Inaugural Survey on the State of HIV Primary Care

Provider Comparisons Across HIV Specialists and HIV Primary Care Providers

Executive Summary

HIV specialists are decreasing in number despite increasing demands on the HIV healthcare 'system.' Fewer new providers are entering the field, due at least in part to the lack of a pipeline for developing new providers in medical schools, and current specialists are retiring, 'burning out' from the perceptual complexity of HIV treatment, or pursing alternate funding. In light of these trends, the *HealthHIV Inaugural Survey on the State of HIV Primary Care* demonstrates people living with HIV are receiving HIV primary care from other specialties.

Parallel to the HIV workforce changes, the CDC released *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings* in 2006. These revised recommendations call for HIV testing to become routine, which would significantly expand the potential pool of people tested for and diagnosed with HIV. Given this plausible influx, it is necessary to assess the capacity of all primary care providers to deliver care for these new patients.

The *HealthHIV Inaugural Survey on the State of HIV Primary Care* provides a unique set of findings to inform clinicians, program directors, and policymakers on the status, challenges, and opportunities for providing HIV primary care across the United States. This survey illustrates broad support among primary care providers to accommodate newly diagnosed people living with HIV and have primary care organizations serve as a "medical home" for patients with HIV. HIV primary care providers clearly recognize the need to address the disease within their communities. They are implementing HIV training for current staff, seeking technical assistance, and are in need of new resources and increased funding in every region of the United States.

Analyses of the survey questions were undertaken to compare responses among participants identifying as HIV specialists or as a HIV primary care provider. Top-line findings include the following:

- 62% of respondents who identify as HIV specialist indicate their HIV caseload "increased" or "increased dramatically," while 43% of HIV primary care providers indicate the same;"

- HIV specialists more frequently indicate they could serve as a one-stop shop, or medical home, for HIV-positive patients. Nearly 55% of HIV primary care providers indicate they can provide a medical home to HIV positive patients;

- HIV specialists (69%) and HIV primary care providers (65%) both indicate it is very to extremely likely that they would be able to accommodate an influx of HIV-positive patients; and

- The greatest needs identified by HIV specialists are mental health care, substance abuse referral and on-site treatment, and oral health care. HIV primary care providers indicate they are providing many HIV related services and in similar proportions to the HIV specialists. The HIV primary care providers also indicate antiretroviral therapy and HIV treatment education are the greatest needs among their patients.

Introduction

The number of HIV specialists is decreasing. While fewer of these specialists are entering the field and current specialists are exiting due to retirement, 'burn out,' and competing reimbursement rates, this survey illustrates there is broad support among primary care providers to accommodate newly diagnosed people living with HIV and have their organizations serve as the "medical home" for patients with HIV. Primary care providers are patients' first source of health care and include general and family medicine.

The *HealthHIV Inaugural Survey on the State of HIV Primary Care* demonstrates people living with HIV are receiving HIV primary care. In 2006, the CDC released *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings*. These revised recommendations call for HIV testing to become routine, thus potentially and significantly expanding the pool of people tested for and diagnosed with HIV. With an influx in the number of people identified with HIV plausible, it is necessary to assess the capacity of healthcare providers to provide care to these new patients.

The *HealthHIV Inaugural Survey on the State of HIV Primary Care* provides a unique set of findings to inform clinicians, program directors, and policymakers on the status, challenges, and opportunities for providing HIV primary care across the United States. Primary care providers (and HIV specialists in particular) clearly recognize the need to address the disease within their communities. Primary care providers are implementing HIV training for current staff, seeking technical assistance, and are in need of new resources and funding in every region of the United States.

Annual publication of the *State of HIV Primary Care* survey will allow HealthHIV to perform multiyear trend analyses illustrating HIV case-load changes, service challenges and

opportunities, and targeted technical assistance and capacity building resources to address the needs of primary care providers. An in-depth understanding of how the disease is affecting specific regions allows HealthHIV to provide leadership through networking and facilitating the adoption of lessons learned across the primary care community. An ongoing evaluation of model primary care programs connects the efforts at the local level to larger regional, statewide, and national trends in HIV care. The *HealthHIV Inaugural Survey on the State of HIV Primary Care* provides a unique set of findings to inform clinicians, program directors, and policymakers on the status, challenges, and opportunities for providing HIV primary care across the United States.

Survey Implementation

The *HealthHIV Inaugural Survey on the State of HIV Primary Care* was created to investigate practice/organization settings, services, patient characteristics, needs and barriers, HIV caseload, medical home feasibility, and steps for accommodating newly diagnosed patients with HIV. The survey was pilot tested among a sample of HIV specialists, which resulted in a 32-item, 15-minute instrument that was disseminated online and through professional conferences. Collaborators who assisted in the promotion of the survey include MedScapeCME and ViralEd.

Analyses of each question were undertaken to compare responses from survey participants who identified as HIV specialists and HIV primary care providers. All respondents to the survey were asked in one question to identify with only one specialty. Those individual respondents indicating HIV as their specialty (a total of 148 respondents) were analyzed separately from all other respondents and removed to a separate data set. A second question asked if respondents provided HIV primary care. Those respondents answering

"yes" (421) were subsequently analyzed. The resulting analyses for both provider types, HIV specialist and HIV primary care provider are presented in the following sections.

Findings

Respondent Characteristics

The racial/ethnic compositions of the HIV specialists and HIV primary care providers are listed in Figures 1 - 2. Since clinicians could only select one specialty area from among a list of 31 items, they had to commit to one specialty area though they may serve HIV patients. Comparing the demographic distributions of respondents by specialty area informs subsequent analyses of clinician representation.

As shown in Figure 1, the majority (53%) of HIV specialists are White/Caucasian, followed by Hispanic/Latino(a) (18%), African American (17%), Asian (5%), Caribbean (3%), Native Hawaiian or other Pacific Islander (3%), and American Indian/Alaska Native (1%).

