County through 1986, about one-third lived in this group of zip codes. Thus, the survey overrepresents persons living in central San Diego and underrepresents persons living in more suburban and rural areas of San Diego County. However, the survey did include about 25 percent of the total of about 200 PWAs estimated to be alive in San Diego County at the time of the survey, and can reasonably be taken to be at least roughly representative of the overall population of patients in the county at the time of the survey, who were predominantly white homosexual men.

RESULTS

As expected given available knowledge about the demographic composition of the AIDS patients in San Diego County, the study population was a predominantly Caucasian group (Table 1). All respondents were male. As of January of 1987, 98 percent of cases of AIDS in San Diego County residents had been reported in males. Although our survey did not ask persons to identify themselves by risk group, over 93 percent of the reported cases in San Diego County have been in men who identified themselves as homosexual or bisexual, and we believe our respondents primarily represent this risk group as well. Ninety-three percent of respondents indicating ethnicity were Caucasian, which compares to the 89 percent Caucasian proportion for San Diego County AIDS cases.

TABLE 1 NEAR HERE

The study population was relatively well educated. Only one had less than a high school education, and most (88 percent) had at least some post-high school education. Thirty-eight percent had college degrees, including the 15 percent of the total who had graduate degrees. Mean annual income before diagnosis was $20,300. About half the respondents (49 percent) were in the age group 30 to 39. Twenty-nine percent were 40 or over while 22 percent were under 30.

Study findings indicated that the social and economic impact of the disease had been profound both for those diagnosed with AIDS and those diagnosed with ARC. Only 18 percent of the total study population (24 percent of those with ARC and 10 percent of those with AIDS) were still working full-time at the time of the survey. Another 9 percent were working part-time, but most were unemployed.

Many, but by no means all, of the respondents who were no longer employed received disability or welfare benefits. Eighty-four percent of non-employed AIDS patients, but only 41 percent of those with ARC, relied on Supplemental Security Income (SSI) and/or Social Security disability benefits. Many of those with ARC relied on local general assistance welfare payments, savings, family, or a lover; the proportion of non-employed ARC patients who relied on these sources or who had no income was 41 percent. These results reflect the fact that a diagnosis of AIDS as defined by the CDC brings with it eligibility for federal entitlement programs such as Supplemental Security Income, while ARC patients have a much more difficult time establishing eligibility for these programs. (Importantly, SSI eligibility brings with it eligibility for Medicaid in most states including California, while in California those dependent on local general assistance programs receive financial benefits considerably lower than those provided by SSI and are not eligible for Medicaid).

As a result of loss of employment and relatively low or non-existent benefit payments in many cases, survey respondents had typically suffered dramatic income declines since diagnosis. Mean income at the time of survey completion was $11,800, or 58 percent of pre-diagnosis income. The majority (69 percent) had incomes under $10,000. When asked about their greatest unmet area of need for help, the most frequent response both for PWARCs (32 percent) and for PWAs (38 percent) was "financial".

In addition to the income loss, patients had typically suffered a number of other negative socioeconomic sequelae of the disease. Almost half (46 percent) had been unable to pay for needed medical care; this was true of nearly two-thirds of the ARC patients (64 percent) and of nearly one-third of the AIDS patients (29 percent). Difficulty in keeping up with household chores was an even more prevalent problem, affecting 70 percent of ARC patients and 47 percent of AIDS patients. AIDS patients were more likely to be eligible for entitlements which brought with them access to home care services, but still did not have all their needs met in this area.

Other socioeconomic problems encountered included loss of a job due to health problems (50 percent), loss of a job due to fear or discrimination (19 percent), loss of friends due to fear (41 percent), loss of housing due to fear or discrimination (13 percent), loss of housing because of the loss of income (21 percent), rejection by some family members (34 percent), and difficulty with transportation (34 percent). Of 11 such areas about which respondents were questioned, ARC patients had encountered problems more frequently in 8 of the areas, often by wide margins, while AIDS patients had experienced problems more frequently in 3 areas (Table 2). The difference was highly significant ($p < .01$ by chi-square) for inability to pay for medical care, but did not attain statistical significance in the other areas.

