Consumer Key Informant Findings on HIV and Substance Abuse

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INTRODUCTION

The Health and Disability Working Group at the Boston University School of Public Health conducted a survey of individuals who are HIV positive and have current or past substance abuse histories. The goal of this survey was to obtain information from the consumer perspective regarding experiences with substance abuse treatment, primary medical care, and support services, and to understand what consumers perceive as the barriers to obtaining substance abuse treatment and primary medical care.

This information augments 50 key informant interviews with individuals who work in the fields of substance abuse treatment, health care, research, education, and public policy, and who are considered "professional experts" in the area of HIV. Both surveys were carried out to obtain input that could inform other activities of the Evaluation and Program Support Center on HIV and Substance Abuse funded by the Health Research Services Administration (HRSA).

The two surveys were different in that we used different sampling methodologies and needed to ask some questions of each group that were not relevant for the other group. Nevertheless, the overall purpose of both surveys was to obtain input from a variety of perspectives that will assist us in:

- Developing performance standards
- Identifying innovative programs
- Defining important public policy and research issues

In this report, we summarize the results of the consumer survey.

SURVEY METHODOLOGY

Sample

The consumer survey sample was a convenience sample of HIV positive substance users who were identified as a result of obtaining some form of care (medical care, substance abuse treatment, or support services). The survey was conducted during the spring of 2000 at four agencies:

- Boston Detox in Boston, Massachusetts, which provides alcohol and drug detoxification and step-down services in a short-term residential program on a public hospital campus;
- Health Care for the Homeless, Inc. in Baltimore, Maryland, which provides and coordinates health care and related services for people who are homeless;
- Outreach, Incorporated in Atlanta, Georgia, which provides support groups, transportation services, street outreach, an in-house substance abuse treatment program, and aftercare for people living with HIV/AIDS and/or addictions; and

- Pomeroy House, operated by Women and Children's Family Services in San Francisco, California, which provides substance abuse treatment for pregnant, postpartum, and parenting women in a residential setting that allows their children to remain with them.

The criteria for participation in the study were a positive HIV test, a current or recent history of substance abuse, and receipt of services at one of the participating agencies at the time the survey was administered. The study population was a small, non-randomized convenience sample of individuals who were HIV positive and either actively using substances or in recovery. As such, these results cannot be generalized to cover the experiences, needs, and barriers of all HIV positive substance users.

Survey Design and Administration

A survey was developed that included questions about:

- Demographic characteristics;
- Substance use and substance abuse treatment history;
- Experiences with substance abuse treatment, primary medical care, and support services;
- What people liked about the services they received; and
- Barriers to receiving services.

Before the study started it was approved by the Boston University Institutional Review Board. The survey was then sent to the program directors at each of the agencies. They left copies of the survey and blank envelopes in an area at the program that was accessible to those interested in participating. The cover letter included written instructions for completing the survey. An informed consent form was to be returned in the same envelope. After approximately one month, the program directors returned all the sealed envelopes to the Health and Disability Working Group.

DATA ANALYSIS

After the surveys were returned, data were analyzed. Of the 36 surveys returned, 12 individuals did not meet the eligibility criteria. This included all of the respondents from the residential program in California. Data from the 24 valid surveys were analyzed using standard analytic techniques and then coded. Due to the small numbers, the data were entered into an Excel spreadsheet for analysis. Simple descriptive techniques were then calculated. Below we present the results of this analysis.

RESULTS

Demographic Characteristics

Of the 24 survey respondents, 15 were male, 8 were female, and 1 was transgender. The age range of the sample was between 27 and 49, with a mean age of 37.2 years.

Seventeen respondents were African American, 3 were Caucasian, 3 were Latino/a, and 1 reported Other for race/ethnicity. When asked about sexual orientation, 17 reported they were heterosexual, 3 stated they were homosexual, 1 stated he/she was bisexual, and 3 did not respond. Fifteen reported having some type of health insurance coverage, and 9 were uninsured. Of those who were insured, Medicaid was the most common form of insurance.

Substance Use History

Twenty-one individuals provided information about their age when they first used alcohol or illicit drugs. The average age at first use was 18.6 years old, with a range from 12 to 39 years. More than half of the population began at age 16 or younger.

When asked what drug or drugs they use, or recently used regularly, the one most frequently used was heroin, reported by 11 respondents. Crack and alcohol use were each reported by seven respondents, and cocaine use was reported by five respondents. Six respondents reported polysubstance use.

The majority of the respondents (20 individuals) reported that they were currently in recovery for their substance use. This included 10 individuals who were currently in the detoxification/step-down program. Fourteen respondents reported their length of time in recovery. For those with more than six months of recovery, the average length of time in recovery was 2.3 years.

Substance Abuse Treatment Experience

The median number of times respondents had been in substance abuse treatment was 5.5, with a range from 1 to 52 treatment episodes reported. For their most recent experience with substance abuse treatment, respondents reported a wide array of modalities, and many reported multiple modalities. Self-help groups, detoxification, and group counseling were reported most frequently, followed by individual counseling and residential treatment. Aftercare, outpatient care, family counseling, and methadone maintenance were also cited, but far less often.