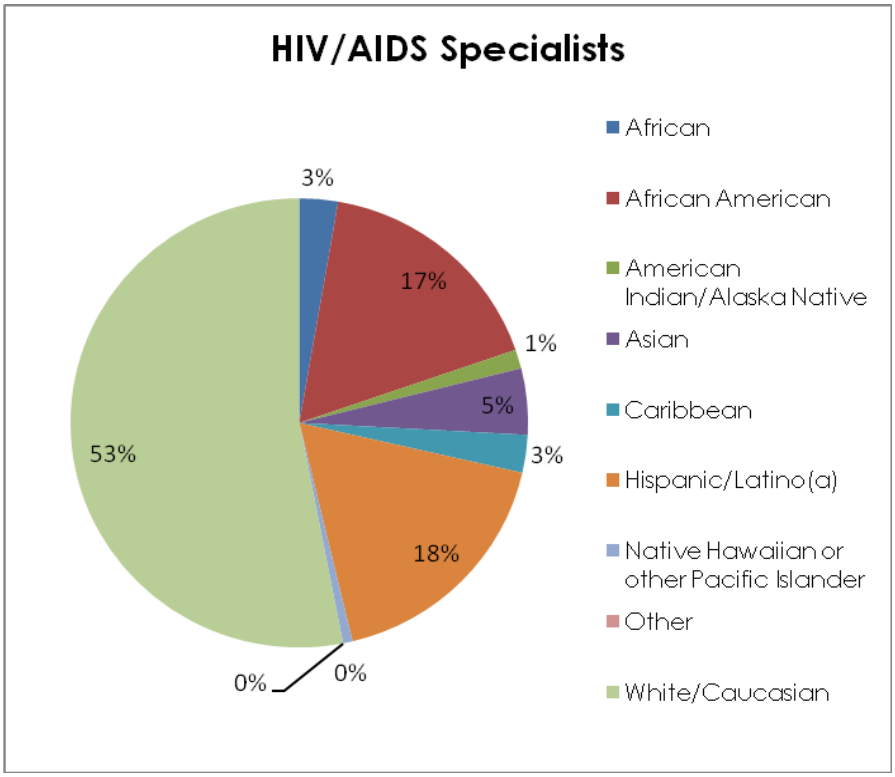

Figure 1. HIV specialists' racial/ethnic profile.

In comparison, the racial/ethnic composition of the HIV primary care provider respondents shown in Figure 2 illustrates the following proportions: 62% are White/Caucasian, followed by Asian (12%), Hispanic/Latino(a) (11%), African American (9%), 3% African, 2% Caribbean, and 1% indicate "other."

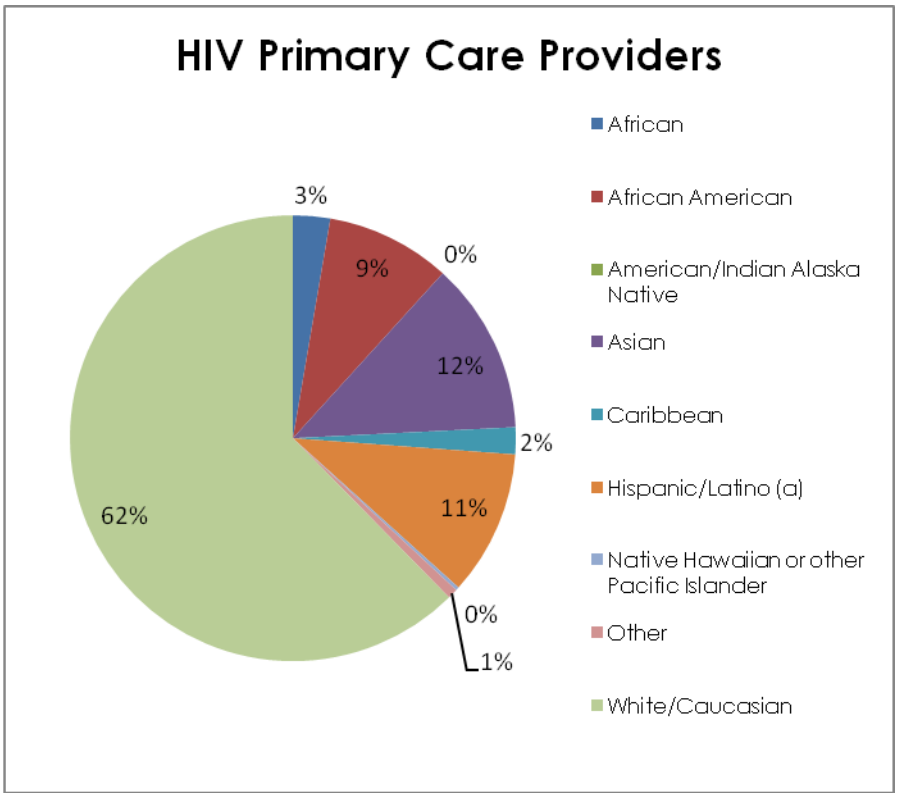

Figure 2. HIV primary care providers' racial/ethnic profile.

The settings of HIV specialists and HIV primary care providers are listed in Table 1. While the largest proportions of respondents are consistently found in urban/metropolitan settings, HIV primary care providers comprise a smaller proportion of non-urban/rural respondents.

Table 1

Provider Settings

	HIV Specialists	HIV Primary Care Providers
Non-Urban/Rural	15%	13%
Suburban	5%	17%
Urban/Metropolitan	76%	58%
Other/Mixed	4%	12%

The practice or organization types of the two groups (HIV specialists and HIV primary care providers) are similarly listed in Table 2. The largest proportion of HIV specialists practice in public clinics, the largest proportion of infectious diseases specialists practice in academic settings (e.g., teaching hospitals), and respondents representing all other specialties are predominantly in public hospitals or private settings.

