

Mental Health and People Living with HIV/AIDS in the Boston Eligible Metropolitan Area

Additional Analyses from the Massachusetts and Southern New Hampshire HIV/AIDS Consumer Study

SUMMARY REPORT

INTRODUCTION

In 2009, JSI Research and Training Institute (JSI) conducted a comprehensive service needs assessment for people living with HIV/AIDS (PLWH) for the Massachusetts Department of Public Health (MDPH) Office of HIV/AIDS and the Boston Public Health Commission (BPHC) HIV/AIDS Services Division. The study included a broad range of questions, including barriers to services, experiences living with HIV/AIDS, quality of life, stigma, and self-sufficiency.

Initial analyses of the data indicated that a large number of respondents in the Boston Eligible Metropolitan Area (EMA) had been diagnosed with a mental health condition in the prior three months (47%). JSI researchers and BPHC staff, as well as members of the Boston EMA HIV Health Services Planning Council were interested in conducting additional analyses to learn more about those with mental health issues. This paper reports the results of this analysis.

METHODS

The study's primary method of data collection was a two-part survey. Phase I was distributed by mail and included questions about service needs and barriers, as well as key demographics. A \$3 up-front gift card incentive was included in the mailing. Phase II was a longer survey that could be taken online, by phone, or by mail. Only those who responded to the Phase I survey were eligible for the longer Phase II survey. A \$25 gift card was offered as incentive to take the Phase II survey. Both surveys were available in four languages – English, Spanish, Portuguese, and Haitian-Creole.

HIV case management programs and the Massachusetts HIV Drug Assistance Program (HDAP) mailed surveys to a random sample of their clients, including on those who had agreed to receive mail from the programs and were at least 18 years of age. To ensure that the sample was representative of the state and the Boston Eligible Metropolitan Area (EMA), providers in western Massachusetts were asked to sample at a higher rate than those in eastern Massachusetts, and providers in New Hampshire were asked to send surveys to all of their clients. To capture responses from homeless PLWH or those without a permanent address, JSI staff met with clients of the Boston Health Care for the Homeless Program and administered the survey to those who were willing to participate. To reach PLWH who were not have been in care, HIV peer support programs were asked to distribute surveys to any clients that may not have been in care. For more details on the methods of this study, see the *Massachusetts and Southern New Hampshire HIV/AIDS Consumer Study Final Report*.

A total of 5,060 Phase I surveys were distributed and 1,791 were completed and returned; 1,339 lived within the Boston EMA. Of the 1,791 who completed the Phase I survey, 1,528 volunteered to take the longer, Phase II survey, and 1,066 were completed and returned; 763 of lived in the Boston EMA. Complete details on the survey samples, including extensive demographic data, are described in the *Massachusetts and Southern New Hampshire HIV/AIDS Consumer Study Final Report*.

Analyses were conducted in SAS version 9.1 (SAS Institute, Inc., Cary NC). Proportions were calculated for categorical variables. Differences between proportions were tested using Chi-Square statistics. A p-value less than 0.05 was considered indicative of a statistically significant difference.

All results presented in this report represent statistically significant differences between the groups being compared, unless otherwise noted.

RESULTS

Results in this report are divided into five sections: (1) prevalence of mental health conditions, (2) characteristics of those with a recent mental health diagnosis (3) other experiences (4) health, adherence, and services for those diagnosed with a mental health condition, and (5) other conditions or dual diagnoses.

Prevalence of Mental Health Conditions

Forty-seven percent of respondents in the Boston EMA reported that they had been diagnosed with a mental health condition in the three months prior to the survey (hereafter referred to as “recent mental health diagnosis”). Thirty-six percent had not been diagnosed, but had experienced symptoms in the prior 30 days. Seventeen percent were neither diagnosed nor had experienced mental health symptoms.

