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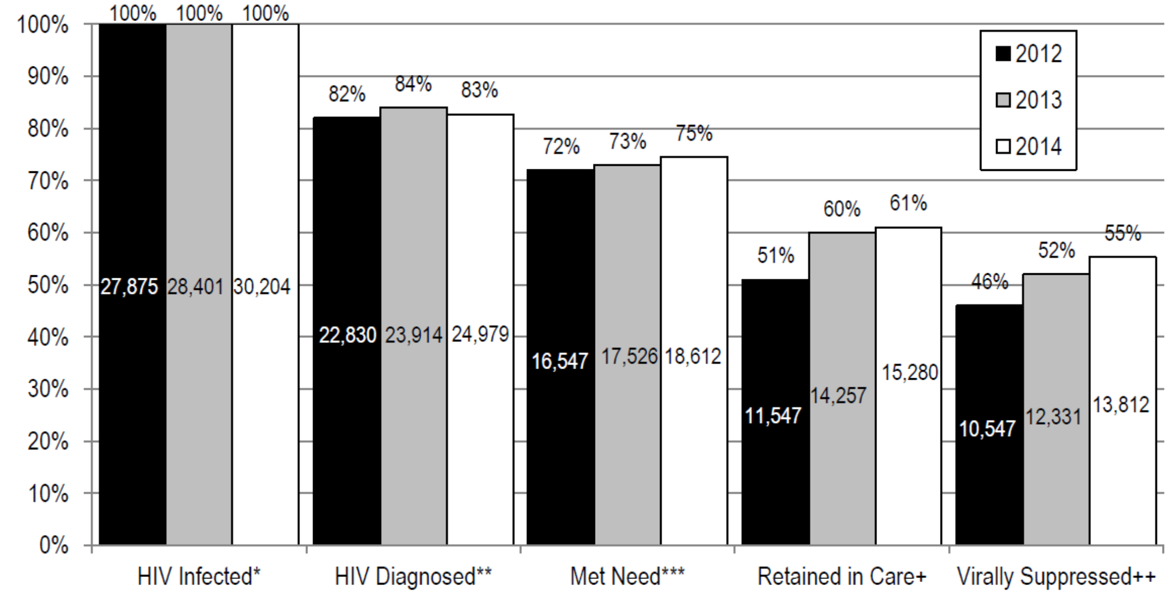
Retention in Care – Houston Area

Epidemiologic Data

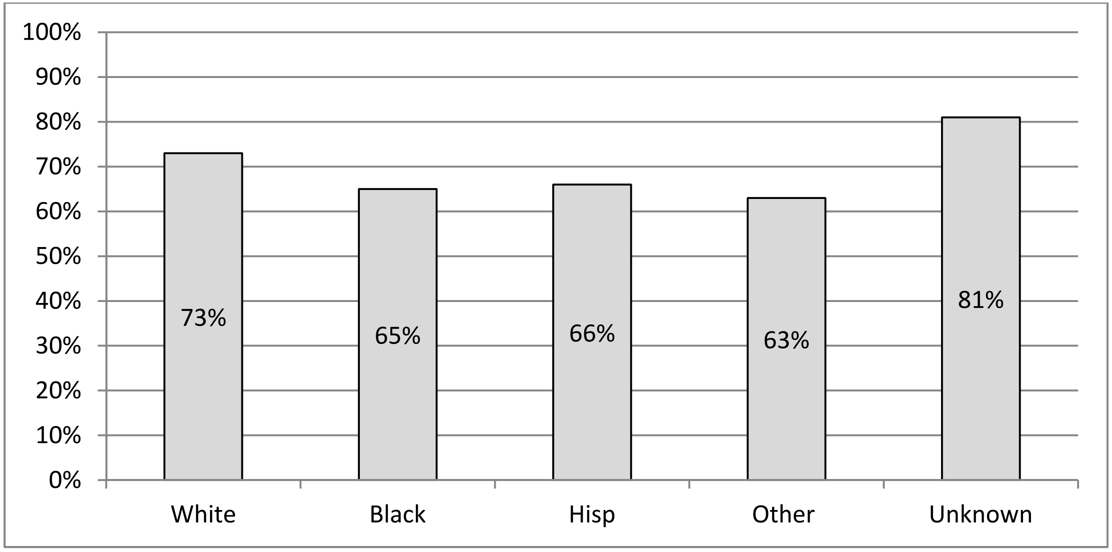
- 75% of diagnosed PLWH in the Houston EMA were in care (at least one: medical visit, ART prescription, VL test, or CD4 test) at the end of 2014
- 61% of diagnosed PLWH in the Houston EMA were ***retained*** in care (at least 2 visits or labs, at least 3 months apart) at the end of 2014
- Retention increases to 67% when virally suppressed diagnosed PLWH in the Houston EMA are presumed to be retained in care. However, this method of calculating retention is problematic as viral suppression is measured as the last viral load test of the calendar year, which may not reflect retention in care throughout the year.

Houston EMA HIV Care Continuum, 2012-2014



*No. person who are HIV positive in 2012, 2013, and 2014 in the Houston EMA (diagnosed + undiagnosed estimate).
**No. persons who are HIV positive in 2012, 2013, and 2014 in the Houston EMA.
***No. persons with met need in 2012, 2013, and 2014 in the Houston EMA.
+No. persons with retained in care (PLWHA with at least 2 visits, labs, or ARVs in 12 months, at least 3 months apart) in 2012, 2013, and 2014 in the Houston EMA.
++No. persons whose last viral load test of 2012, 2013, 2014 <=200 (among persons with >=1 VL test) in the Houston EMA.

Houston EMA Retention[1] by Race/Ethnicity, 2014



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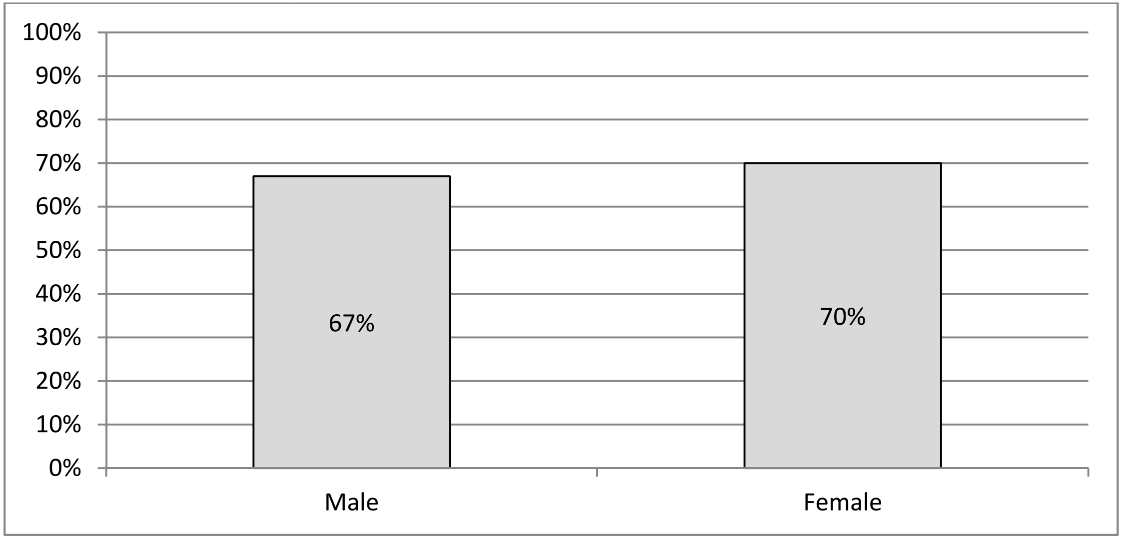
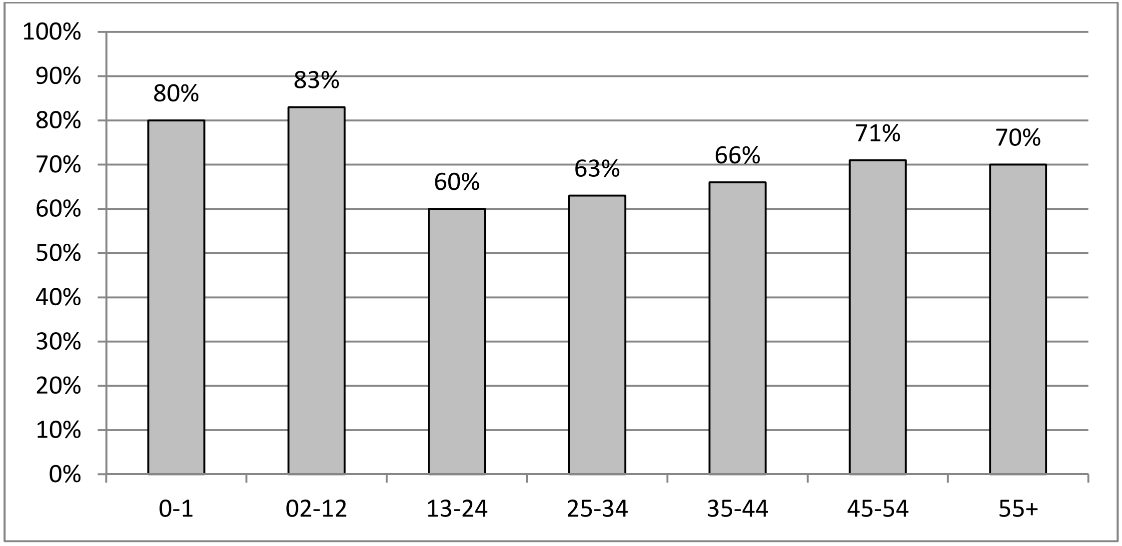
[1] Includes viral suppression