Respondents were asked whether they preferred substance abuse treatment programs that were specific to their gender, race/ethnicity, sexual orientation, or HIV status. Twenty individuals answered this question. Ten said they preferred population-specific programs. Ten others said they did not care. Those who preferred population-specific programs included:

- 7 of the 10 male respondents;
- 2 of the 8 female respondents;
- 1 of the 1 transgender respondent;
- 3 of the 3 Caucasian respondents;
- 4 of the 17 African American respondents;
- 2 of the 3 Latina/o respondents;
- 1 of the 1 Other racial/ethnic group respondent;

- 7 of the 17 heterosexual respondents; and
- 2 of the 3 gay/lesbian respondents.

Although only three individuals said there was ever a time they wanted substance abuse treatment but were unable to get it, respondents did identify numerous barriers to accessing substance abuse treatment. The most frequently identified barriers were related to stigma, comfort with treatment, and confidentiality. Specifically, these barriers included concerns about other people finding out their HIV status, negative attitudes about HIV by substance abuse treatment staff, and personal comfort issues regarding readiness for treatment. The only other barrier cited more than once was long waits for treatment.

When asked what helped them stay clean and sober, the most common responses were reasons like spirituality, fear of dying young, not wanting to hurt one's self or other people, honesty, and being in programs that make them feel comfortable.

HIV Medical Care

The majority of respondents (22 individuals) were currently seeing a doctor or nurse for their HIV care. Eighteen reported taking medications for their HIV infection. Eighteen reported liking their health care providers. When asked what they liked, 14 of the respondents said that their health care provider cared about and understood them. The other four respondents said they liked that their provider was knowledgeable about HIV and could explain it to them.

Although almost all of the respondents were in care for their HIV infection, 18 reported experiencing some type of barrier to this care. The most frequently reported concern was not wanting people to know about their HIV status. Other barriers included judgmental attitudes of providers, medical care not being a priority, not wanting their medical provider to know about their substance abuse, long waits for appointments, and getting lost in the referral process.

Other Services

Twenty-one respondents reported they had no need for other services. Of the three who did report a need for other services that were difficult to obtain, they identified mental health services, eye care, and housing.

DISCUSSION

Although not a representative sample of HIV positive substance users, this small convenience sample provides information specific to the personal experiences of HIV positive substance users who are currently engaged in some form of care. This information is useful in understanding the system of care from the perspective of consumers. It has both validated the information previously obtained from the

professional expert key informants and highlighted some important differences that programs may want to consider in order to provide effective services for HIV positive substance users. It also points out the importance of not making assumptions about what consumers need and want. Rather, it is critical that consumers be asked these questions directly.

Some important findings about barriers to care and what makes a program successful emerged from this study. First, the barriers to medical care and substance abuse treatment identified by consumers were similar. Primarily, they reflected issues of confidentiality, stigma, and lack of comfort. This underscores the importance of sensitive, caring, confidential treatment. Our professional key informants had not considered these barriers as important as our consumer informants did.

Second, consumers believed that what made programs successful were staff sensitivity and attitudes. Our professional key informants shared this perspective. Descriptions of sensitive staff were almost identical between the two groups, with the professional key informants describing staff who "are 'user-friendly' [and] non-judgmental about drug use," "exhibit a commitment to issues around HIV/AIDS," "listen to the needs of the consumers," and "are persistent and consistent, [getting] people to trust them."

Third, half of the consumers and almost half of the professional key informants cited the existence of population-specific programs as being important for program success. It is interesting that this was viewed as important by as large a proportion of Caucasians and heterosexuals as it was by those of other races and those who were gay, lesbian, and bisexual.

Other important issues also emerged. First, the study participants had a great deal of collective experience in substance abuse treatment. The repeated episodes appears to corroborate a professional key informant's experience that people have "treatment careers," going in and out of treatment many times before being able to successfully end their addictions. This may also account for the feeling among the respondents that they were almost always able to access the substance abuse treatment and support services they needed and that insurance status was not a barrier to care.

Second, the majority of respondents were in care for their HIV infection and were taking HIV medications. This finding is important when thinking about initiating complex treatment regimens.

Limitations of the Study

The results of this study are based on the responses of a convenience sample, and not on a randomized, scientific sample of HIV positive substance users. Thus, the experiences are specific to this small group and cannot at this time be generalized to cover a larger group of HIV positive substance users. Also, all of the respondents were engaged in some form of care or were receiving support services. As such, their responses may be very different from responses that may be given by HIV positive substance users who are

completely outside the system of health care. This may explain the differences in responses between our professional key informants and our consumer sample regarding the importance of access to care, health insurance, and support services.

A larger study that includes people who are not currently or who have never been in the system of care would be useful. It would help in developing generalizations for program design, evaluation, and standards established to guide the future development of treatment and care for this population.