Table 1: Mental Health Status

Mental Health Status	%	(n=727)
Diagnosed with a mental health condition in prior 3 months (recent mental health diagnosis)	47%	342
Not diagnosed but had mental health symptoms in prior 30 days	36%	262
No diagnosis and no symptoms	17%	123
Total	100%	727

Of those with a recent mental health diagnosis, 49% had also been diagnosed with an alcohol or drug problem at some point in their lives. Another twenty-one percent of those with a recent mental health diagnosis *may* have had a potential problem with alcohol or drugs based on a “yes” response to at least two of the four CAGE questions on the survey.¹

The most common mental health diagnoses among respondents are listed in Table 2. Depression and anxiety were the two most common conditions.

¹ The CAGE questions are used to quickly screen for problems with alcohol. The four questions were adapted to reference alcohol and/or drug use and were limited to three months prior to the survey. A positive response to at least two of the questions may indicate a problem with alcohol or drugs.

Table 2: Most Common Mental Health Diagnoses Among Respondents*

Mental Health Diagnoses in Prior Three Months*	(n=342)
Depression	84%
Anxiety	62%
Bipolar disorder	25%
Panic disorder	25%
Posttraumatic stress disorder (PTSD)	25%
Attention deficit hyperactivity disorder (ADHD)	11%
Other mental health condition	5%
Schizophrenia	4%
*Respondents could select more than one option.	

Characteristics of PLWH Diagnosed with Mental Health Condition

The demographic characteristics of PLWH diagnosed with a mental illness are shown in Table 3. Analysis was initially performed on three groups: (1) those with a recent diagnosis, (2) those with recent symptoms but no diagnosis, and (3) those with no diagnosis and no symptoms. Percentages for those with symptoms but no diagnosis were either close to the recent diagnosis group, close to the no diagnosis and no symptoms group, or in between the two groups. Because this group did not stand out as being appreciably different from either of the other two groups, results are presented only for those with and without a recent mental health diagnosis.

In general, those with a recent mental health diagnosis were primarily male (64%), insured (97%), and had been living with HIV for at least five years (77%). A significantly higher proportion of those with a recent mental health diagnosis than those without were White and Hispanic, born in the US, and living with Hepatitis C.

Table 3: Significant Differences in Characteristics of PLWH with and without a Recent Mental Health Diagnosis¹

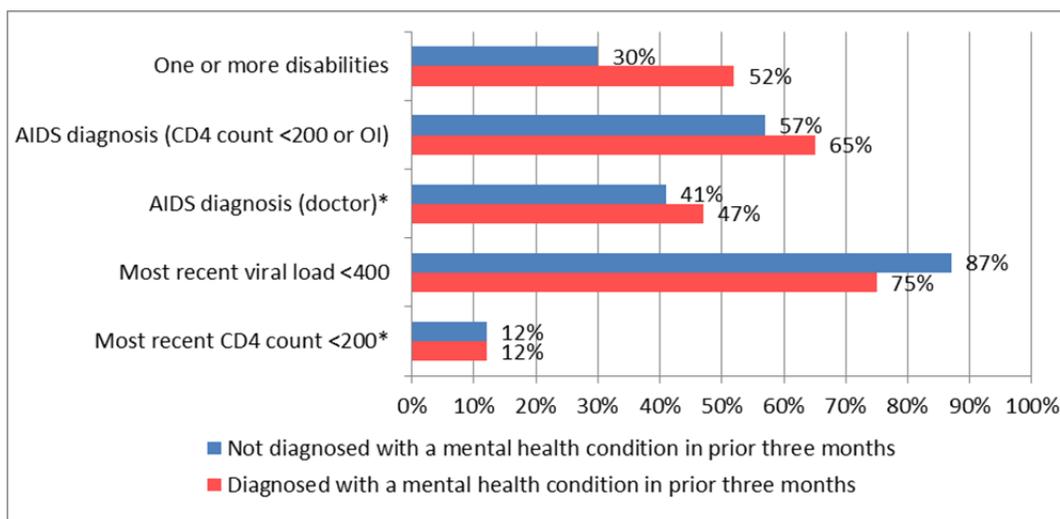
	Recent Mental Health Diagnosis	
	Yes	No
Race	(n=342)	(n=386)
Non-Hispanic White	53%	51%
Non-Hispanic Black	16%	24%
Hispanic	21%	14%
Non-Hispanic Other	6%	7%
Unknown/missing	4%	3%
Place of Birth	(n=340)	(n=377)
U.S./Puerto Rico/territories	93%	87%
Other conditions	(n=339)	(n=377)
Hepatitis C	35%	23%
Housing status	(n=338)	(n=384)
Owns home	77%	84%
¹ There were no significant differences based on gender, sexual orientation, poverty status, insurance status, time since diagnosis, or transmission/risk factor.		