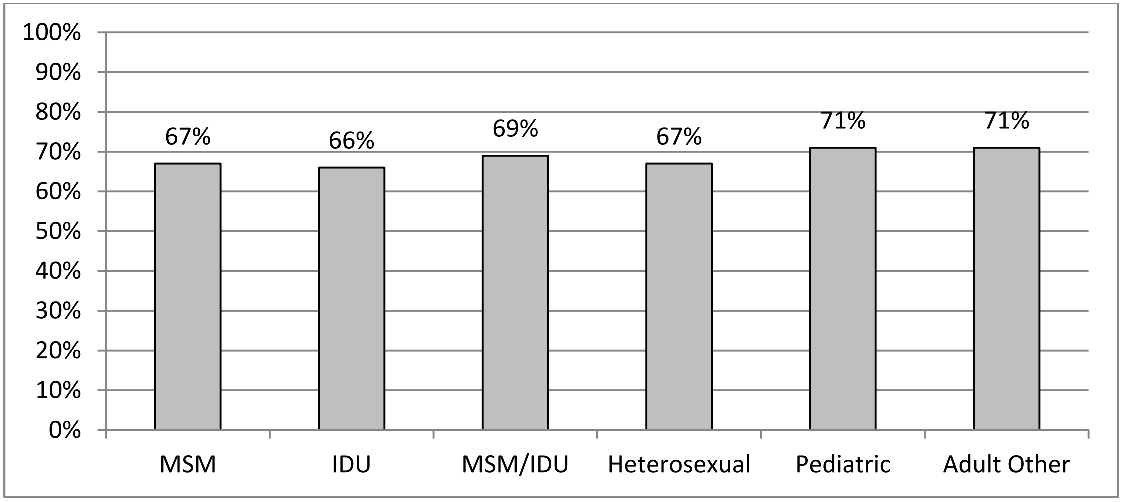
Houston EMA Retention[2] by Sex, 2014



Houston EMA Retention[3] by Age Range, 2014



Houston EMA Retention[4] by Age Range, 2014



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[2] Includes viral suppression

[3] Includes viral suppression

[4] Includes viral suppression

2014 Needs Assessment

- **Current unmet need:**
  - At the time the 2014 Needs Assessment (NA) report was written, the National HIV/AIDS Strategy (NHAS) goal for retention in HIV medical care was 80%. The NHAS Update released in 2015 increased this goal to at least 90% of diagnosed cases by 2020.
  - 93% of NA respondents reported being in HIV care in the past 12 months (likely a result of the data collection process); According to the Texas Department of State Health Services, 61% of diagnosed PLWH in the Houston EMA were retained in care at the end of 2014
- **Continuity of care:**
  - 73% of NA respondents reported never experiencing an interruption in care (being out of care for at least 12 months) since their diagnosis.
- **Barriers to retention:**
  - 27% of respondents reporting an interruption in HIV care for 12 months or more since first entering care identified the following as the most common reasons for the interruption:
    - Not feeling sick
    - Problems with substance use
    - Having other priorities at the time
  - Common write-in reasons for interruption in care were:
    - Incarceration
    - Relocation
    - Denial about HIV positive status
- **Supports for retention in care:**
  - When provided with factors that support retention in care, respondents identified the following as the most common supports for retention:
    - Desire to stay healthy
    - Support from a doctor or nurse
    - Seeing the benefits of treatment
  - Common write-in supports for retention were:
    - Personal motivation
    - Support of social networks
    - Support of staff
    - A policy or program that provides support

Special Studies

- **2013 - Access to HIV Care among Transgender and Gender Non-Conforming People in Houston**
  - 78% of respondents reporting barriers to care identified the following as the most common barriers:
    - Lack of transportation
    - Being treated poorly by staff due to gender variance
    - Lack of funds to pay for services
    - Denial about HIV positive status
  - 19% cited lack of provider familiarity with transgender needs as a barrier to care

Program Outcomes

- **FY 2013 Ryan White Part A Final Outcomes Report Highlights**
  - Percentages of RW/A Program clients retained in care in FY 2013 after accessing select services:
    - 78% - Primary medical care
    - 56% - Medical case management
    - 51% - Clinical case management
    - 49% - Service linkage

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RESEARCH ARTICLE Open Access

Barriers and facilitators to patient retention in HIV care

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Abstract

Background: Retention in HIV care improves survival and reduces the risk of HIV transmission to others. Multiple quantitative studies have described demographic and clinical characteristics associated with retention in HIV care. However, qualitative studies are needed to better understand barriers and facilitators.

Methods: Semi-structured interviews were conducted with 51 HIV-infected individuals, 25 who were retained in care and 26 not retained in care, from 3 urban clinics. Interview data were analyzed for themes using a modified grounded theory approach. Identified themes were compared between the two groups of interest: patients retained in care and those not retained in care.

Results: Overall, participants identified 12 barriers and 5 facilitators to retention in HIV care. On average, retained individuals provided 3 barriers, while persons not retained in care provided 5 barriers. Both groups commonly discussed depression/mental illness, feeling sick, and competing life activities as barriers. In addition, individuals not retained in care commonly reported expensive and unreliable transportation, stigma, and insufficient insurance as barriers. On average, participants in both groups referenced 2 facilitators, including the presence of social support, patient-friendly clinic services (transportation, co-location of services, scheduling/reminders), and positive relationships with providers and clinic staff.

Conclusions: In our study, patients not retained in care faced more barriers, particularly social and structural barriers, than those retained in care. Developing care models where social and financial barriers are addressed, mental health and substance abuse treatment is integrated, and patient-friendly services are offered is important to keeping HIV-infected individuals engaged in care.

Keywords: Retention, Engagement, HIV, Care, Barriers, Facilitators

Background

In order to optimally benefit from HIV care and treatment, HIV-infected individuals must complete several steps along a care continuum – HIV testing and diagnosis, linkage to and retention in primary HIV care, and receipt and adherence to antiretroviral therapy (ART) [1, 2]. Retention in care is essential in this process, providing opportunities to monitor response to HIV therapy, prevent HIV-associated complications, and deliver ancillary services [3–9]. Moreover, retention in care improves survival and reduces the risk of HIV transmission to others [10, 11]. Despite these advantages, only 50–75 % of HIV-infected individuals in the United States (U.S.) linked to care meet national retention in care standards (e.g. completion of two or more HIV primary care appointments per year) [2, 12–16].

Multiple cohort and survey studies have examined predictors of retention in care, noting that younger age, male sex, black race/ethnicity, and use of intravenous drugs are associated with poor retention [2, 10, 12–14, 17, 18]. Conversely, patients receiving case management services and individuals with fewer unmet needs are more likely to consistently engage in care than their counterparts [19, 20]. However, these studies are limited by the type of information available in medical records and

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collected in questionnaires, primarily emphasizing demographic and clinical characteristics. To better understand the full range of factors impacting retention in care, a more qualitative approach is needed.

Some qualitative studies have examined patient-reported barriers and facilitators to retention in care [21–29]. On the patient-level, concerns about privacy, avoidance and disbelief of HIV serostatus, ability to cope with HIV stigma, and substance use have been identified as barriers [21–25]. Patients also described clinic-level barriers such as transportation problems and lack of clinic staff to consistently answer and return phone calls [23, 24, 30]. Facilitators to engagement in care included positive relationships with healthcare providers and a strong social support system [23, 24, 30]. Certain qualitative studies additionally focused on specific populations, such as women of color and those living in rural areas [26–29]. Patient-reported barriers to care in these populations included substance use, depression, stigma, and competing life activities such as family responsibilities and work schedules [26–29]. Similar to other studies, facilitators to care included having a positive patient/provider relationship and access to transportation [26–28].