Table 2

Practice or Organization Types

	HIV Specialists	HIV Primary Care Providers
Academic	15%	15%
Private	10%	26%
Public Clinic	45%	5%
Public Hospital	18%	35%
Other	12%	19%

Patient Characteristics

When asked whether people of color make up over 50% of their patient population, 65% of HIV specialists indicate yes and 46% of HIV primary care providers indicate yes. The following question asked respondents about the racial/ethnic composition of their patients. Figures 4 – 5 illustrates the demographic profiles of patients treated by the two provider types. HIV specialist respondents indicate they serve a majority (45%) African American

patient population, followed by Hispanic/Latino(a) (22%), White/Caucasian (20%), other categories (7%), African (2%), Asian (2%), Caribbean (1%), and American Indian/Alaska Native (1%).

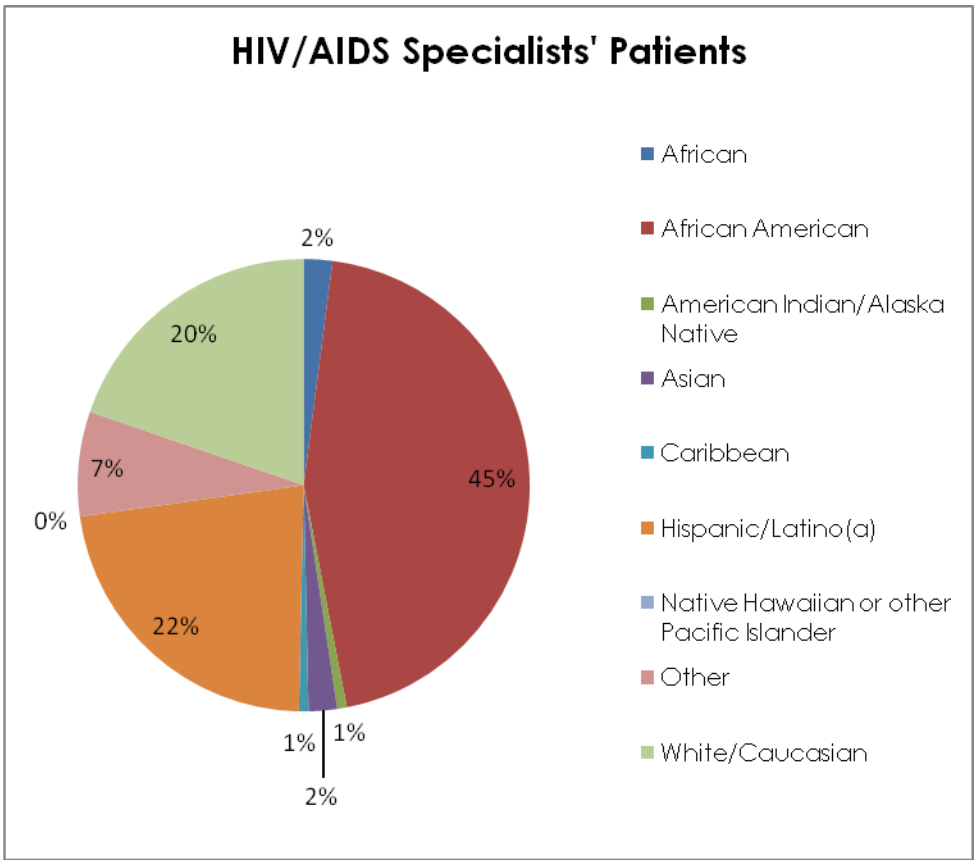

Figure 4. Racial/ethnic profile of HIV specialists' patients.

In comparison, the racial/ethnic composition of the HIV primary care providers shown in Figure 5 illustrate the following proportions: 39% White/Caucasian, 26% African American, 16% Hispanic/Latino(a), 7% other demographic categories, 6% Asian, 3% African, 1% Caribbean, 1% American Indian/Alaska Native, and 1% representing unknown races and ethnicities.

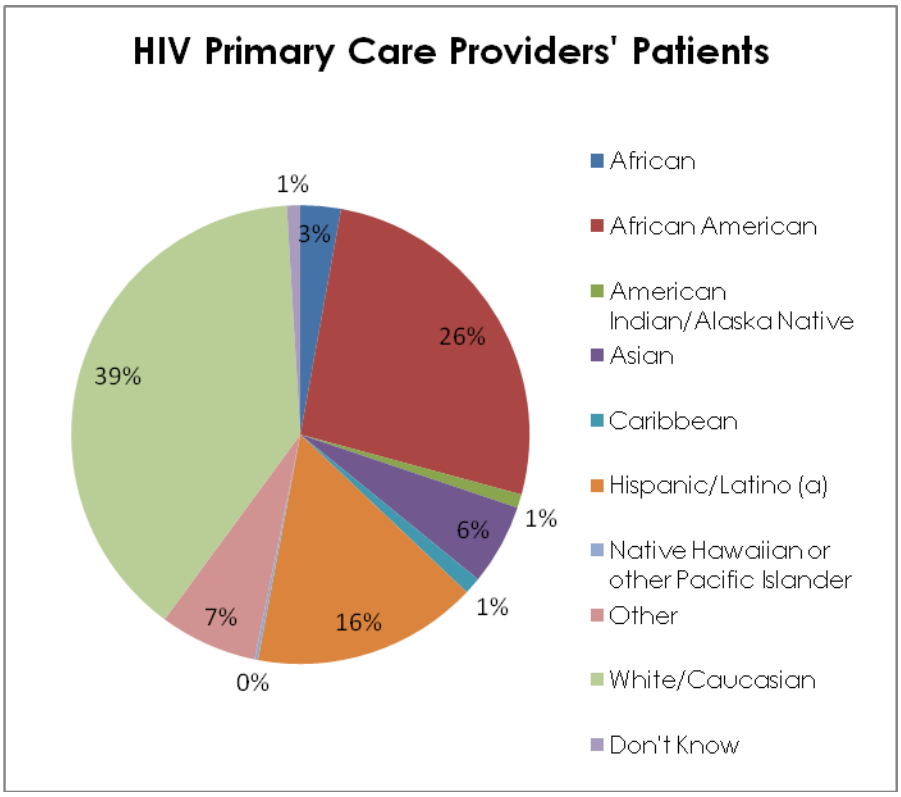

Figure 5. Racial/ethnic profile of HIV primary care providers' patients.