Health Status, Adherence, and Service Needs

This section explores the health status of PLWH with a recent mental health diagnosis, as well as their adherence to HIV medication treatment, and use of and need for various services.

Health status. Using several measures of health status included on the survey, PLWH with a recent mental health diagnosis were not as healthy as those without a recent diagnosis. As shown in Figure 1, a significantly higher proportion of PLWH with a recent mental health diagnosis than those without reported that they had (1) one or more disabilities, (2) an AIDS diagnosis (based on self-report of CD4 count or OI), and (3) a higher viral load.

**Figure 1: Significant Differences in Health Status
Between PLWH with and without a Recent Mental Health Diagnosis**



*Results are not significantly different across groups at the 0.05 level.

Data displayed in Table 4 also suggest lower health status among PLWH with a recent mental health diagnosis. A significantly higher portion of PLWH with a recent mental health diagnosis than those without reported that their health status was “fair/poor” and that they were dealing with three or more chronic diseases in addition to HIV.

**Table 4: Significant Differences in Health Status
Between PLWH with and without a Recent Mental Health Diagnosis**

	Recent Mental Health Diagnosis	
	Yes	No
Health status	(n=338)	(n=383)
Excellent/very good	29%	41%
Good	35%	34%
Fair/poor	36%	25%
Number of chronic diseases	(n=339)	(n=377)
0 diseases	7%	18%
1 disease	18%	21%
2 diseases	24%	24%
3+ diseases	52%	38%

Medication adherence. While the vast majority of those with and without a recent mental health diagnosis were taking HIV medications (90% and 93%, respectively), the analysis indicates that PLWH with a recent mental health diagnosis had more trouble adhering to their HIV medications. As shown in Table 4, a significantly higher proportion of PLWH with a recent mental health diagnosis than those without reported that they (1) had stopped taking their HIV medications for more than a week in the prior six months, (2) had ever missed a dose in the prior two weeks, and (3) had missed a dose one to two times in the same time period.

An analysis of the reasons for not taking medications revealed two significant differences. Specifically, those with a recent mental health diagnosis were significantly less likely than those without a diagnosis to say they weren't taking medications to avoid side effects or because they had a change in their daily routine.

**Table 5: Significant Differences in HIV Medication Adherence
Between PLWH with and without a Recent Mental Health Diagnosis**

	Recent Mental Health Diagnosis	
	Yes	No
Taking antiretrovirals¹	(n=315) 90%	(n=363) 93%
Stopped taking HIV medications for more than a week in prior six months	(n=271) 17%	(n=326) 10%
Ever missed a dose of HIV medications in the prior 2 weeks	(n=278) 43%	(n=334) 33%
How often missed a dose of HIV medications in the past 2 weeks?	(n=278)	(n=334)
Never	58%	67%
1-2 times	34%	27%
3-4 times	6%	3%
5 or more times	2%	3%
Reasons for not taking medications	(n=47)	(n=31)
Wanted to avoid side effects	15%	36%
Change in daily routine	6%	29%

¹These data provided for reference only; differences are not significant at the 0.05 level.

