Informational Barriers to Care Among persons living with HIV/AIDS in the Houston EMA

A special study of the
Comprehensive HIV Planning Committee
Houston Ryan White Planning Council

FINAL
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Introduction

In 2009, the Comprehensive HIV Planning Committee of the Houston Ryan White Planning Council commissioned a special study aimed at informational barriers to care among persons living with HIV/AIDS. The impetus of this study stemmed from findings in the 2005 and 2008 Houston Area HIV/AIDS Needs Assessments in which "information" was identified as the #1 barrier to care. The goal is to gain some insight into the operational meaning of "informational barriers to care."

The findings in this study are based on survey responses from persons living with HIV/AIDS (PLWHAs) receiving clinical and supportive services from select agencies in the Houston metro area. We chose to utilize surveys in order to maximize data and quantify factors related to informational barriers to care.

Methodology

The findings of this study were based on 157 self-administered surveys by PLWHAs receiving clinical and/or supportive services from six Houston-area agencies. Surveys were two pages in length, with 25 numbered items. Questions were multiple choice format, with a few open-ended items. Participants self-administered the surveys and none indicated need for assistance. A $10 gift card for Wal-Mart was offered upon completion of each survey.

At the beginning of every survey session, a survey administer explained the purposes of the survey and overall study. Surveys were completely anonymous – first and last names were not collected during the course of the study. In exchange for each completed survey, the last 4-digits of a gift card were written on the top of the survey form. This was done for accounting purposes and to document that each gift card was linked to a completed survey.

Survey items were based on needs assessment items and suggestions from Comprehensive Planning Committee members. Most surveys took less than 30 minutes to complete. Survey data were analyzed by SPSS.

Limitations

There were a few limitations to this study that are worth noting when interpreting the results. First, survey sites were concentrated in the Houston metropolitan area. Second, the majority of respondents were in care. Third, due to differences in how some surveys were administered, it is possible that one or more individuals took a survey more than once. Although surveys were administered on different days at a certain agency, past experience administering surveys at this agency, as well as the fact that many clients attend the same clinic multiple days a week, mean we cannot be certain that the surveys are unduplicated. While it is unlikely that there are a high number of duplicated surveys, it is still a possibility. Lastly, due to differences in survey administration, a number of surveys had missing or incomplete data.

Participants

The majority of the 157 surveys were administered in English (88%). The top three zip codes were 77022, 77021 and 77018.

Participants had been positive an average of 10 years, ranging from 2 months to 29 years. Almost all were in-care, per HRSA definition (no viral load test, CD4 test or prescribed HIV medications in 12 consecutive months).

Approximately half (54%) of the participants were male, and 43% were female. There were 4 survey participants that identified as male-to-female transgendered. The majority of participants were Black/African-American (67%); 19% were Hispanic., 9% White and 5% identified as other race/ethnicity categories.

English was, by far, the preferred language spoken during doctor visits (85%). Spanish was preferred by 13% of participants and 3% stated that they had no language preference. The majority (85%) of participants were US citizens while 3% had green cards and 1% had some type of visa. Eleven percent of participants chose not to report their citizenship/immigration status.

Almost a third (29%) of participants were unemployed, and 40% were not working due to disability. Sixteen percent had full-time jobs, 12% had part-time jobs and 4% had temporary/odd jobs. One participant was retired.

Eighteen percent of participants reported being released from jail or prison within the past 12 months, and 4% of all respondents said they were eligible for veteran benefits.

The majority (88%) of respondents reported sleeping most often in an apartment or house. Five participants reported sleeping most often in a shelter or on the street.

The following table shows a detailed demographic breakdown of the 157 survey participants.