HIV Related Services

Respondents were asked to indicate how many HIV patients are cared for annually within their practice/organization (Table 3). They were presented ranges of less than 5, 6-20, 21-50, 51-100, 101-200, Over 200 or Don't know. Not surprisingly, a greater proportion (79%) of HIV specialists indicated they serve over 200 HIV patients. More surprisingly, 36% of HIV primary care providers indicate they serve over 200 HIV patients.

Table 3

Number of HIV Patients

	HIV Specialists	HIV Primary Care Providers
Less than 5	0	12%
6-20	2%	6%
21-50	3%	9%
51-100	3%	10%
101-200	11%	8%
Over 200	79%	36%
Don't know	2%	19%

HIV Caseload Changes

Respondents were asked to describe any changes to their overall HIV caseload over the previous year. Across all specialist categories, survey respondents indicated their HIV caseload is increasing (see Table 3). More than half of HIV specialist respondents indicate their HIV caseload "increased," and 14% indicate it "increased dramatically." Thirty-six percent of HIV primary care providers indicate their HIV caseload "increased," and 7% indicated it "increased dramatically."

Table 4

Providers' Caseload Changes

	HIV Specialists	HIV Primary Care Providers
Increased dramatically	14%	7%
Increased	60%	36%
Stayed the same	18%	29%
Decreased	5%	5%
Decreased dramatically	2%	3%
Don't know	1%	19%

A follow-up question asked respondents who indicated any increase in their HIV caseload to select from the ranges presented in Table 5. Among the respondents answering this question, 67% of HIV specialists indicate their HIV caseload increased by 1-24%, compared with 60% of HIV primary care providers for the same caseload increase range. Thirty percent of HIV specialists and 26% of HIV primary care providers indicate an approximate percentage increase of 25-49% to their HIV caseload.

Table 5

HIV Caseload Percent Changes

	HIV Specialists	HIV Primary Care Providers
1 – 24%	67%	60%
25 – 49%	30%	26%
50 – 74%	1%	4%
75 – 100 %	1%	3%
Greater than 100%	-	1%
Don't know	1%	5%

Primary care providers were asked to select from a list of HIV related services that they currently provide. They were then asked to select from the same list to indicate which services, if any, their patients most need. Figures 7 and 8 illustrate comparisons among the needs and services indicated by HIV specialists and HIV primary care providers.

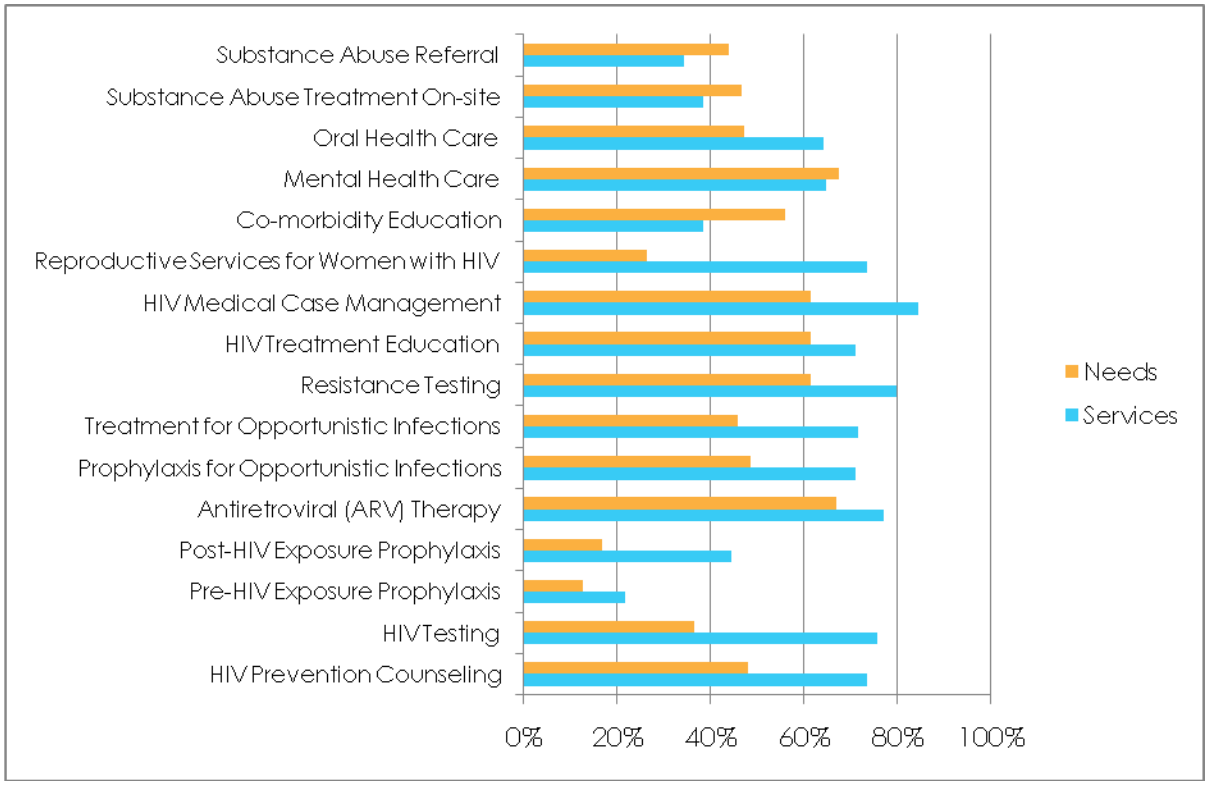

Figure 7. Needs and services according to HIV specialists.

Figure 7 shows that despite a diverse number of service offerings, there are still prevalent HIV service-related needs. Substance abuse treatment on-site, oral health care, and mental health care stand out as needs that outweigh services.

In comparison, Figure 8 illustrates services and needs according to HIV primary care providers. While HIV primary care providers are providing a great number of HIV related services, particularly HIV testing, antiretroviral therapy, and HIV treatment education there remain needs. Antiretroviral therapy, HIV treatment education, and mental health care are three most commonly selected needs for patients among the HIV primary care providers. On-site substance abuse treatment was selected as a need in greater proportion than it was selected as a service provided. Subsequent data collection for the *HealthHIV Inaugural Survey on the State of HIV Primary Care* will compare needs and service offerings to this baseline to determine emerging service gaps.