Service needs and utilization. As part of the assessment of HIV service needs, survey respondents were asked to indicate their need for and use of 19 HIV-related services in the six months prior to the survey. Response options included “needed and used” (met need), “needed but couldn’t get” (unmet need), and “didn’t need, didn’t use.” As shown in Table 6, for seven of the 19 services on the survey, there were statistically significant variations in the proportion who reported a met need for each service. For all seven, the proportion who reported that they “needed and used” the service was significantly higher among those with a recent mental health diagnosis. Of note, 76% of those with a recent mental health diagnosis reported that they had needed and used professional mental health treatment or counseling services, more than double those without a diagnosis.

**Table 6: Significant Differences in Met Need for Services
Between PLWH with and without a Recent Mental Health Diagnosis**

Services Needed and Used in Prior Six Months	Recent Mental Health Diagnosis			
	Yes		No	
	%	n	%	n
Help coordinating and planning for HIV care and other services	80%	319	73%	360
Professional counseling or treatment for a mental health issue	76%	310	36%	356
Help taking medications regularly and dealing with side-effects	54%	308	42%	358
Help paying for rent	42%	311	30%	352
Services that help deal with alcohol and/or drug use	34%	312	23%	354
Helping finding a place to live	33%	311	23%	354
Help with legal issues	32%	300	22%	356

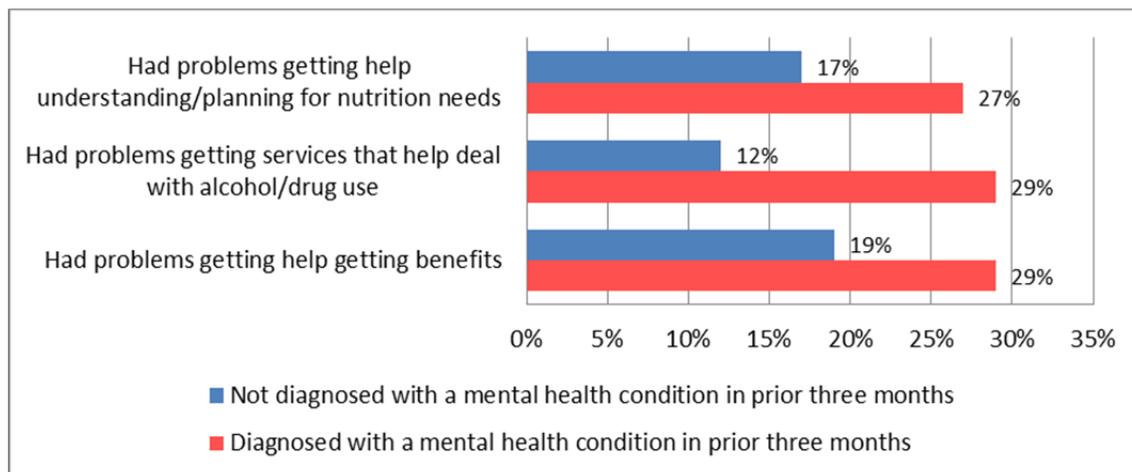
As shown in Table 7, there were also statistically significant variations in the proportion who reported an unmet need for seven services. For all of these services, the proportion who reported that they “needed but couldn’t get” the service was significantly higher among those with a recent mental health diagnosis than those without.

**Table 7: Significant Differences in Unmet Need for Services
Between PLWH with or without a Mental Health Diagnosis**

Services	Recent Mental Health Diagnosis			
	Yes		No	
	%	n	%	n
Helping finding a place to live	21%	311	14%	354
Meals delivered to my home	16%	308	10%	355
Help understanding/planning nutrition needs	15%	305	10%	354
Help taking care of partner, parent or other adult family member	13%	298	7%	353
Help getting benefits	10%	317	6%	357
Services that help deal with alcohol and/or drug use	8%	312	3%	354
Help paying for or getting drugs for HIV/AIDS and related health issues	7%	315	3%	361

Barriers. As part of the survey, respondents were asked to identify any barriers they experienced when accessing services. As shown in Figure 2, a significantly greater proportion of PLWH with a recent mental health diagnosis than those without reported experiencing a barrier to accessing three specific services (nutritional counseling, substance abuse services, and help getting benefits).