TABLE 2 NEAR HERE

While PWARCs suffered from conditions usually considered to be less severe than PWAs, and are believed to have a less uniformly grave prognosis, they had also typically been ill for a longer period. Most of the PWAs had been diagnosed within the previous year; only 9 (18 percent) had been diagnosed prior to 1986. The majority had not received a diagnosis of ARC prior to being diagnosed with AIDS; only 11 of the 50 PWAs reported being diagnosed with ARC prior to an AIDS diagnosis. Where possible, PWAs were recontacted to confirm the absence of a previous ARC diagnosis. PWARCs typically had lived with a diagnosed HIV-related condition for considerably longer than PWAs. A majority (59 percent) had been diagnosed prior to 1986, and almost a quarter (22 percent) had been diagnosed prior to 1985, with diagnosis dates stretching back as far as 1981. Mean time since the first ARC or AIDS diagnosis for PWAs (N=50) was 9.16 months (standard deviation = 9.13 months), while mean time since diagnosis for the PWARCs (N=53) was 14.66 months (standard deviation = 14.87 months). For the 11 persons diagnosed first with ARC, the mean time interval from ARC to AIDS diagnosis was 9.82 months (standard deviation = 9.57 months). The overall mean time interval from diagnosis of AIDS or ARC to the time the survey was completed by all respondents (N=103) was about one year (mean = 11.99 months; standard deviation = 12.73 months).

When respondents were asked to volunteer additional symptoms not mentioned on the checklist (Table 2), 24 percent of PWARCs versus none of the PWAs mentioned "fatigue" specifically. When asked how HIV-related medical problems had limited usual activities, about 80 percent of PWARCs and 74 percent of PWAs responded that lethargy or fatigue interfered with daily activities. PWARCs were more likely to report having their activities limited by pain or by decreased concentration than PWAs and were more likely to have suffered night sweats, severe diarrhea, or headaches (Table 3).

Frequency and duration of hospitalization was greater for PWAs (Table 1). Over 75% of PWAs reported one or more episodes of hospitalization since diagnosis compared to only 37% of PWARCs, and 47% of PWAs versus 17% of PWARCs had been hospitalized for a total of more than 9 days since diagnosis.

TABLES 3 and 4 NEAR HERE

Table 4 presents responses to areas of need listed on the questionnaire. Respondents were asked to rate how well each listed need was met using a Likert-type scale (1 = not at all met; 5 = very adequately met). The proportion of persons reporting unmet needs was higher for PWARCs than for PWAs in 14 of 16 need areas asked about, with the difference statistically significant ($p < .05$) in 4 of the areas; neither of the two differences in the other direction was statistically significant. In addition, a mean needs satisfaction score was calculated for each area of need for PWA and PWARC respondents. Again, PWARCs indicated that their needs were being less than adequately met (represented by a mean score below 3.0) in more than half of the areas of need whereas mean scores for PWAs were less than 3.0 in only two areas of need. Mean need satisfaction score was lower for PWARCs than for PWAs in 14 of the 16 areas (significantly so in four areas) and higher for PWARCs in only two areas (significantly so in one of the two). When data for respondents from both groups were combined, the greatest unmet need was clearly income.

DISCUSSION

As compared with the rest of the nation, San Diego County's population of PWAs and PWARCs contains relatively fewer persons with social histories of poverty, poor education, and other indicators which would suggest a lack of personal, economic, and social resources. Even though PWAs and PWARCs in San Diego tend to have high levels of education and relatively high pre-diagnosis occupational status and income, they were overwhelmed by the disabling impact of the disease, and their social and economic resources were typically unable to meet the needs precipitated by their illness. Most PWAs and most PWARCs were no longer able to be employed, and PWARCs in particular were likely to have no health coverage at all; only 13% of PWARCs received Medicaid despite their typically very low or nonexistent incomes. The result was an inability to meet many basic needs of everyday life as well as to pay for medical care; nearly two-thirds of PWARCs had been unable to pay for needed medical care (Table 2).

As of February 1987, over 400 San Diego County residents had met CDC criteria for a diagnosis of AIDS; the County ranked third in California for number of AIDS cases and seventeenth among metropolitan areas in the United States. About 200 PWAs were alive in San Diego County at the time of the survey, and about 25 percent of them were reached by and completed the survey. Although the results may not be entirely representative of all PWAs in the area, it is apparent that the problems experienced by PWAs are already quite serious and will undoubtedly get worse as the numbers increase. The needs of the PWA population in San Diego and areas like it, while not of the magnitude of those in New York, San Francisco or Los Angeles, will increasingly strain health care and social services systems.