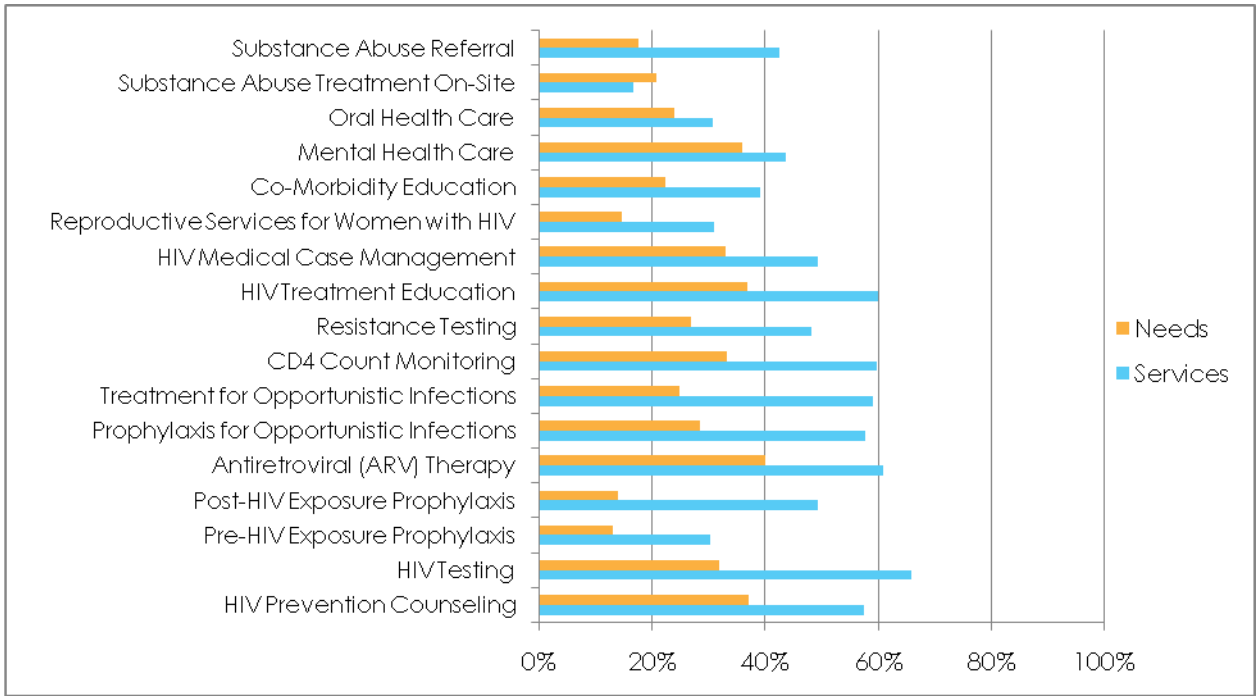

Figure 8. Needs and services according to HIV primary care providers.

Clinical Treatment Standards Use in Practice

The survey also provided respondents the opportunity to indicate which clinical treatment standards, guidelines, and/or recommendations they follow in their practice. Selecting as many of the standards as are applicable, more than half of the HIV specialists (54%) said they follow the *Guidelines for the Use of Antiretroviral Agents in HIV-1 Infected Adults and Adolescents*. The same proportion of HIV specialists say they follow the *Guidelines for Prevention and Treatment of Opportunistic Infections in HIV-Infected Adults and Adolescents*. Only 34% of HIV primary care providers indicate they follow the *Guidelines for the Use of Antiretroviral Agents in HIV-1 Infected Adults and Adolescents*, and the same proportion indicate they follow the *Guidelines for Prevention and Treatment of Opportunistic Infections in HIV-Infected Adults and Adolescents.*

Relatively fewer HIV specialists indicate they follow the clinical standards for perinatal and/or pediatric HIV care, and 36% of HIV specialists in particular make use of the *Public Health Service Task Force Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States* compared to 23% of HIV primary care providers. An additional 22% of HIV specialists and 14% of HIV primary care providers report following the *Guidelines for Prevention and Treatment of Opportunistic Infections among HIV-Exposed and HIV-Infected Children*. Eighteen percent of HIV specialists and 10% of HIV primary care providers use the *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection*.

Barriers to Providing and Receiving HIV Primary Care

Survey respondents were asked to describe the barriers to providing HIV care to HIV positive patients. Respondents were presented a list of sixteen common barriers to providing HIV care and were asked to check all applicable items. Clinicians across both provider categories (HIV specialists and HIV primary care providers) most frequently indicate funding limitations, followed by transportation and lack of clinical staff time to take on new roles/new procedures as barriers. Table 5 illustrates the rank order of barriers among each provider category and the variation across the clinician types by selection frequency.

An additional point of interest is the relative proportion of the different types of clinicians that selected item responses. While funding limitations is the most frequent item response across both clinician types, this was selected by 63% of HIV specialists and only 19% of HIV primary care providers. Across both clinician types, there are significant percentage drops between the most frequently selected barriers. Only 39% of HIV specialists and 12% of HIV primary care providers selected transportation.