Figure 2: Barriers to Services



Service experiences. As part of several questions intended to assess PLWH experiences when using services, respondents were asked to indicate who, if anyone, had spoken with them about mental health topics or substance use in the six months prior to the survey. As shown in Table 8, a significantly higher proportion of those with a recent mental health diagnosis than those without said that someone had talked with them about mental health topics.

Table 8: Discussions about Mental Health Topics with PLWH with and without Recent Mental Health Diagnosis

<i>In the prior 6 months, who has talked with you about mental health topics?</i>	Recent Mental Health Diagnosis	
	Yes (n=338)	No (n=378)
Anyone (at least one of the below)	88%	50%
Medical provider	66%	31%
Case manager	37%	21%
Other HIV provider	19%	7%
Mental health counselor	60%	20%
Substance abuse counselor	13%	4%
Support group member	13%	7%
Other PLWH I know	13%	6%
Family/friends	23%	14%
All differences in this table are statistically significant		

In addition to mental health discussions, a significantly higher proportion of PLWH with a recent mental health diagnosis than those without said that someone had talked with them about alcohol or drug use in the prior six months (see Table 9).

Table 9: Discussions about Alcohol/Drug Use with PLWH with and without Recent Mental Health Diagnosis

<i>In the prior 6 months, who has talked with you about alcohol/drug use?</i>	Recent Mental Health Diagnosis	
	Yes (n=331)	No (n=371)
Anyone (at least one of the below)	63%	47%
Medical provider	45%	33%
Case manager	32%	20%
Other HIV provider	16%	9%
Mental health counselor	35%	8%
Substance abuse counselor	15%	6%
Support group member	14%	9%
Other PLWH I know	15%	7%
Family/friends	23%	13%
Differences in this table are statistically significant		

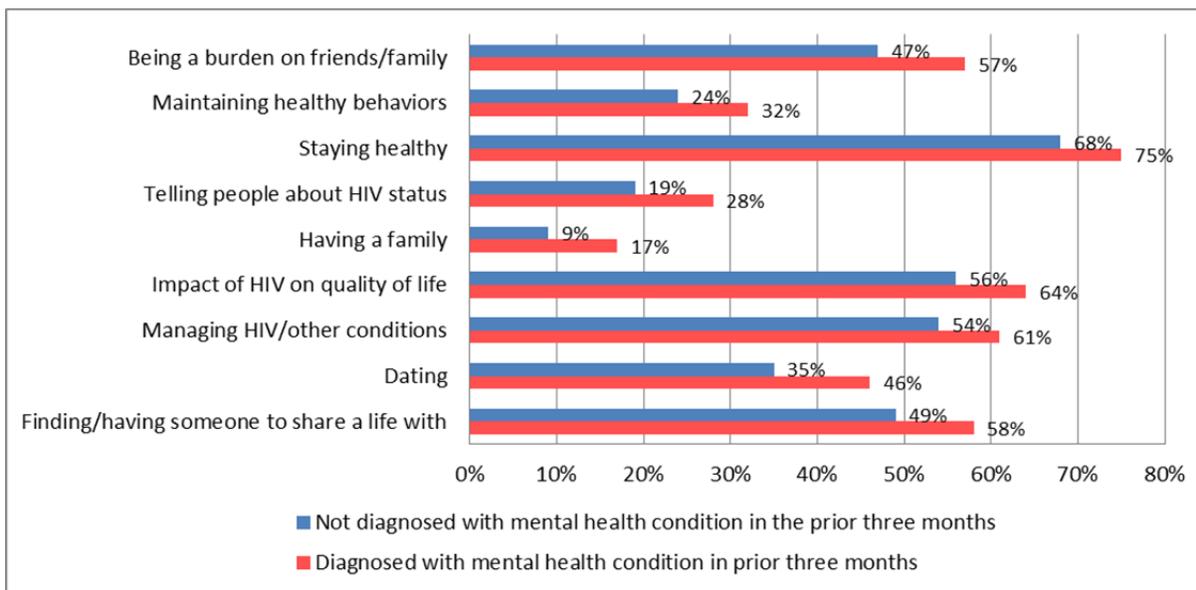
Similarly, a significantly higher percentage of those with a recent mental health diagnosis than those without (69% vs. 56%) said that someone had talked with them about their sexual health in the six months prior to the survey.