In addition to the better-publicized needs of PWAs, the survey identified the severe nature of the unmet needs of the larger population of PWARCs. Contrary to original expectations, these unmet needs were found to be at least as great in magnitude as those of PWAs. This appears to be the result of the longer period of illness experienced by PWARCs, which had often exhausted their resources, and the greater difficulty PWARCs experienced in qualifying for public benefits such as Social Security disability, Supplemental Security Income, and Medicaid, which have utilized a diagnosis of AIDS, but not of ARC, as presumptive proof of disability. Medicaid in particular is crucial since few in either the PWA or PWARC category can benefit from Medicare benefits available to other disabled individuals, as a result of the two-year waiting period.

One major need identified by PWAs and PWARCs is for medical care which is not only technically good but accessible and perceived as well coordinated, available in emergencies, caring, and with good communication among patients, their significant others, and the care providers. Almost all respondents reported a strong unmet need for psychological counseling. Because most psychological counseling requires sufficient income to pay psychologists and psychiatrists, this finding is not surprising.

Help with homemaking chores was another important unmet need, with PWARCs reporting more difficulty in this area. Again, this may be because PWARCs are less likely to have access to entitlement programs providing homemaker assistance. Without special funding streams for PWARCs, their situation could become even worse as the numbers increase and as the homemaker assistance resources of charitable and voluntary organizations are exhausted attempting to meet the needs of persons with AIDS. The economic crisis for PWARCs and PWAs is becoming an even more urgent issue as costly medications like AZT come into wider use.

Persons with ARC have been characterized as living in a "limbo of Hell", and comments to this effect have been made when results of this survey were discussed with other researchers, and with PWARCs and PWAs. Their situation has been described by one patient as "life in the gray zone."[2] Once a person meets CDC criteria for a diagnosis of AIDS, there is some certainty about the future. Although at the present time a diagnosis of AIDS implies death from the disease, usually within about 2 years, it also means automatic entitlement to various programs that make meeting daily activities of living somewhat easier. The process of coping psychologically with this terminal diagnosis is, of course, extremely stressful. As with cancer and other catastrophic or terminal diagnoses,[3] psychosocial adaptation as the physical disease evolves has been discussed in terms of a multi-stage reaction process, with progression from initial shock through anger and denial to ultimate acceptance and preparation for dying.[4,5,6] The uncertainty of an ARC diagnosis, however, may be even more stressful, with great anxiety surrounding each new symptom. Symptoms particularly characteristic of ARC, such as very severe chronic diarrhea, extreme fatigue and night sweats can be devastatingly disabling[7] while not engendering the same degree of attention by medical providers as may more specific conditions accompanying AIDS.

Because of limited resources among care providers, persons with AIDS may be able to access the health care system with greater ease because their symptoms may be viewed as more serious and in need of more immediate intervention. For example, treatment for *Pneumocystis* pneumonia is most effective if begun early, and receives a high priority for medical care. Medical care can be more difficult for PWARCs to obtain, and this pattern appears anecdotally to be true even where service availability is relatively good. In San Francisco, for example, the presence has been noted of "...a great many people with ARC who have debilitating conditions and need all the services we can provide, yet some of them may not qualify for services because they do not have the strict AIDS clinical diagnosis, as defined by the Centers for Disease Control."[8] The number of persons with ARC, which is not a reportable disease, has been estimated to be from two to five times or more the number of PWAs; as of June 1987 this would represent 70,000 to 175,000 cases in the U.S. ARC often progresses to AIDS but frequently is a cause of long-term and severely disabling morbidity without progressing to AIDS, and can be a cause of death even without such progression.

Few survey data are yet available on the adequacy with which economic, medical, and other needs of daily life of PWAs and PWARCs are met. There are some indications that PWARCs may manifest more psychological distress than those with the full-blown disease.[9] Our findings support the view that coping with ARC can be in some respects more difficult than coping with AIDS, and that needs for some services -- for example, psychological counseling -- may actually be greater.