Our study adds to prior literature by identifying barriers and facilitators to retention in care using contemporary data collected from a diverse population of HIV-infected individuals. Uniquely, we investigate and compare the experiences of patients who are retained and not retained in care to better understand the differences between these groups, including both the number and type of barriers and facilitators to retention in care they report.

Methods

Study design, sample, and recruitment strategy

We recruited HIV-infected adults (≥18 years) from three urban, Ryan White Program funded clinics in Philadelphia – Hospital of the University of Pennsylvania MacGregor Infectious Diseases Clinic, Temple University Comprehensive HIV Program, and the Jonathan Lax Treatment Center at Philadelphia FIGHT – between March and November 2013 - to participate in qualitative, semi-structured interviews. Two clinics were university affiliated, and one was community-based. These clinics offered access to many Ryan White-funded and community services including counseling, support groups, transportation assistance, social work services, and case management to help individuals apply for housing and income assistance.

Using purposive sampling, a nonprobability sampling technique whereby subjects are selected because of specific characteristics, patients with varying retention patterns were invited by phone or approached while in the clinic waiting room to participate in the study. All participants provided written informed consent and were compensated $25 for their time. Recruitment concluded when we reached thematic saturation in our sample.

A multidisciplinary research team, comprised of experts in HIV care, health behavior science, and qualitative research methods, was responsible for the study design, data collection, and analysis. The study was approved by the University of Pennsylvania Institutional Review Board, Temple University Institutional Review Board, and Philadelphia FIGHT Institutional Review Board.

Data collection

For each patient, sociodemographic (age, race/ethnicity, HIV transmission risk factor, health insurance coverage) and clinical data (CD4 cell counts, ART regimen) at the time closest to the interview date were abstracted from the medical record. Retention was based on the U.S. *National HIV/AIDS Strategy* (NHAS) metric, with retained individuals defined as completing 2 or more primary HIV care visits separated by ≥ 90 days in the 12-month period prior to the interview date [31]. Primary HIV care visits refer only to medical care appointments and do not include nursing, pharmacy, laboratory, social services, or other types of visits. HIV viral suppression was categorized as suppressed (HIV-1 RNA ≤ 400 copies/mL) and not suppressed (HIV-1 RNA > 400 copies/mL) based on the median value in the 12-month period before the interview date. A suppression cut-off of 400 copies/mL was chosen to facilitate comparison with other studies.

We developed a semi-structured interview guide designed to elicit patients' perspectives on managing their HIV infection. Interview questions were based on a literature review of barriers and facilitators to HIV care and treatment, which included 20 articles published over the past 10 years, and discussions with experts involved in the care of people living with HIV. Each interview lasted 20–30 min, and was conducted by a trained interviewer familiar with the study goals and skilled in qualitative interview techniques. The interview began with open-ended questions exploring patients' experiences with HIV medical care and treatment. Then, patients were asked to reflect on barriers and facilitators to retention in care, relationships with their providers and clinic staff, and experiences navigating the healthcare system. Following this, patients were asked to comment on their health beliefs, support networks, and ability to address problems that may compromise clinic attendance. Finally, patients had the opportunity to share general reflections regarding their experience managing their HIV infection.

After piloting the interview guide with 6 participants, whose data were included in the final analytic sample, the research team met to review early transcripts and adjust the interview guide to better capture patients' perspectives.

Data analysis

All interviews were audio recorded, professionally transcribed, and imported into NVivo10 software for analysis (QSR International, Melbourne, Australia). Descriptive analyses of the sample were conducted. Interview data were analyzed for themes and patterns using a modified grounded theory approach, a methodology that involves iterative development of concepts about what is occurring in the data as they are collected [32]. The process develops themes and sub-themes that emerge “from the ground” based on responses to the questions. First, an initial set of transcripts was reviewed line-by-line to generate a working coding scheme. Then, using this scheme, we independently coded a second set of transcripts and revised the scheme until no new themes were identified. A subset of 12 transcripts (approximately 20 % of the total sample) was double-coded to check for inter-rater reliability. Inter-rater reliability was compared across a total of 15 nodes. A kappa could be calculated for 8 of the 15 nodes. Of the 8 nodes where kappa was calculated, the median kappa was 1 with a range of 0.75–1. Of the 7 nodes where kappa could not be calculated, there was perfect agreement for 3 nodes and disagreement in 1 of 12 interview transcripts for 4 nodes. Lastly, a subset of the research team applied the final coding scheme to all transcripts.

After all transcripts were coded, the data was synthesized in summary tables. The frequency for each identified barrier and facilitator to retention in care was categorized into tertiles: high, medium, low. For the total sample and each group of interest (patients retained in care and patients not retained in care), a barrier or facilitator was classified as high if more than 40 % of participants identified the theme, medium if 21–39 % of participants identified the theme, and low if less than 20 % of participants identified the theme. Identified barriers and facilitators were qualitatively compared between the two groups of interest: patients retained in care and those not retained in care.

Results

A total of 51 HIV-infected patients were interviewed; 25 retained in care and 26 not retained in care. (Table 1) The median age was 45 years (range 24–65), with 27 male patients (53 %) interviewed. Most participants were of minority race/ethnicity (87 %), reported heterosexual transmission as their HIV risk factor (69 %), and were on Medicaid or uninsured (73 %). All but two patients (96 %) were on ART. Over half of the sample (69 %) had a CD4 cell count ≥ 350 cells/mm^3 and 57 % were virologically suppressed.

Overall, participants identified 12 types of barriers and 5 types of facilitators to retention in care. Barriers and facilitators were associated with patient, clinic/health system, and environmental factors. On average, retained individuals endorsed 3 barriers, while persons not retained in care endorsed 5 barriers. Both groups (participants retained and not retained in care) commonly (high tertile) discussed depression and mental illness, feeling sick, and competing life activities as barriers. In addition, individuals not retained in care commonly (high tertile) endorsed expensive and unreliable transportation, experiencing stigma, and insufficient insurance as barriers. On average, participants in both groups referenced 2 facilitators. Both groups commonly (high tertile) discussed the presence of social support, patient-friendly clinic services (transportation, co-location of services, scheduling/reminders), and positive relationships with providers and clinic staff as facilitators.

Tables 2 and 3 categorize barriers and facilitators to retention in care, respectively; display selected quotes; and show the relative frequency (high, medium, low) with which each theme was discussed overall and by each patient group (retained in care and non-retained in care). A more detailed analysis of the barriers and facilitators to retention in care is presented below.

Barriers to retention in care

Competing life activities

Regular attendance at clinic is not always the top priority for some participants; competing life activities was a barrier in the high tertile for both those individuals retained and not retained in care. Caring for children or elderly family members, work, and school were among the most commonly mentioned obstacles. Requesting time off for appointments was difficult and some participants mentioned struggling to find a job that was flexible enough to allow them to effectively manage their HIV infection.

Feeling sick

Feeling sick was a barrier in the top tertile for both groups and was commonly a reason for skipping or rescheduling appointments. Participants related their symptoms to a range of factors including medication side effects, compromised immune systems that made common colds and the flu more potent, and feeling emotionally low.

Stigma

Stigma was a barrier in the high tertile for patients not retained in care and a barrier in the medium tertile for those retained in care. Many participants reported hesitancy to disclose their status to family, friends, and acquaintances. Uncertainty about how family, friends, or the public would respond to their status made some patients anxious and affected their ability to attend appointments. Attempting to avoid disclosure in the waiting room, laboratory, and pharmacy created additional obstacles for these participants and discouraged regular clinic attendance.