Other Experiences

This section includes findings related to growing older with HIV/AIDS and experiences with HIV-related stigma among those with a recent mental health diagnosis.

Aging. Respondents were asked to indicate what they think or worry about as they grow older living with HIV/AIDS. As shown in Figure 3, for a number of issues, a significantly higher proportion of PLWH with a recent mental health diagnosis than those without reported that they think about these issues. The most common worry was staying healthy. A high percentage of respondents were also worried about the impact of HIV on quality of life, managing HIV or other conditions that come with aging, finding or having someone to share a life with, and being a burden on friends and family.

Figure 3: Significant Differences in Concerns about Growing Older Living with HIV/AIDS Between Respondents with and without a Recent Mental Health Diagnosis



Experiences with stigma. To assess experiences with HIV-related stigma, the survey included 12 validated statements with which respondents were asked to agree or disagree. Cluster analysis of the responses identified four factors represented by the 12 stigma statements in the survey. These included (1) negative self-image, (2) disclosure concerns, (3) negative perceptions of how others see PLWH, and (4) experiences of discrimination/rejection.

Those with a recent mental health diagnosis were more likely to have reported experiences of HIV related stigma. As illustrated in Table 10, for 11 of the 12 stigma statements, the proportion of respondents who agreed/strongly agreed with each statement was significantly higher among PLWH with a recent mental health diagnosis than those without a diagnosis.

**Table 10: Significant Differences in Stigma Experiences
Between PLWH with and without a Recent Mental Health Diagnosis**

Factor	<i>Strongly agree or agree that . . .</i>	Recent Mental Health Diagnosis			
		Yes		No	
		%	n	%	n
2	Worry that people who know I have HIV will tell others	62%	335	51%	383
2	Most people are uncomfortable around someone with HIV	62%	338	48%	386
2	Work hard to keep my HIV a secret	55%	334	45%	384
1	Feel isolated from the rest of the world	53%	336	33%	381
2	It is hard for PLWH to have long term relationships	53%	337	43%	385
3	Most people believe a PLWH deserves it for how he/she lived	49%	336	35%	384
3	People's attitudes make me feel worse about myself	49%	334	27%	385
4	Stopped hanging out with someone because of reaction to my HIV	47%	334	28%	383
4	Have lost friends/family by telling them I have HIV	44%	335	28%	386
1	Feel guilty because I have HIV	43%	335	30%	381
1	Having HIV makes me feel like a bad person	21%	337	13%	385

The Dually Diagnosed

Survey respondents were considered to have a “dual diagnosis” if they (1) had a recent mental health diagnosis and (2) screened positive for a potential alcohol/drug problem based on the CAGE questions (described previously). Of the EMA survey sample, 72 respondents (9.4%) met this definition for dually diagnosed. For the analyses described in this section, the dually diagnosed group was then compared with three other groups: (1) those with a diagnosed mental health condition only, (2) those with a potential substance abuse problem only, and (3) those with neither a mental health nor substance abuse problem.