TOTAL SURVEYS - ENGLISH - SPANISH	TOTAL = 157 138 (88%) 19 (12%)
Zip Code (most common)	77022, 77021, 77018, 77004, 77002, 77026
Number of years HIV positive	Average = 10 years Range = 2 months to 29 years
In-care status - In Care - Out of Care	 155 (99%) 2 (1%)
Gender - Male	 85 (54%)

- Female - Transgender (MtF)	68 (43%) 4 (3%)
Race/Ethnicity - White - Black/African-American - Hispanic - Multiracial/Asian/Other	 14 (9%) 105 (67%) 30 (19%) 7 (5%)
Preferred language during doctor visits - English - Spanish - Either (no preference)	 133 (85%) 20 (13%) 4 (2%)
Immigration Status - Citizen - Permanent Resident - Visa - Other/Prefer not to say	 132 (85%) 5 (3%) 2 (1%) 16 (11%)
Job status - Full Time - Part Time - Temporary/Odd Jobs - Not working due to disability - Unemployed - Retired	 25 (16%) 18 (12%) 6 (4%) 62 (40%) 45 (29%) 1 (1%)
Released from jail/prison in the past year	27 (18%)
Eligible for veteran benefits	6 (4%)
Housing Status - Apartment/House - Group Home/Halfway House - Shelter - Street	 138 (88%) 14 (9%) 4 (3%) 1 (1%)

- *Numbers and/or percentages may not add up to 157 or 100% due to missing data.*

Entry to Care

Most participants received their HIV diagnoses at clinics (38%) or hospitals (25%). About 11% received their diagnosis in the jail or prison. About 10% of respondents did not remember their place of diagnosis, or simply provided a city or state name.

Location of HIV Diagnosis	**N (%)**
Clinic	60 (38%)
Hospital	39 (25%)
Jail/Prison	17 (11%)
Doctor's Office	12 (8%)
Social Service Agency/Community Testing Site	9 (6%)

Substance Abuse/Mental Health Treatment Program	2 (1%)
Other: (army recruiter, don't remember, specific location not given)	16 (10%)

- *Missing data = 2*

More than half (58%) of respondents reported entering care within 1 month after receiving their HIV diagnosis, and 22% received care within 6 months. Nine percent entered care between 6 to 12 months and 10% entered care after one year. One participant reported never having received any sort of HIV-related care.

Time between diagnosis and first doctor's visit:	**N (%)**
Less than 1 month	91 (58%)
1 – 6 months	35 (22%)
6 – 12 months	14 (9%)
More than 12 months	15 (10%)
Never	1 (1%)

The top reasons for delaying care for more than 6 months was being depressed or having emotional problems (10%), being afraid (7%) or being in denial about living with HIV (7%).

Reasons for waiting more than 6 months to enter care	**N (%)**
I was depressed or had emotional problems	15 (10%)
I was afraid	11 (7%)
I didn't want to believe I was infected	11 (7%)
I was doing drugs	9 (6%)
I didn't have a stable place to live	8 (5%)
I didn't feel sick	7 (5%)
I didn't want to take any medications	7 (5%)
I was in jail/prison	5 (3%)
I didn't have the money	5 (3%)

The majority of respondents (91%) received their medical care most often from a clinic, compared to a hospital (1%) or doctor's office (5%).

Regular Source of Medical Care	**N (%)**
Clinic	143 (91%)
Hospital	2 (1%)
Doctor's Office	7 (5%)

As shown in the table below, the majority of respondents reported receiving care within the past 6 months. Prescriptions for HIV medications showed the most variability – however, depending on health factors such as an individual's length of diagnosis or overall health, HIV medications might not be required.

	Last Doctor's Visit	Last Viral Load Test	Last CD4 Test	Last Prescription for HIV Meds
In the last 6 months	147 (94%)	143 (92%)	142 (90%)	126 (80%)
Between 6 – 12 months	6 (4%)	9 (6%)	7 (5%)	6 (4%)
More than 1 year ago	1 (1%)	1 (1%)	3 (2%)	7 (5%)
Never/Don't Know	2 (1%)	3 (2%)	4 (3%)	16 (10%)

Getting information about needed services

Among the 157 participants, primary medical care, HIV medications and dental services were the services most needed in the previous 12 months. Participants reported that it was hardest to get information about dental services.