Table 1 Sample demographic and clinical characteristics, overall and by retention in care status

Characteristic[a]	Total	Retained in care[h]	Not retained in care[h]
	(N = 51)	(N = 25)	(N = 26)
Age (years)[b]			
18-29	4 (8 %)	1 (4 %)	3 (12 %)
30-39	11 (22 %)	2 (8 %)	9 (35 %)
40-49	18 (35 %)	10 (40 %)	8 (31 %)
≥50	18 (35 %)	12 (48 %)	6 (23 %)
Sex			
Male	27 (53 %)	19 (76 %)	8 (31 %)
Female	24 (47 %)	6 (24 %)	18 (69 %)
Race/Ethnicity			
White	6 (12 %)	3 (12 %)	3 (12 %)
Black	41 (80 %)	21 (84 %)	20 (77 %)
Hispanic	3 (6 %)	1 (4 %)	2 (8 %)
Other	1 (2 %)	0 (0 %)	1 (4 %)
HIV risk factor[c]			
MSM	13 (26 %)	8 (32 %)	5 (19 %)
Heterosexual	35 (69 %)	14 (56 %)	21 (81 %)
IDU	3 (6 %)	3 (12 %)	0 (0 %)
Insurance[d]			
Private	4 (8 %)	1 (4 %)	3 (12 %)
Medicaid	34 (67 %)	17 (68 %)	17 (65 %)
Medicare	10 (18 %)	6 (24 %)	4 (15 %)
Uninsured	3 (6 %)	1 (4 %)	2 (8 %)
ART regimen[e]			
PI	29 (57 %)	16 (64 %)	13 (50 %)
NNRTI	15 (29 %)	7 (28 %)	8 (31 %)
Integrase	5 (10 %)	2 (8 %)	3 (12 %)
Not on ART	2 (4 %)	0 (0 %)	2 (8 %)
CD4 cell count (cell/mm^3)[f]			
≤ 200	8 (16 %)	6 (24 %)	2 (8 %)
201-350	8 (16 %)	2 (8 %)	6 (23 %)
351-500	8 (16 %)	4 (16 %)	4 (15 %)
> 500	27 (53 %)	13 (52 %)	14 (54 %)
Viral suppression[g]			
Suppressed	29 (57 %)	17 (68 %)	12 (46 %)
Not suppressed	22 (43 %)	8 (32 %)	14 (54 %)

Abbreviations: *ART* antiretroviral therapy, *MSM* men who have sex with men, *IDU* injection drug use, *PI* protease inhibitor, *NNRTI* non-nucleoside reverse transcriptase inhibitor

[a] Characteristics and values within the 12-month period prior to interview date

[b] Age on the date of interview

[c] Patients who had IDU in combination with another risk factor (e.g. MSM, HET) were classified as IDU

[d] Patients with both Medicare and Medicaid were grouped as Medicare

[e] Patients were considered to be on ART if they concomitantly received ≥ 3 antiretroviral drugs (excluding ritonavir) during the 12-month period prior to the interview date. ART regimen prescribed closest to the interview date was grouped using the following hierarchy: (1) PI-based; (2) NNRTI-based; and (3) integrase inhibitor-based

[f] CD4 cell count closest to the date of interview

[g] HIV viral suppression was categorized as suppressed (HIV-1 RNA ≤ 400 copies/mL) and not suppressed (HIV-1 RNA > 400 copies/mL) based on the median value in the 12-month period before the interview date

[h] Retention in care was defined as completing 2 or more primary HIV care visits separated by ≥ 90 days in the 12-month period prior to the interview date

Depression and mental illness

Participants in both groups commonly (high tertile) identified symptoms of depression and other mental illnesses (e.g. post-traumatic stress disorder, schizophrenia, anxiety, and bipolar disorder) as barriers. Participants experiencing depression described sleeping through appointments and sometimes not wanting to “bother” with traveling to clinic. In addition, depressed participants felt apathetic about their ’health care, with some stating that they did not care whether they lived or died.

Expensive and unreliable transportation

Patients who were not retained in care more often (high tertile) discussed transportation-related challenges relative to other barriers, as compared to retained patients where transportation-related challenges were in the medium tertile. Specific issues included the inability to afford bus/subway passes or carfare, unreliable shuttle van services, and the impact of inclement weather on public transportation and bike riding. Some participants also mentioned heavy traffic and the cost and availability of parking as barriers.

Insufficient health insurance

Non-retained patients more commonly (high tertile) expressed challenges with health insurance as compared to retained patients (low tertile). Participants found the process of enrolling in health insurance complicated and slow, affecting their ability to schedule appointments and receive medications in a timely manner. In addition, co-pays associated with medical visits deterred some participants from seeking care.

Table 2 Barriers to retention in care for people living with HIV

Barriers	Selected patient quotes	Total patients	Retained	Not retained
1. Competing Life Activities	"Of course, mother of four. Work 40-hour full-time job, come home to a full-time job, single mom. So yeah, I mean, there are times, like I said, from exhaustion. Sometimes – most times, it's just sheer exhaustion. I'm tired, you know. Before I know it, I'm asleep somewhere and I'm sleeping so long, it's the next day. But when I get up, I will take it. It's far and few between, but it happens. It happens." -NR Female	High	High	High
2. Feeling Sick	"Maybe because it was cold or it was raining and I was sick and I didn't feel like coming, even though I was sick, because I know like in the past I will be feeling sick as hell, but I couldn't even have the strength to get up to come to see the doctor." -R Female	High	High	High
3. Stigma	"You don't want to see nobody you know and all that kind of stuff. I hate the waiting room, I wish I could put on my hood and walk right through there when I leave." -R Male	High	Medium	High
4. Depression & Mental Illness	"It impacts a lot. It can impact a lot especially depending on I guess my emotional state. Depending on how bad I feel I'm not gonna move at all, I'm just not gonna come out the house, no matter what the reason that may have brought it on, whether it was me, an argument or fight with my husband, the kids driving me crazy today, no matter what brought it on, depending on how bad I feel, I'm just not gonna come because of my depression." -NR Female	High	High	High
5. Expensive & Unreliable Transportation	"Well, what makes it hard sometimes if you don't have money to get here. If you don't have a car, that's one thing. And what makes it easy is when you have transportation to come here. And it's accessible if you're on a bus route. It's right on the [Specific bus route]. It's easy to get here. And that's about it. Sometime you can't come because you don't have the money. That's a factor." -NR Male	High	Medium	High
6. Insufficient Health Insurance	"I'd say about the last two years, it's gotten to a point whereas though things they used to cover they don't cover no more. And being – having this disease, we need a lot of things done. They don't send out no letter, no nothing, just saying you can't have this done no more or it's going to be an extra charge. They don't say nothing. I get to the place like the dentist. I have bone loss. And I had an appointment. I went to the appointment, and they're telling me it's not covered." -R Male	Medium	Low	High
7. Forgetfulness	"If I'm rushing out of the house and I forget to just grab them and put them in my purse or something. That's most of the time when I forget." -R Female	Medium	Medium	Medium
8. Substance Abuse	"I forgot a lot of appointments. I was on drugs and I didn't – I wouldn't come in for like months, six months, to a year. I'm just getting back on track." -R Female	Medium	Medium	Medium
9. Negative Experiences with Clinic Spaces & Processes	"I still went…He just run in and out of the office, leave me sitting – first of all, you sat an hour just to get triaged. Then they stuck in a room, you sat another half an hour, 45 min. Then he'd come and he's be on the phone, he'd be in and out, just write you a script and send you on your way. Every once in a while he gave you blood work. Back then it was like an easy gig. But I left him and I found – the Gods called up, no for real man, it was a blessing." -R Male	Medium	Medium	Medium
10. Challenges with Appointment Scheduling	"Then if I come to appointment, I have to schedule back and forth. She say 11:30, but on the paper I got last time, it was 12:30. So I get her 12:00, she say it's too late, I have to go back and reschedule. And I rescheduled again for the 26th, it took another month." -NR Female	Low	Low	Medium
11. Difficult Relationships with Clinic Staff Including Providers	"The social worker, [Participant's Social Worker], and I am not a fan of her. I am not a fan of her. She thinks she's here doing you a favor. She is manipulative, ring the rule, send you up the steps and down and around and about and then all around. I cannot take that social worker behavior. Just get to the point and lead me in the right direction and tell me what the steps to take. I'm not here to ask you for a handout or what you can offer me personally from a clinical standpoint, a professional standpoint, please assist me with this matter. She make it seem as if she is doing you a favor." -R Female	Low	Low	Medium
12. Inconsistent, Unstable, or Inadequate Housing	"I'm going through a situation right now with my living conditions. I haven't took my medications in about three weeks now. I discussed - because I am going through – I'm living right now in a warehouse with my cousin who was also evicted because of some of the legal bullcrap we had to go through with my niece and other stuff which annoys me. But right now I'm staying with him so I'm going through a lot of stress with that. I guess I could have continued taking it but I just never been down to get the pills or whatnot." -R Male	Low	Low	Low

Abbreviations: *R* retained, *NR* not retained

The frequency for each identified barrier to retention in care was categorized into tertiles: high, medium, low