Persons with ARC generally manifest less specific symptoms than PWAs (Table 3); many of these symptoms do not respond well to medical treatment. In addition, because of the uncertainties associated with a diagnosis of ARC, the individual is often unsure of the significance of symptoms and uncertain whether the current illness will "make criteria for AIDS" or not. Thus, contact with health care providers may occur often due to anxiety but may be met with a perceived lack of responsiveness or inadequate communication by medical providers (Table 4).

Persons with AIDS and persons with ARC represent only the tip of the iceberg of persons infected with the human immunodeficiency virus. As more infected persons become symptomatic, resource and service needs will continue to increase. This survey indicates severe deficits in both categories at a time when the numbers of PWAs and PWARCs in San Diego County were relatively small. The magnitude of the unmet needs both for PWAs and for PWARCs, and particularly the severity of the latter, suggest that the dimensions of the coming crisis in AIDS care may be even greater than anticipated, and suggest the need to develop new financing mechanisms not only for those acutely ill with AIDS but for the larger group of PWARCs.

Persons with HIV infection themselves have been among those most acutely aware of the political and practical implications of language. Thus, for example, the tendency of the media to refer to "AIDS victims" has been strongly resisted by persons with AIDS or HIV infection, as casting them in a preconceived victim role. Similarly, the term IVDA, or intravenous drug abuser, with its pejorative connotations, has been largely replaced by IVDU and more recently by injection drug user (since not all persons at risk through needle sharing use needles intravenously). But the misleading semantic implications of talking about AIDS when we mean the HIV epidemic, talking about persons with AIDS when we mean the HIV-infected, and talking about AIDS health care when we mean HIV health care are continuing to shape the way in which the epidemic is seen and in which the policy issues are framed. This is particularly the case since the distribution of cases of full-blown AIDS represents the past of the epidemic, not its present and certainly not its future. Refocusing both our language and our policies on the broader problem of HIV infection is more than just a matter of semantic clarity. It is part of the reorientation that is needed away from thinking about persons dying with AIDS and towards persons living with HIV.

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TABLE 1. Demographic characteristics of respondents to survey of persons with ARC (PWARC=54) and persons with AIDS (PWA=50) in San Diego County, California, surveyed between October of 1986 and February of 1987.

DEMOGRAPHIC CHARACTERISTIC	PWARC		PWA	
	N	%	N	%
AGE				
20 - 29	10	18.8	13	28.3
30 - 39	32	60.4	19	41.3
40 or over	11	20.8	14	30.4
	53	100.0	46	100.0
ETHNICITY				
Caucasian	51	98.1	37	88.1
Black, Hispanic, American Indian	1	1.9	5	11.9
	52	100.0	42	100.0
EDUCATION				
High School or less	5	9.4	7	14.0
Some college	24	45.3	18	36.0
Bachelor's or graduate degree	18	34.0	21	42.0
Technical	6	11.3	4	8.0
	53	100.0	50	100.0
EMPLOYMENT STATUS and INCOME				
Current employment at the time of survey				
Full-time employment	13	24.1	5	10.2
Part-time employment	6	11.1	3	6.1
Not employed	35	64.8	41	83.7
	54	100.0	49	100.0
HOSPITALIZATIONS				
Hospitalization since diagnosis				
Yes	20	37.0	37	75.5 ***
Hospitalized more than 9 days total since diagnosis	8	17.3	23	46.9 **

** differences statistically significant ($p < .01$)

*** differences statistically significant ($p < .001$)

TABLE 2. Responses of PWARC and PWA to the question "Have any of the following happened to you?" PWARC = persons with ARC (N=54); PWA = persons with AIDS (N=50). Respondents were asked to check all items that applied to them.