By a number of measures included in the surveys, PLWH with a dual diagnosis were not as healthy as the comparison groups. For example, 25% of dually diagnosed PLWH reported a CD4 count below 200 (based on their most recent test), and 66% reported a viral load below 400; both proportions were significantly higher than among the three comparison groups.²

When asked about their health at the time of the survey, dually diagnosed PLWH rated their health status lower than other groups. Specifically 40% of the dually diagnosed reported “fair” or “poor” health status, significantly higher than the comparison groups, and 29% rated their health as “good,” a significantly lower proportion than the other three comparison groups.

PLWH with a dual diagnosis were also living with more chronic conditions than other groups. Specifically, 50% of dually diagnosed PLWH said they had three or more chronic diseases, a proportion that was roughly equivalent to those with a recent mental health diagnosis, but significantly higher than

²The percentage of the dual diagnosis group that had a diagnosis of AIDS from a doctor was not significantly different from the other comparison groups (51%).

among those with a substance abuse problem only and those with neither a recent mental health diagnosis nor a substance abuse problem.

Among PLWH with a dual diagnosis, data on the need for and use of two services (professional mental health counseling/treatment and substance abuse services) were analyzed. In terms of mental health counseling/treatment, the proportion of dually-diagnosed who needed and used this service was not significantly different than those with only a mental health diagnosis. However, those with a dual diagnosis were more likely than the other comparison groups to report three specific barriers to accessing mental health services (see Table 11), including experiencing transportation problems, choosing not to go, and “other” (not specified).

Table 11: Significant Differences in Barriers to Mental Health Services

Barrier	Dual Diagnosis (n=72)	Only Recent Mental Health Diagnosis (n=268)	Only Recent Substance Abuse Condition (n=58)	No Mental Health or Substance Abuse Condition (n=350)
Transportation problems	13%	8%	4%	3%
Chose not to go	7%	2%	0%	3%
Other	10%	3%	5%	8%

In terms of substance abuse services, 74% of those with a dual diagnosis said that substance abuse services were essential, significantly higher than the proportion among the three comparison groups. More than one-half (55%) said they needed and used substance abuse services, but 20% reported an unmet need for these services. Both of these percentages were significantly higher for the dual diagnosis group than for the other three comparison groups.

Beyond mental health and substance abuse services, those with a dual diagnosis also reported difficulties getting and keeping housing. As shown in Table 12, the dually diagnosed were significantly more likely than those without either diagnosis to have had challenges getting housing and keeping housing. They were also significantly more likely to have had an unmet need for help paying rent. No differences were identified when compared to those with either a mental health or substance abuse condition only.

Table 12: Significant Differences in Housing Challenges and Service Needs

	Dual Diagnosis (n=72)	No Mental Health or Substance Abuse Condition (n=350)
Had trouble getting housing	41%	21%
Had trouble keeping housing	43%	22%
Unmet need -- help paying rent	36%	20%

Analysis of the HIV-related stigma responses suggests that dually-diagnosed PLWH have greater experiences of stigma than other groups. As shown in Table 13, significantly higher percentages of the dual diagnosis strongly agreed/agreed with 10 of 12 stigma statements compared to the other three

groups. For more information on the stigma questions included in the survey and the four-factor analysis performed, see the “experiences with stigma” section discussed previously.

**Table 13: Significant Differences in Stigma Experiences
Among PLWH with a Dual Diagnosis and Three Comparison Groups**

Factor	Stigma Statement	% Agreed/Strong Agreed			
		Dual Diagnosis (n=70)	Recent Mental Health Diagnosis Only (n=265)	Recent Substance Abuse Condition Only (n=56)	No Mental Health or Substance Abuse Condition (n=350)
2	Worry that people who know I have HIV will tell others	76%	58%	50%	50%
2	Most people are uncomfortable around someone with HIV	65%	61%	54%	47%
1	Feel isolated from the rest of the world	65%	50%	51%	30%
2	It is hard for PLWH to have long term relationships	68%	49%	54%	42%
3	Most people believe a PLWH deserves it for how he/she lived	66%	44%	48%	33%
3	People’s attitudes make me feel worse about myself	60%	46%	41%	24%
4	Stopped hanging out with someone because of reaction to my HIV	55%	45%	26%	29%
4	Have lost friends/family by telling them I have HIV	53%	42%	22%	30%
1	Feel guilty because I have HIV	56%	40%	34%	29%
1	Having HIV makes me feel like a bad person	30%	18%	17%	12%