Table 3 Facilitators to retention in care for people living with HIV

Facilitator	Selected patient quotes	Total patients	Retained	Not retained
1. Positive Relationships with Clinic Staff Including Provider	"When Dr. [Doctor's Name] speaks, I take it to heart because I know he is really concerned about me. I don't know about every other doctor. I can only tell you about Dr. [Doctor's Name]. I know he's concerned and I know his concerns are valid so when he suggests or says, okay, [Name], I always try to do it." -R Male	High	High	High
2. Social Support	"Sometimes I'm not able to go to the food bank, but I'll call my children. I've called my two daughters or my son, and somebody will drop something off. They say, ma, we don't want you to be there and not have nothing to eat. We know it's important that you've got to take your medicines. So sometimes when I can't make it to the food bank, they look out for me and bring me something over to the house." -R Female	High	High	High
3. Patient-friendly Clinic Services	"Because they give you transportation back and forth… So they make sure I have that when I come. So there's really no excuse." -R Female "They usually call me the day before or a couple days before and I usually put it in my phone on my calendar." -NR Male "So it's just convenient that everything is in one place, I can go to the doctors, I can get my medicine, I can go to my groups, and I can do this all in one, between the two buildings." -NR Female	High	High	High
4. Patient Initiated Reminder Strategies	I: "What things help you making your appointments?" R: "The alarm on my phone. It's aggravating. I'll turn it off, it'll turn back on… Yeah. I fixed it that way. I got five alarms and I'll set them all 10 min apart." -R Male	Low	Low	Medium
5. Flexible Schedule	"Basically just me. I just will go. I mean I try to schedule where I don't have nothing to do that week. When nothing else is coming up and if I have an appointment, it will just be my appointment that I have to go to that week without anything else bothering me. Clearing it out, yeah." -R Female	Low	Low	Low

Abbreviations: *R* retained, *NR* not retained
The frequency for each identified facilitator to retention in care was categorized into tertiles: high, medium, low

Forgetfulness

Both groups sometimes (medium tertile) discussed challenges remembering appointment dates. Losing an appointment slip, not writing a reminder note, or not entering information into a phone or calendar were common actions that led to missed appointments. Participants also referenced having a busy lifestyle as an obstacle to remembering appointment dates.

Substance abuse

Substance abuse was in the medium tertile for both patients retained and not retained in care. These participants described forgetting or dismissing thoughts about attending appointments when actively using drugs. Retained participants mentioned substance abuse as an issue they struggled with in the past but had overcome.

Negative experiences with clinic space and processes

Participants in both groups sometimes (medium tertile) referenced negative experiences at their clinic. Several participants mentioned frustration about clinic wait times that can extend to several hours; some also mentioned frustration that being 15 min late could result in a cancelled appointment. Many participants disliked the waiting room experience for a range of reasons including fear of unintentional disclosures and conflict with other patients. Challenges with referral paperwork and long waits for laboratory testing were also mentioned as barriers to appointment adherence.

Challenges with appointment scheduling

Non-retained patients more often (medium tertile) discussed difficulties with scheduling appointments as compared to other barriers, while this barrier was in the lowest tertile for retained participants. Patients described challenges with their clinic's scheduling system and limited hours as well as their own lack of privacy when scheduling appointments over the phone.

Difficult relationships with clinic staff including providers

Both groups mentioned strained relationships with current or past health care providers or clinic staff; though this barrier was in the middle tertile for non-retained patients and in the low tertile for retained patients. Participants were sometimes unwilling to share details about their health or listen to providers' instructions if they felt patronized or disrespected.

Inconsistent, unstable, or inadequate housing

Unstable housing was a barrier mentioned (low tertile) by both patients retained and not retained in care. For some participants, housing insecurity caused significant stress and created obstacles for daily living that affected appointment adherence. Without a stable phone number, participants were unable to receive reminder phone calls and maintain contact with their provider. Also without a place to shower and bathe, participants were self-conscious about visiting the clinic. In addition, frequent address changes sometimes prevented patients from completing the necessary paperwork required to maintain their health insurance.

Facilitators of retention in care

Positive relationships with clinic staff including providers

For both the retained and non-retained groups, positive relationships with clinic staff including the HIV providers was one of the most commonly (high tertile) discussed facilitators. Patients reported that a strong relationship with their provider increased confidence in their provider's recommendations and advice. Moreover, having a supportive patient-provider relationship created a sense of trust, allowing patients to honestly share their health experiences and adherence behaviors. Many patients stated that they enjoyed coming to the clinic and felt supported by clinic staff. These patients described staff as professional, sincere, patient, and caring.

Social support

Both groups commonly (high tertile) referenced people in their lives who supported their appointment adherence. Children, siblings, partners, relatives, friends, neighbors, clinic staff, and support groups were all discussed as important sources of support. These people and groups reminded and motivated participants to attend appointments, and helped assure that participants had food and transportation.

Patient-friendly clinic services

Patients retained and not retained in care commonly (high tertile) discussed a range of clinic services that made attending appointments easier, including transportation assistance, convenient scheduling processes, reminder phone calls, and co-location of medical and ancillary care services. Non-retained and retained patients both commonly referenced the benefit of transportation services, including free bus/subway passes and van services. Similarly, both groups mentioned the value of a convenient scheduling process, which included the ability to schedule appointments over the phone or in-person; talking to a live person instead of an automated system; and schedulers that work with patients to find the earliest and most convenient appointment time. Participants also discussed the benefit of reminder phone calls in facilitating appointment adherence. Some participants appreciated the ability to accomplish multiple tasks in the same location, such as participating in a research study or attending a support group before or after a scheduled appointment.

Patient initiated reminder strategies

The benefits of appointment reminder tools were referenced by both retained and non-retained patients; however, this facilitator was in the medium tertile for those non-retained in care and in the low tertile for those retained in care. Participants commonly mentioned personal systems like calendars and alarms for organizing appointment schedules. Participants inputted appointment date information into electronic (mobile device) and paper calendars and set alarms to remind themselves of upcoming appointments.

Flexible schedule

An open, flexible schedule was identified by some (low tertile) retained and not retained patients as a facilitator of retention in care. The ability to schedule appointments at multiple times during the day made it easier to get and keep appointments. Clearing a schedule on appointment days or even during the week of an appointment was mentioned as a strategy for assuring appointment attendance.

Discussion

Retention in care is a critical element of the HIV care continuum and is necessary for successfully managing HIV infection. This study adds to the existing literature by examining differences in barriers and facilitators to retention in care for patients with varying retention patterns. Individuals in the retained and non-retained groups expressed common barriers and facilitators to retention in care. However, as a group, non-retained individuals identified more barriers and more often discussed stigma, expensive and unreliable transportation, insufficient health insurance, challenges with appointment scheduling, and difficult relationships with clinic staff as obstacles.

Participants from both groups described common struggles to consistently attending clinic visits, including dealing with competing life priorities (e.g. caring for children or elderly family members), feeling physically sick, and being depressed. Caregivers of chronically ill individuals, particularly in underprivileged populations, may experience substantial economic strains due to lost wages, social isolation, and depressive symptoms [33–35]. Moreover, studies have shown that caregiver responsibilities may prevent people from attending their own appointments or reaching their own full health potential [36]. The use of new technologies, including secure electronic messaging and videoconferencing, could address some of these barriers by increasing access to care and medical information [37, 38]. However, these modalities have been limited by lack of uptake and integration with our current financial reimbursement systems, privacy concerns, and provider comfort using these technologies [39]. Consistent with other studies, patients who felt sick or depressed were more likely to miss their appointments [28, 29, 36, 40–42]. Successfully integrating psychiatric and psychosocial treatment into HIV care, when possible, may serve as a tool for improving both retention in care and HIV clinical outcomes [43–46].

Participants in the non-retained group more commonly identified stigma, expensive and unreliable transportation, insufficient health insurance, challenges with appointment scheduling, and difficult relationships with clinic staff as barriers to retention in care compared to the retained group. While major advances in the treatment of HIV have been made, negative perceptions and stigma associated with the disease have not evolved as rapidly [47, 48]. Non-retained individuals commonly (high tertile) cited stigma as a barrier compared to retained individuals (middle tertile). This difference may be a consequence of different experiences or varying perceptions of similar experiences between the groups. Patients retained in care may also have stronger social supports or access to mental health care, which have been identified as protective against stigma [49, 50], than those not retained in care. Additional studies are needed to better understand how patients perceive stigma and its subsequent impact on health behaviors, particularly among individuals with otherwise similar social, economic, and behavior backgrounds and experiences. Interventions, such as skill building through peer coaching, education programs to gain a better understanding of HIV disease, and connecting HIV-infected individuals with community resources and peers, may help patients combat stigma and improve their engagement in healthcare [19, 51, 52].