Table 5

Specialists' Barriers to Providing HIV Primary Care

Rank	HIV Specialists	%	HIV Primary Care Providers	%
1	Funding limitations	63	Funding limitations	19
2	Transportation	39	Transportation	12
3	Lack of clinical staff time to take on new roles/new procedures	34	Lack of clinical staff time to take on new roles/new procedures	10
4	Lack of support staff time to take on new roles/new procedures	30	Perceived complexity of HIV medical treatment	8
5	Lack of referral partners	21	Lack of support staff time to take on new roles/new procedures	7
6	Language/translation services	18	Language/ translation services	7
7	Staff turnover	15	Lack of referral partners	5
8	Immigration/citizenship documentation requirements	13	Staff turnover	5
9	Lack of organizational leadership	12	Lack of organizational leadership	4
10	Perceived complexity of HIV medical treatment	11	Stigma or avoidance of HIV issues among staff	4
11	Lack of cultural competency/fluency	9	Lack of cultural competency/fluency	3
12	Stigma or avoidance of HIV issues among staff	8	Immigration/citizenship documentation requirements	3
13	Avoidance of sexual issues among staff	7	Homophobia	2
14	Homophobia	7	Avoidance of sexual issues among staff	2
15	Racism	5	Avoidance of drug abuse issues among staff	2
16	Avoidance of drug abuse issues among staff	3	Racism	1

Community Barriers to Accessing Care

Providers were also presented with a list of barriers people with HIV face in their community when seeking HIV related services. Across the two clinician types, substance abuse and mental illness are among the top three barriers. Among HIV specialists, only HIV stigma from the community was selected as frequently as substance abuse.

Table 6

Providers Indicating Community Barriers for People with HIV

Rank	HIV Specialists	%	HIV Primary Care Providers	%
1	HIV stigma from the community	64	Substance abuse	14
2	Substance abuse	64	Mental illness	14
3	Mental illness	62	Lack of transportation	11
4	Homelessness	56	Homelessness	11
5	Lack of transportation	53	Immigration/citizenship documentation concerns	7
6	Immigration/citizenship documentation concerns	39	Homophobia	7
7	Lack of childcare services	32	Client/service hours of operation not responsive to patient needs	6
8	Homophobia	22	HIV stigma from health care providers	5
9	Client/service hours of operation not responsive to patient needs	22	HIV stigma from the community	5
10	HIV stigma from health care providers	21	Lack of child care services	5
11	Racism	15	Racism	2

Primary Care Organizations as "Medical Homes" for Patients with HIV

When asked if it is feasible for primary care organizations to serve as the "medical home" (i.e., one stop shop of integrated services) for patients with HIV, 72% of HIV specialists indicate yes, compared with 55% of HIV primary care providers. The broad support among the respondents indicates the potential for these primary care provider organizations to address the disease across the U.S.

Absorbtive Capacity for Newly Diagnosed HIV Patients

When asked how likely their practice/organization would be able to accommodate newly diagnosed HIV patients if CDC recommendations for routine testing are implemented, specialists provided an interesting set of responses that are illustrated in Figures 10 - 11. Figure 10 shows that HIV specialist respondents indicate high degrees of likelihood (i.e., 33% extremely likely and 36% very likely).

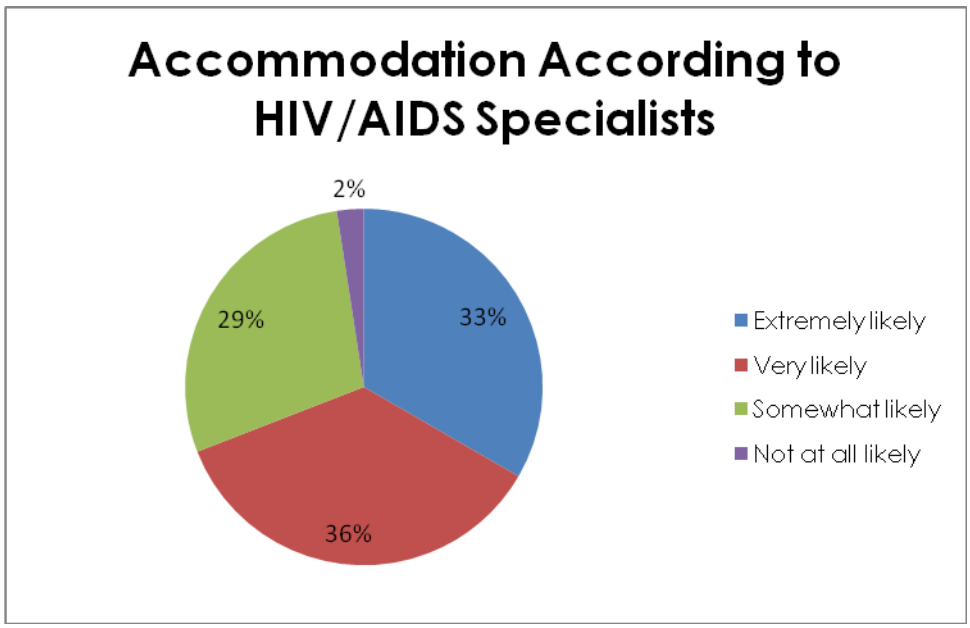

Figure 10. HIV specialists' likelihood of accommodating HIV.

In comparison, 65% of HIV primary care providers similarly indicate it is likely to accommodate newly diagnosed HIV patients. Twenty-nine percent indicate "extremely likely," 36% indicate "very likely," 29% indicate "somewhat likely," and 6% indicate "not at all likely."