DISCUSSION

Based on the 2009 survey of PLWH in Massachusetts and southern New Hampshire nearly 50% of all respondents reported that they had been diagnosed with a mental health condition in the three months prior to the survey. For this reason, additional analyses were conducted to focus more specifically on the unique needs and experiences of PLWH with mental health conditions.

As described above, there were some positive findings from these analyses. For example, the proportion of PLWH who were in care and taking HIV medications was high and did not vary significantly whether or not respondents had a recent mental health diagnosis. In addition, those with a recent mental health diagnosis were more likely than those without to report having had discussions with someone about mental health, substance use, and sexual health issues. Finally, over 75% of PLWH with a recent mental health diagnosis reported that they needed and used professional mental health

counseling or treatment services in the six months prior to the survey, a proportion that was significantly higher than those without a recent diagnosis.

Nonetheless, it is also clear from the results of these analyses that mental health issues had impacts on the health status, service needs, and quality of life of PLWH. As presented above, those with a recent mental health diagnosis were more likely than those without to have (1) had a lower health status; (2) had a greater need for and use of HIV-related services; (3) had an unmet need for services and experienced barriers to access; (4) experienced challenges with adherence to HIV medication; (5) reported concerns about growing older living with HIV; and (6) experienced HIV-related stigma.

The analyses also show that having had a substance abuse issue in addition to a recent mental health diagnosis (“dually diagnosed”) further exacerbated some of the identified challenges and impacts. For example, those who were dually diagnosed were significantly more likely than those with either a substance abuse or mental health condition alone (or neither) to have (1) had lower health status, (2) been living with three or more chronic conditions in addition to HIV, (3) experienced barriers to mental health services, (4) had an unmet need for substance abuse services, (5) had trouble getting or keeping housing, and (6) experienced HIV-related stigma.

CONCLUSION

The results of this analysis indicate that a mental health diagnosis is a significant variable for understanding the differential needs, experiences, and quality of life of PLWH. In general, this population is not as healthy as those not diagnosed with a mental health diagnosis and are more likely to miss doses of HIV medication.

In terms service delivery, the assessment of service needs and utilization presents a contradiction. On one hand, a significantly higher proportion of PLWH with a recent mental health diagnosis than those without reported that they needed and used 12 of 19 HIV-related services. This suggests not only that this group may have greater need for services, but also that services are available to address them. On the other hand, the proportion who reported that they needed but could not get 12 services was higher among PLWH with a recent mental health diagnosis than those without, suggesting some difficulty in accessing services, barriers, or lack of availability.

An examination of barriers to services revealed that a significantly higher proportion of PLWH with a recent mental health diagnosis than those without reported experiencing a barrier for three services – (1) nutritional counseling, (2) substance abuse services, and (3) help with getting benefits. The barriers to substance abuse services is notable, particularly when considering the needs of those who are dually diagnosed, of which 20% said they needed but could not get substance abuse services.

Lastly, living with a mental health diagnosis in addition to HIV presents unique challenges for PLWH and responses to these challenges should be informed by an understanding of these differential experiences. For example, in terms of HIV-related stigma, PLWH with a recent mental health diagnosis were more likely than those without to have agreed with the HIV stigma statements, suggesting that the combination of HIV and mental health issues enhances the perception and experience of stigma among this group. Similarly, PLWH with mental health issues were more likely than those without to report that they worried about a range of issues as they grow older living with HIV. Once again, this suggests that the combination of HIV and mental health issues presents unique challenges to PLWH that can impact their need for services, their self-sufficiency, and their quality of life.