Expensive and unreliable transportation was commonly (high tertile) discussed as a barrier in the non-retained group, but was in the middle tertile for the retained group. Differences in income, place of residence, and access to individuals who can provide transportation may explain this finding. Prior studies demonstrate that clinics providing support services, including transportation and case management, have better retention rates than those without these services [36, 53–55]. Insufficient health insurance was a high tertile barrier for not retained patients and a low tertile barrier for retained individuals, despite both groups having a similar insurance distribution. While both groups had similar insurance patterns, it may be that those retained in care are better able to navigate the healthcare system and use their insurance coverage effectively to obtain care than those not retained.

Challenges with appointment scheduling and difficult relationships with clinic staff were both in the lowest tertile of barriers for the retained group, but in the middle tertile for patients not retained in care. Satisfaction with the clinic experience predicts whether or not patients return for care [56, 57]. Moreover, patients' perception of the clinic experience depends not only on the quality of clinical care delivered but also on interactions with clinic staff, appointment wait times, and scheduling efficiency [56, 57]. Among people living with HIV, satisfaction with care has been shown to be positively associated with retention in care and adherence to ART [58]. Non-retained patients may have been less satisfied with their clinic experience and for that reason did not return for appointments or remain engaged in care. Additional research is needed to better understand the differences between patients retained and not retained in care, since despite similar demographic characteristics between the groups they differed in their perceptions about barriers to care.

Both the retained and non-retained groups commonly (high tertile) mentioned supportive patient-provider/patient-staff relationships, patient-friendly clinic services, and social support as highly important facilitators to retention in care. Studies examining the patient-provider relationship have found that interaction styles that reduce social distance with the patient and improve patient comprehension of health issues lead to improved engagement in HIV care [59, 60]. Similarly, patient-friendly clinic services, such as patient orientation to the clinic or open access scheduling, have been documented to reduce missed appointments [36]. In HIV infection, brief face-to-face meetings with clinic staff upon returning for care, interim visit calls, appointment reminder calls, and missed visit follow-up calls improved visit adherence in a randomized control trial of usual care versus enhanced personal contact [61].

There are several limitations to this study. Though we were able to recruit a large number of individuals not retained in care, there may be differences in those patients who were unable to be recruited. These patients may be even less engaged in care, and thus may have different barriers and facilitators than participants in this study. Additionally, patients' responses may have been influenced by social desirability bias. Ensuring confidentiality and training interviewers to avoid judgmental reactions helped minimize this risk. Finally, the findings of this study may not generalize to other populations, as our patients, clinical practices, and geographic and cultural environment may vary from others. Moreover, not all barriers and facilitators identified may apply to the same degree across populations and locales.

Conclusions

This qualitative analysis builds on prior research, which describe barriers and facilitators to engagement in care, by comparing the type and frequency of barriers and facilitators between individuals retained and not retained in care. This analysis offers insights for providers, clinic administrators, and health policy makers seeking to improve retention in care. Developing care models where social and financial barriers are routinely assessed and addressed, mental health and substance abuse treatment is integrated, and patient-friendly services are offered is important for keeping HIV-infected individuals engaged in care and for meeting national retention metrics.

Competing interests

BRY: Received investigator-initiated research support (to the University of Pennsylvania) and honorarium from Gilead Sciences.

Authors' contributions

Conceived and designed the study: BRY LMJ KG JPM JAS. Contributed to data acquisition: LS AM CWH JH KM. Analyzed and interpreted the data: BRY LS FM AM CWH LMJ JPM JAS. Contributed to the writing of the manuscript: BRY LS FM AM CWH LMJ JH KM KG JPM JAS. All authors read and approved the final manuscript.

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References

1. Centers for Disease Control and Prevention (CDC). Vital signs: HIV prevention through care and treatment–United States. MMWR Morb Mortal Wkly Rep. 2011;60(47):1618–23.
2. Fleishman JA, Yehia BR, Moore RD, Korthuis PT, Gebo KA. Establishment, retention, and loss to follow-up in outpatient HIV care. J Acquir Immune Defic Syndr. 2012;60(3):249–59.
3. Mugavero MJ. Improving engagement in HIV care: what can we do? Top HIV Med. 2008;16(5):156–61.
4. Ulett KB, Willig JH, Lin HY, et al. The therapeutic implications of timely linkage and early retention in HIV care. AIDS Patient Care STDs. 2009;23(1):41–9.
5. Berg MB, Safren SA, Mimiaga MJ, Grasso C, Boswell S, Mayer KH. Nonadherence to medical appointments is associated with increased plasma HIV RNA and decreased CD4 cell counts in a community-based HIV primary care clinic. AIDS Care. 2005;17(7):902–7.
6. Giordano TP, White Jr AC, Sajja P, et al. Factors associated with the use of highly active antiretroviral therapy in patients newly entering care in an urban clinic. J Acquir Immune Defic Syndr. 2003;32(4):399–405.
7. Lucas GM, Chaisson RE, Moore RD. Highly active antiretroviral therapy in a large urban clinic: risk factors for virologic failure and adverse drug reactions. Ann Intern Med. 1999;131(2):81–7.
8. Yehia BR, Kangovi S, Frank I. Patients in transition: avoiding detours on the road to HIV treatment success. AIDS. 2013;27(10):1529–33.
9. Yehia BR, Fleishman JA, Moore RD, Gebo KA. Retention in Care and Health Outcomes of Transgender Persons Living With HIV. Clin Infect Dis. 2013;57(5):774-6.
10. Mugavero MJ, Lin HY, Willig JH, et al. Missed visits and mortality among patients establishing initial outpatient HIV treatment. Clin Infect Dis. 2009;48(2):248-56.
11. Metsch LR, Pereyra M, Messinger S, et al. HIV transmission risk behaviors among HIV-infected persons who are successfully linked to care. Clin Infect Dis. 2008;47(4):577-84.
12. Yehia BR, Fleishman JA, Metlay JP, et al. Comparing different measures of retention in outpatient HIV care. AIDS. 2012;26(9):1131–9.
13. Rebeiro P, Althoff KN, Buchacz K, et al. Retention among North American HIV-infected persons in clinical care, 2000-2008. J Acquir Immune Defic Syndr. 2013;62(3):356–62.
14. Mugavero MJ, Westfall AO, Zinski A, et al. Measuring retention in HIV care: the elusive gold standard. J Acquir Immune Defic Syndr. 2012;61(5):574–80.
15. HI Hall ELF, P Rhodes, DR Holtgrave, C Furlow-Parmley, T Tang, KM Gray, SM Cohen, J Skarbinsk. Continuum of HIV care: differences in care and treatment by sex and race/ethnicity in the United States. Paper presented at: AIDS 2012; Washington, DC.
16. Mugavero MJ, Amico KR, Horn T, Thompson MA. The state of engagement in HIV care in the United States: from cascade to continuum to control. Top HIV Med. 2013;57(8):1164–71.
17. Giordano TP, Visnegarwala F, White Jr AC, et al. Patients referred to an urban HIV clinic frequently fail to establish care: factors predicting failure. AIDS Care. 2005;17(6):773–83.
18. Giordano TP, Hartman C, Gifford AL, Backus LI, Morgan RO. Predictors of retention in HIV care among a national cohort of US veterans. HIV Clin Trials. 2009;10(5):299–305.
19. Cunningham CO, Sohler NL, Wong MD, et al. Utilization of health care services in hard-to-reach marginalized HIV-infected individuals. AIDS Patient Care STDs. 2007;21(3):177–86.
20. Rumptz MH, Tobias C, Rajabiun S, et al. Factors associated with engaging socially marginalized HIV-positive persons in primary care. AIDS Patient Care STDs. 2007;21 Suppl 1:S30–39.
21. Beer L, Fagan JL, Valverde E, Bertolli J. Never in Care P. Health-related beliefs and decisions about accessing HIV medical care among HIV-infected persons who are not receiving care. AIDS Patient Care STDs. 2009;23(9):785–92.
22. Konkle-Parker DJ, Amico KR, Henderson HM. Barriers and facilitators to engagement in HIV clinical care in the Deep South: results from semi-structured patient interviews. J Assoc Nurses AIDS Care. 2011;22(2):90–9.
23. Rajabiun S, Mallinson RK, McCoy K, et al. "Getting me back on track": the role of outreach interventions in engaging and retaining people living with HIV/AIDS in medical care. AIDS Patient Care STDs. 2007;21 Suppl 1:S20–29.
24. Mallinson RK, Relf MV, Dekker D, Dolan K, Darcy A, Ford A. Maintaining normalcy: a grounded theory of engaging in HIV-oriented primary medical care. Adv Nurs Sci. 2005;28(3):265–77.
25. Smith LR, Fisher JD, Cunningham CO, Amico KR. Understanding the behavioral determinants of retention in HIV care: a qualitative evaluation of a situated information, motivation, behavioral skills model of care initiation and maintenance. AIDS Patient Care STDs. 2012;26(6):344–55.
26. Kempf MC, McLeod J, Boehme AK, et al. A qualitative study of the barriers and facilitators to retention-in-care among HIV-positive women in the rural southeastern United States: implications for targeted interventions. AIDS Patient Care STDs. 2010;24(8):515–20.
27. Quinlivan EB, Messer LC, Adimora AA, et al. Experiences with HIV testing, entry, and engagement in care by HIV-infected women of color, and the need for autonomy, competency, and relatedness. AIDS Patient Care STDs. 2013;27(7):408–15.
28. Messer LC, Quinlivan EB, Parnell H, et al. Barriers and facilitators to testing, treatment entry, and engagement in care by HIV-positive women of color. AIDS Patient Care STDs. 2013;27(7):398–407.
29. Moneyham L, McLeod J, Boehme A, et al. Perceived barriers to HIV care among HIV-infected women in the Deep South. J Assoc Nurses AIDS Care. 2010;21(6):467–77.
30. Christopoulos KA, Massey AD, Lopez AM, et al. "Taking a half day at a time": patient perspectives and the HIV engagement in care continuum. AIDS Patient Care STDs. 2013;27(4):223–30.
31. The White House Office of National HIV/AIDS Policy. The National HIV/AIDS Strategy of the United States. 2010.
32. Tashakkori ATC. Handbook of mixed methods in social and behavioral research. 2nd ed. Thousand Oaks, CA: Sage; 2010.
33. Mitchell MM, Knowlton A. Caregiver role overload and network support in a sample of predominantly low-income, African-American caregivers of persons living with HIV/AIDS: a structural equation modeling analysis. AIDS Behav. 2012;16(2):278–87.

34. Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. Ann Inten Med. 2000;132(6):451–9.
35. Grunfeld E, Coyle D, Whelan T, et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. Can Med Assoc J. 2004;170(12):1795–801.
36. Horstmann E, Brown J, Islam F, Buck J, Agins BD. Retaining HIV-infected patients in care: where are we? Where do we go from here? Clin Infect Dis. 2010;50(5):752–61.
37. Hersh WR, Helfand M, Wallace J, et al. Clinical outcomes resulting from telemedicine interventions: a systematic review. BMC Med Inform Decis Mak. 2001;1(1):5.
38. Charles BL. Telemedicine can lower costs and improve access. Healthc Financ Manag. 2000;54(4):66–9.
39. Dixon RF. Enhancing primary care through online communication. Health Aff. 2010;29(7):1364–9.
40. Weiser SD, Riley ED, Ragland K, Hammer G, Clark R, Bangsberg DR. BRIEF REPORT: factors associated with depression among homeless and marginally housed HIV-infected men in San Francisco. J Gen Intern Med. 2006;21(1):61–4.
41. Riley ED, Wu AW, Perry S, et al. Depression and drug use impact health status among marginally housed HIV-infected individuals. AIDS Patient Care STDs. 2003;17(8):401–6.
42. Tello MA, Jenckes M, Gaver J, Anderson JR, Moore RD, Chander G. Barriers to recommended gynecologic care in an urban United States HIV clinic. J Womens Health. 2010;19(8):1511–8.
43. Wyatt GE, Longshore D, Chin D, et al. The efficacy of an integrated risk reduction intervention for HIV-positive women with child sexual abuse histories. AIDS Behav. 2004;8(4):453–62.
44. Weber R, Christen L, Christen S, et al. Effect of individual cognitive behaviour intervention on adherence to antiretroviral therapy: prospective randomized trial. Antivir Ther. 2004;9(1):85–96.
45. Safren S, Knauz R, O'Cleirigh C, et al. CBT for HIV medication adherence and depression: process and outcome at post-treatment and three-month cross over. Ann Behav Med. 2006;31:S006.
46. Sikkema KJ, Wilson PA, Hansen NB, et al. Effects of a coping intervention on transmission risk behavior among people living with HIV/AIDS and a history of childhood sexual abuse. J Acquir Immune Defic Syndr. 2008;47(4):506–13.
47. Herek GM, Capitanio JP, Widaman KF. HIV-related stigma and knowledge in the United States: prevalence and trends, 1991-1999. Am J Public Health. 2002;92(3):371–7.
48. Grov C, Golub SA, Parsons JT, Brennan M, Karpiak SE. Loneliness and HIV-related stigma explain depression among older HIV-positive adults. AIDS Care. 2010;22(5):630–9.
49. Logie C, Gadalla TM. Meta-analysis of health and demographic correlates of stigma towards people living with HIV. AIDS Care. 2009;21(6):742–53.
50. Emlet CA, Brennan DJ, Brennenstuhl S, et al. Protective and risk factors associated with stigma in a population of older adults living with HIV in Ontario, Canada. AIDS Care. 2013;25(10):1330–9.
51. Bradford JB. The promise of outreach for engaging and retaining out-of-care persons in HIV medical care. AIDS Patient Care STDs. 2007;21(S1):S-85–91.
52. Stangl AL, Lloyd JK, Brady LM, Holland CE, Baral S. A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come? J Int AIDS Soc. 2013;16(3Suppl 2):18734.
53. Keller SC, Yehia BR, Momplaisir FO, Eberhart MG, Share A, Brady KA. Assessing the overall quality of health care in persons living with HIV in an Urban environment. AIDS Patient Care STDs. 2014;28(4):198–205.
54. Higa DH, Marks G, Crepaz N, Liau A, Lyles CM. Interventions to improve retention in HIV primary care: a systematic review of US studies. Curr HIV/AIDS Rep. 2012;9(4):313–25.
55. Gardner EM, McLees MP, Steiner JF, del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. Clin Infect Dis. 2011;52(6):793–800.
56. Billing K, Newland H, Selva D. Improving patient satisfaction through information provision. Clin Experiment Ophthalmol. 2007;35(5):439–47.
57. Salisbury C, Wallace M, Montgomery AA. Patients' experience and satisfaction in primary care: secondary analysis using multilevel modelling. BMJ. 2010;341:c5004.
58. Dang BN, Westbrook RA, Black WC, Rodriguez-Barradas MC, Giordano TP. Examining the link between patient satisfaction and adherence to HIV care: a structural equation model. PLoS ONE. 2013;8(1):e54729.
59. Mallinson RK, Rajabiun S, Coleman S. The provider role in client engagement in HIV care. AIDS Patient Care STDs. 2007;21(S1):S-77–84.
60. McCoy L. HIV-positive patients and the doctor-patient relationship: perspectives from the margins. Qual Health Res. 2005;15(6):791–806.
61. Gardner LI, Giordano TP, Marks G, et al. Enhanced personal contact with HIV patients improves retention in primary care: a randomized trial in 6 US HIV clinics. Top HIV Med. 2014;59(5):725–34.

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Increasing retention in care, ART adherence and viral suppression

WHAT IS THE HIV CARE CONTINUUM?

Antiretroviral therapy (ART; see Fact Sheet 403) can reduce the risk of serious illness, death or transmission of HIV. ART is now recommended for all people living with HIV (PLHIV) in a strategy called "treatment as prevention" (TasP).

Yet, only half of people living with HIV (PLHIV) around the world are aware of their status. Among those who know their HIV status, many do not receive ART in a timely manner, fail to stay engaged in care, or do not achieve sustained viral suppression.

The **HIV care continuum** is a way of describing the steps in the care and treatment of PLHIV and include:

- Diagnosis (HIV testing; fact sheet 102)
- Getting into medical care
- Staying in medical care
- Prescription of ART
- Achieving viral suppression (undetectable viral load; see Fact Sheet 125)

The care continuum can help communities and health programs understand how well PLHIV receive care and treatment, improve health and prevent new infections.

WHAT ARE THE IAPAC GUIDELINES?

The International Association of Providers of AIDS Care (IAPAC), through a multidisciplinary panel of international advisors, developed the first comprehensive, evidence-based guidelines for optimizing the HIV care continuum, with an aim to increase HIV testing coverage, linkage to care, treatment coverage, engagement and retention in care, and viral suppression for adults and adolescents (see Fact Sheet 110).