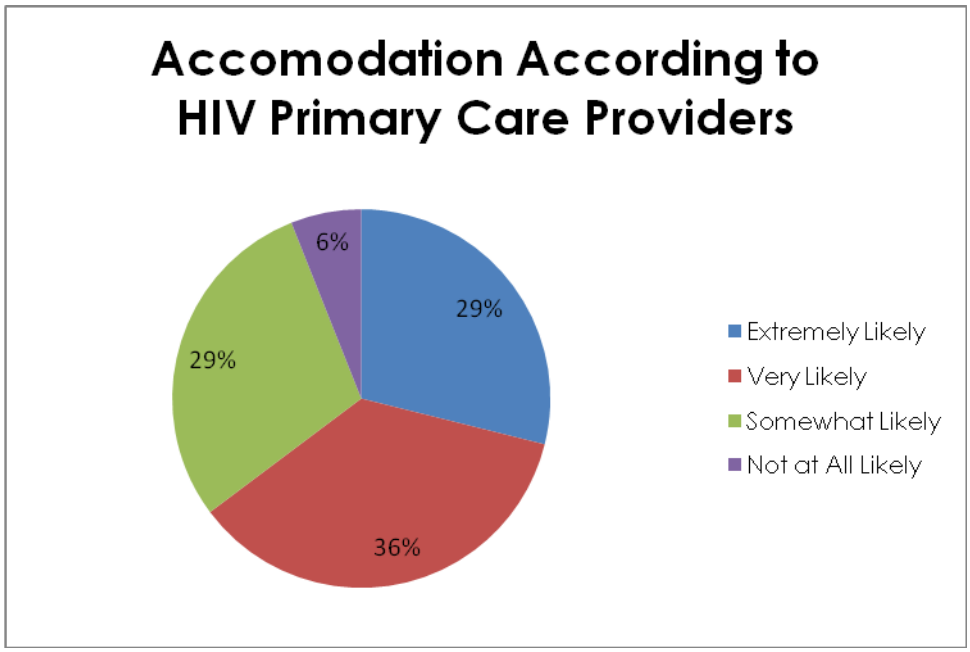

Figure 11. HIV primary care providers' likelihood of accommodating HIV.

Funding Sources

Figure 12 illustrates the funding sources according to HIV specialists, and Figure 13 illustrates the funding sources according to HIV primary care providers. The largest defined funding sources for all specialists are Medicare, Medicaid, client payments, and private insurance. A large "other" category illustrates the breadth of primary care funding streams, and write-in responses include items such as specific grant titles, match funding, and fundraisers/donations.

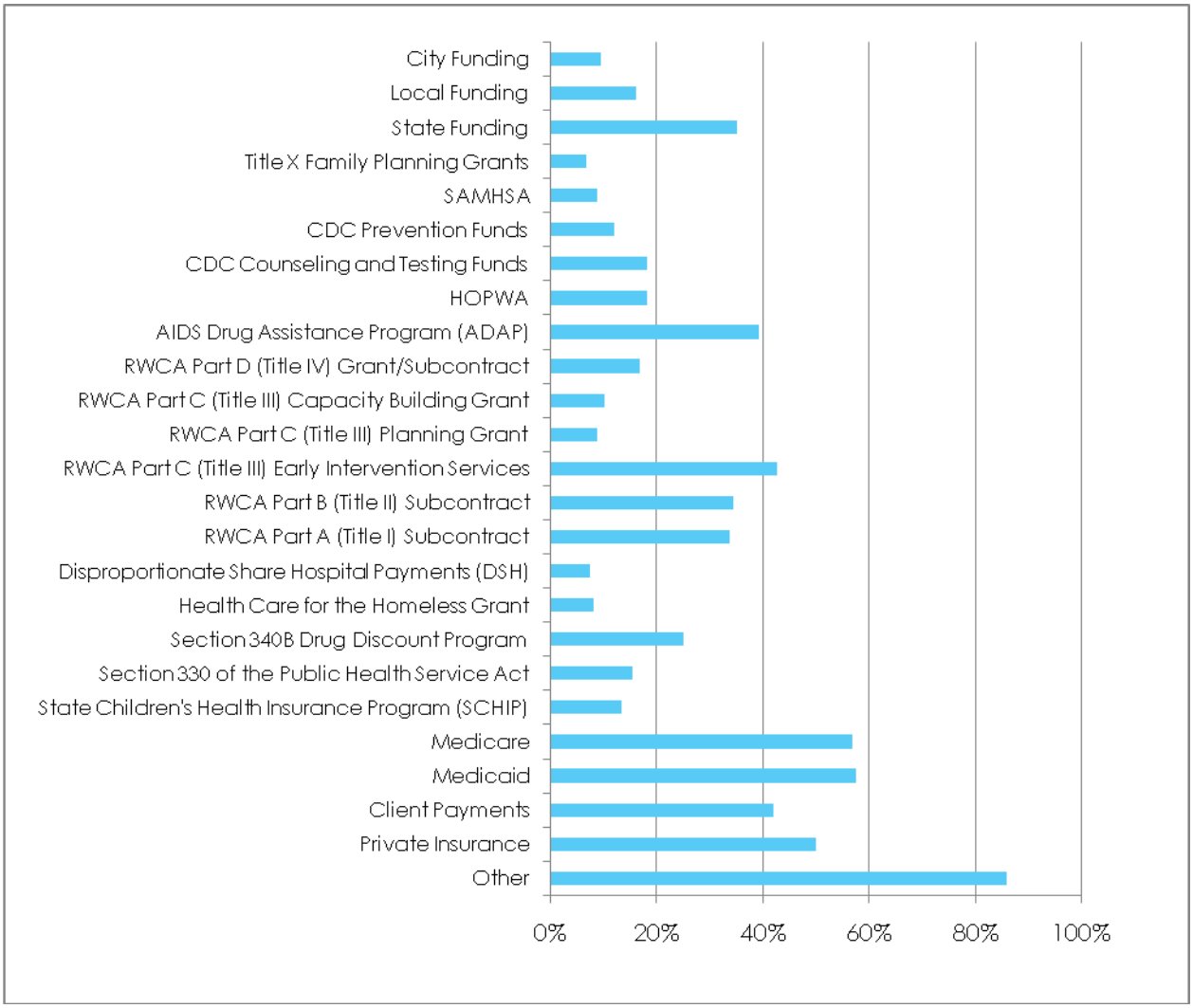

Figure 12. HIV specialists' funding sources.