SITUATION DESCRIBED	NUMBER OF RESPONDENTS (%)	
	PWARC	PWA
Difficulty keeping up with household chores	33 (70.2)	23 (46.9)
Inability to pay for needed medical care	30 (63.8)	14 (28.6) **
Loss of job due to health problems	25 (53.2)	23 (46.9)
Loss of friends due to fear or discrimination	22 (46.8)	17 (34.7)
Difficulty making appointments for outpatient care	21 (44.7)	11 (22.4)
Rejection by some family members	18 (39.1)	14 (28.6)
Difficulty with transportation	17 (36.2)	16 (32.7)
Loss of housing due to loss of income	10 (21.3)	10 (20.4)
Loss of lover	8 (17.8)	9 (18.4)
Loss of job due to fear or discrimination	6 (12.5)	12 (26.1)
Loss of housing due to fear or discrimination	5 (10.6)	7 (14.3)
Other (volunteered responses)		
Isolation	22 (40.7)	17 (34.0)
Other	5 (9.3)	3 (6.0)

**difference statistically significant ($p < .01$)

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TABLE 3. Conditions reported by respondents to survey of persons with ARC (PWARC=54) and persons with AIDS (PWA=50). Question was worded "Have you had any of the following conditions? (check all that apply)." A blank for "other" was also provided. Other conditions reported 5 or more times are included in the table.

CONDITION	PWARC N	 %	PWA N	 %
Kaposi's sarcoma	—		16	32.0
Pneumocystis carinii	—		29	58.0
Other opportunistic infections	20	37.0	19	38.0
Lymphadenopathy	35	64.0	10	20.0 ***
Night sweats	45	83.3	31	62.0 *
Weight loss	36	66.7	35	70.0
Candida	33	61.1	27	54.0
Severe diarrhea	29	53.7	19	38.0
Other				
Fatigue	13	[illegible]	--	***
Headaches	7	[illegible]	--	**
Skin problems	5	9.3	2	4.0
Herpes (zoster or simplex)	5	9.3	4	8.0

* differences statistically significant (p<.05)
** differences statistically significant (p<.01)
*** differences statistically significant (p<.001)

TABLE 4. Responses to areas of need listed on questionnaire; areas of need are listed in sequence of percent differences between persons with ARC (PWARC=54) and persons with AIDS (PWA=50). Needs were scored on a scale as follows: 1=not at all met; 2=somewhat met; 3=adequately met; 4=more than adequately met; 5=very adequately met; NA=not applicable.

AREA OF NEED	NUMBER OF RESPONDENTS		N(%) WITH NEEDS LESS THAN ADEQUATELY MET (scored 1 or 2)			MEAN ($\bar{X}$) NEEDS SATISFACTION SCORE FOR AREA OF NEED		
	PWARC	PWA	PWARC	PWA	%difference (PWARC-PWA)	PWARC	PWA	difference (PWARC-PWA)
Relief for persons providing care	14	17	8 (57.1)	3 (17.7)	39.4	2.57	3.65	-1.08
Day programs (e.g., art therapy)	22	27	14 (63.7)	8 (29.6)	34.1*	2.41	3.26	- .85*
Legal counseling	31	34	21 (67.7)	12 (35.3)	32.4*	2.26	3.26	-1.00*
Household help	30	33	14 (46.7)	6 (15.2)	31.5*	2.80	3.60	- .80*
Communication with medical providers	52	47	18 (34.6)	7 (14.9)	19.7*	3.29	3.66	- .37
Spiritual needs	36	37	15 (41.7)	10 (27.0)	14.7	3.11	3.57	- .46
Social services assistance	36	42	15 (41.7)	13 (31.0)	10.7	2.86	3.47	- .61*
Psychological counseling	45	42	15 (33.3)	11 (26.2)	7.1	3.11	3.40	- .29
Interest in alternative therapies	43	40	18 (41.4)	14 (35.0)	6.4	2.88	3.12	- .24
Access to inpatient care	35	42	6 (17.1)	6 (11.9)	5.2	3.34	3.81	- .47
Access to outpatient care	51	48	13 (25.5)	10 (20.8)	4.7	3.22	3.44	- .22
Opportunity to participate in experimental drug studies	49	42	22 (44.9)	17 (40.5)	4.4	2.92	2.95	- .03
Income	45	47	29 (64.4)	29 (61.7)	2.7	2.44	2.53	- .09
Transportation	42	40	14 (33.3)	13 (32.5)	.8	3.21	3.40	- .19
Housing	46	44	8 (17.4)	12 (27.3)	-9.9	3.61	3.55	.06
Food	47	47	5 (10.6)	10 (21.3)	-10.7	3.89	3.38	.51*

*statistically significant difference ($p < .05$)