Service	Needed the service in the past 12 months	It was hard to get information about the service
Primary Medical Care	146 (93%)	9 (6%)
HIV Medications	130 (83%)	13 (8%)
Dental Services	124 (79%)	23 (15%)
Medical/Clinical Case Management	98 (62%)	6 (4%)
Home Health Care	30 (19%)	4 (3%)
Psychiatric Services or Medicine	79 (50%)	7 (5%)
Psychological Counseling	67 (43%)	8 (5%)
Alcohol/Substance Abuse Treatment Services	41 (26%)	4 (3%)
Rehabilitation Services	39 (23%)	5 (3%)
Other:		
- Community Case Management	1	1
- Housing	4	3
- Immigration assistance	1	1
- Transportation	1	0

Having a Case Manager

A total of 121 (77%) of participants said they had a case manager, and 36 (23%) said they did not. Of the 36 participants without a case manager, 22 said they needed a case manager while 14 said they did not need one.

Barriers to Information

Of the 157 participants, 119 (76%) said it was easy to get information and 38 (24%) said it was hard to get information about services. The top reason getting information was difficult was not knowing how to find the right phone numbers or which agencies to call.

There were no significant differences in access to information by language (English vs. Spanish speakers) or race/ethnicity.

Barrier	N (%)
I don't know how to find the right phone numbers	21 (13%)
I don't know which agencies to call	21 (13%)
I have to wait more than 1 day for someone to return my calls	12 (8%)
I felt afraid	2 (1%)
Staff are not friendly	6 (4%)
I am not eligible for services	4 (3%)
It is hard to reach my case worker	6 (4%)
I don't know where to get information	8 (5%)
Other (unable to read, hard to find information about services offered outside of working hours, language barrier, blind)	7 (5%)

Sources of information

The top three sources of information about services were the Blue Book (61%), their doctor/nurse (52%) and other clients (41%).

Sources of Information	N (%)
Blue Book	95 (61%)
Doctor or Nurse	81 (52%)
Other Clients	64 (41%)
Case Manager	26 (17%)
Internet	21 (13%)
Agency staff (other than Case Manager)	9 (6%)
Friends/Family	5 (3%)
I don't know where to get information	3 (2%)

Use of the Blue Book

Most participants (85%) said they had used the Blue Book. Of those who used the Blue Book, 123 felt the Blue Book was helpful and 10 did not. The top reason the Blue Book was helpful was because it was easy to read and understand.

Helpful	N (%)
It was easy to read and understand	78 (50%)
The information was correct	54 (34%)

I received help from agencies in the Blue Book	64 (41%)
Not Helpful	
It was confusing	6 (4%)
The information was not correct	4 (3%)
I was told I was not eligible for a service	6 (4%)
None of the agencies would help me	5 (3%)

Conclusions

Most participants received their HIV diagnoses at clinics (38%) or hospitals (25%). More than half (58%) of respondents reported entering care within 1 month after receiving their HIV diagnosis, and 22% received care within 6 months. The top reasons for delaying care for more than 6 months was being depressed or having emotional problems (10%), being afraid (7%) or being in denial about living with HIV (7%). The majority of respondents (91%) received their medical care most often from a clinic, and most received some sort of clinical care within the past 6 months.

Primary medical care, HIV medications and dental services were the services most needed by respondents in the previous 12 months. Participants reported that it was hardest to get information about dental services. More than three quarters of participants had a case manager, and most who did not have a case manager felt that they needed one.

Although most (76%) participants said it was easy to get information, most difficulties related to information were related to not knowing how to find the right phone numbers or which agencies to call. The top three sources of information about services were the Blue Book (61%), their doctor/nurse (52%) and other clients (41%).

Recommendations

Based on the findings of this study, the Comprehensive Planning Committee made the following recommendations related to improving information about HIV-related services:

Recommendation 1: Ensure that doctors, nurses and other medical personnel know how to engage clients with, and refer them to, Case Management services.

Recommendation 2: Implement alternative methods of disseminating information from the Blue Book, such as increased visibility of updates provided in the online version of the Blue Book and/or kiosks located at agencies.

Recommendation 3: Continue to disseminate the Blue Book, particularly in clinics, hospital emergency rooms and jails/prisons.

Recommendation 4: Strengthen peer models of client-to-client education.

Recommendation 5: Evaluate and strengthen case manager training to include consumer collaboration and peer perspectives.