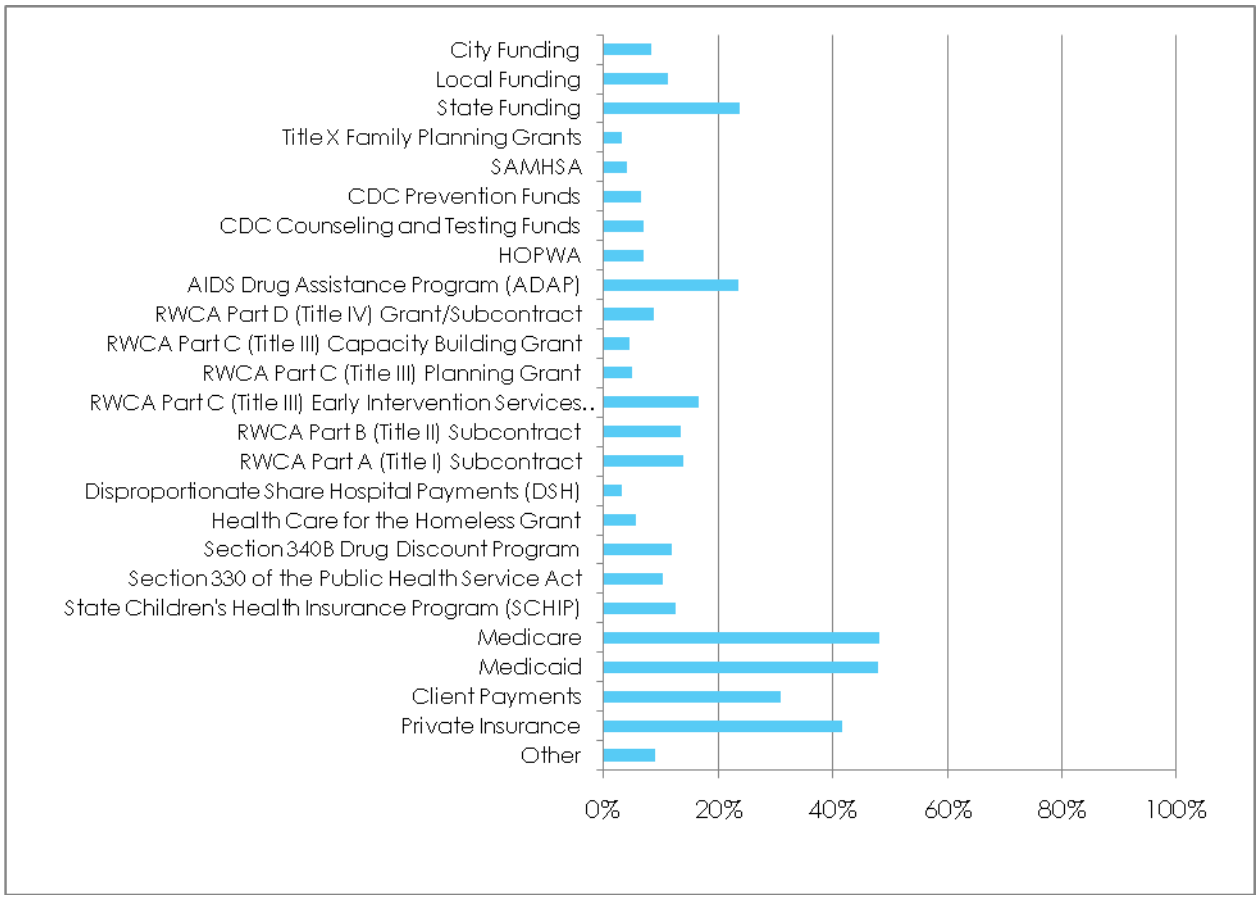

Figure 13. HIV primary care providers' funding sources.

Implications and Recommendations

The analyses of the data by clinical specialty demonstrate the relative roles played by HIV specialists and HIV primary care providers. First, while it is not surprising that HIV specialists in greater proportion see more HIV patients, it is important to note that more than 30% of responding HIV primary care providers also indicate they see more than 200 HIV patients annually in their practices/organizations.

Second, HIV specialists more frequently indicate their HIV caseload "increased" or "increased dramatically." In fact, 62% of HIV specialist respondents indicate their HIV caseload "increased" or "increased dramatically" while 43% of HIV primary care providers

indicate the same. Combined with the falling number of entrants into HIV as a specialty, these numbers indicate the existing specialty infrastructure is nearing its capacity.

Third, HIV specialists more frequently indicate they could serve as a one-stop shop, or medical home, for HIV positive patients. It should come as no real surprise that 72% of responding HIV specialists indicate primary care providers can take on the role of medical home provider for HIV positive patients. What may come as a surprise is this was not a higher proportion. Fifty-five percent of HIV primary care providers indicate primary care providers can provide a medical home to HIV positive patients. Again, it is worthy to note that 45% of HIV primary care providers cannot provide a medical home to HIV positive patients. Perhaps this is due to the perceived complexities involved in treating the overall health and well-being of people living with HIV.

Fourth, it is important to reflect on providers' collective ability to accommodate an increased number of HIV positive patients who will need care if the CDC HIV testing recommendations are fully realized. Both provider types indicate it is very to extremely likely that they would be able to accommodate an influx of HIV positive patients. It is also important to examine the relatively few "not at all likely" responses. Six percent of all HIV primary care providers indicate it is "not at all likely" they would be able to accommodate new HIV patients. This proportion stands in contrast to a smaller proportion of HIV specialists (2%) who indicate it is "not at all likely."

Fifth, HIV specialists and HIV primary care providers are providing a great number of HIV related services ranging from HIV medical case management, HIV testing, antiretroviral therapy and treatment for opportunistic infections. The greatest needs identified by these two provider types are mental health care, substance abuse referral and on-site treatment.

The final point stemming from the findings of this survey is that more HIV primary care providers are needed. Responses clearly show a diminishing and overburdened workforce of HIV specialists and a growing and capable workforce of primary care providers. It is these primary care providers who will be called on to accommodate an increase in their HIV caseload that may result from full implementation of the CDC testing recommendations Both specialists and primary care providers indicate primary care providers could serve as the medical home for HIV positive patients.

Overall, HIV primary care is taking place in the U.S. It is being provided not just by HIV specialists but by HIV primary care providers who do not identify as HIV specialists. Mental health and substance abuse concerns remain significant barriers to patients in their community and in the care and treatment of the patient living with HIV. There are many services being provided in terms of HIV care across the specialties, but mental health and substance abuse services remain critical needs to be filled. Primary care providers may experience their own barriers in providing the "one-stop shop" for HIV patients who have mental health and/or substance abuse needs. In these instances, the connections to other providers in their communities are necessary. Support for and expansion of these networks of care is essential.

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