The panel reviewed the scientific literature on the HIV care continuum and made 36 recommendations for interventions in six subject areas:

- **Optimizing the HIV care environment** (Fact Sheet 111)
- **Increasing HIV testing coverage and linkage to care** (Fact Sheet 112)
- **Increasing HIV treatment coverage** (Fact Sheet 113)
- **Increasing retention in care, ART adherence, and viral suppression** (Fact Sheet 114)
- **Adolescents** (Fact Sheet 115)
- **Metrics for and monitoring of the HIV care continuum** (Fact Sheet 116)

The recommendations are graded by strength and quality of the body of evidence as follows: Strong (A); Moderate (B); Optional (C); Excellent (I); High (II); Medium (III); Low (IV).

RECOMMENDATIONS FOR INCREASING RETENTION IN CARE, ART ADHERENCE, AND VIRAL SUPPRESSION

1. **Systematic monitoring of retention in HIV care is recommended for all patients.** (A II)
    a. Retention in HIV care should be considered as a quality indicator. (B III)
    b. Measuring retention in HIV care using electronic health record and other health system data is recommended. (BII)
    c. Use of clinic databases/surveillance systems for HIV clinical monitoring and population-level tracking is recommended. (B II)

2. **Routine ART adherence monitoring is recommended in all patients.** (A II)
    a. Viral suppression is recommended as the primary adherence monitoring metric. (B II)
    b. Routine collection of self-reported adherence data from patients is recommended. (A II)
    c. Pharmacy refill data are recommended for adherence monitoring. (B II)
3. **Information and communication technologies aimed at supporting patient self-care are recommended.** (B II)
    a. Mobile health technology using weekly interactive components (eg, 2-way text messaging) is recommended. (B I)
    b. Alarm devices are recommended as reminders for PLHIV with memory impairment. (A I)
4. **Patient education about and offering support for medication adherence and keeping clinic appointments are recommended.** (A I)
    a. Pillbox organizers are recommended, particularly for HIV-infected adults with lifestyle-related barriers to adherence. (B II)
5. **Neither directly administered nor directly observed ART is recommended for routine clinical care settings.** (A I)
    a. Directly administered ART is recommended for people who inject drugs and released prisoners at high risk of ART non-adherence. (B I)
6. **Proactive engagement and reengagement of patients who miss clinic appointments and/or are lost to follow-up, including intensive outreach for those not engaged in care within 1 month of a new HIV diagnosis, is recommended.** (B II)
    a. Case management to retain PLHIV in care and to locate and reengage patients lost to follow-up is recommended. (B II)
    b. Transportation support for PLHIV to attend their clinic visits is recommended. (B II)

WHAT'S THE BOTTOM LINE?

The HIV care continuum describes how many people living with HIV know their status, engage in medical care, receive ART and achieve undetectable HIV viral loads.

The IAPAC guidelines are the evidence-based recommendations to improve retention in care, ART adherence and viral suppression for PLHIV.

FOR MORE INFORMATION:

Full text of the IAPAC guidelines is available at http://www.iapac.org/uploads/JIAPAC-IAPAC-Guidelines-for-Optimizing-the-HIV-Care-Continuum-Supplement-Nov-Dec-2015.pdf

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9 in 10 new U.S. HIV infections come from people not receiving HIV care

New CDC analysis reinforces importance of HIV testing and treatment for health and prevention

More than 90 percent of new HIV infections in the United States could be averted by diagnosing people living with HIV and ensuring they receive prompt, ongoing care and treatment. This finding was published today in *JAMA Internal Medicine* by researchers at the Centers for Disease Control and Prevention.

Using statistical modeling, the authors developed the first U.S. estimates of the number of HIV transmissions from people engaged at five consecutive stages of care (including those who are unaware of their infection, those who are retained in care and those who have their virus under control through treatment). The research also shows that the further people progress in HIV care, the less likely they are to transmit their virus.

“By quantifying where HIV transmissions occur at each stage of care, we can identify when and for whom prevention and treatment efforts will have the most impact,” said Jonathan Mermin, MD, MPH, director of CDC’s National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. “We could prevent the vast majority of new infections tomorrow by improving the health of people living with HIV today.”

> **“We could prevent the vast majority of new infections tomorrow by improving the health of people living with HIV today.”**
>
> Jonathan Mermin, MD, MPH, director, CDC’s National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention

The analysis showed that 30 percent of new HIV infections were transmitted from people who did not know that they were infected with the virus, highlighting the importance of getting tested. People who had been diagnosed were less likely to transmit their infection, in part because people who know they have HIV are more likely to take steps to protect their partners from infection.

“Positive or negative, an HIV test opens the door to prevention. For someone who is positive, it can be the gateway to care and the signal to take steps to protect partners from infection.

For someone who tests negative, it can be a direct link to important prevention services to help them stay HIV-free," said Eugene McCray, MD, director of CDC's Division of HIV/AIDS Prevention. "At CDC, we're working hard to make testing as simple and accessible as possible."

Today's analysis suggests that simply being in care can help people living with HIV avoid transmission of their virus. According to the model, people who were engaged in ongoing HIV care, but not prescribed antiretroviral treatment, were half as likely (51.8 percent) as those who were diagnosed but not in care to transmit their virus. Being prescribed HIV treatment further lowered the risk that a person would pass the virus to others.

People who were successfully keeping the virus under control through treatment were 94 percent less likely than those who did not know they were infected to transmit their virus. However, previous national estimates have indicated that just 30 percent of people with HIV have reached this critical step in care.

The study authors stress that effective HIV care offers multiple mechanisms to prevent transmission. For example, in addition to antiretroviral therapy, HIV care should include risk reduction counseling on how to protect their partners, screening and treatment for other sexually transmitted infections, and treatment for mental health and substance use disorders.

To estimate HIV transmission at each stage of care in 2009, the new analysis used statistical modeling based on three national HIV data sources: CDC's Medical Monitoring Project, National HIV Surveillance System, and National HIV Behavioral Surveillance System.

This is the latest in a growing body of evidence that prevention of new infections depends on reaching people who are HIV-positive with testing, care, and treatment. CDC has responded by more extensively focusing its prevention strategy on people living with HIV, while continuing to ensure HIV-negative people have tools and information about all available prevention options, including daily pre-exposure prophylaxis (/nchhstp/newsroom/docs/PrEP-FactSheet-508.pdf).

CDC efforts also include innovative partnerships to make HIV testing simple, accessible, and routine; programs to help health departments and community partners identify and reach out to infected individuals who have fallen out of care; and public awareness campaigns to urge testing and encourage people with HIV to seek ongoing care.

For more on the new analysis and CDC's HIV prevention efforts, visit www.cdc.gov/nchhstp/newsroom (/nchhstp/newsroom).

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Perspective

Linkage, Engagement, and Retention in HIV Care Among Vulnerable Populations: "I'm Sick and Tired of Being Sick and Tired"

There are disparities in engagement and retention in HIV care and outcomes of care across segments of society. For example, HIV mortality rates remain markedly elevated among black women and men compared with their white counterparts. These differences reflect broader disparities across social, economic, and cultural lines. Improvement in engagement and retention in HIV care requires interventions that account for forces present in the socioecologic framework of health behaviors. Improvement in linkage to care at HIV testing is crucial to overall engagement and retention in care. Strategies for linkage to care at testing can help overcome many of the forces that result in failure to engage and remain in care by starting the patient on a solid path to clinical care. This article summarizes a presentation by Victoria A. Cargill, MD, MSCE, at the IAS–USA continuing education program held in New York, New York, in May 2013.

Keywords: *HIV care disparities, linkage to care, socioecologic framework, engagement and retention in care, practitioner behavior*

"I Don't Want To Go to the Hospital"

Patient A is a 34-year-old African American woman who tested positive for HIV infection at 19 years of age. She has given birth to 4 HIV seronegative children, but her first child died at age 6 months due to crib death and another (one of a set of fraternal twins) died at age 9 years from sickle cell crisis. Patient A dropped out of care for 9 years and has since been intermittent in her treatment follow-up. She is nonadherent to medications and appointments. Her mother brought her to the clinic, where she presented with a 70 lb weight loss, thrush, fever, cough, tachypnea, and diarrhea. She stated, "I don'twant to go to the hospital."

Syndemics of Disparities

The above scenario is unfortunately all too common. Since 1985, more than 27 antiretroviral drugs have been approved for use in the United States, an indicator of the progress that has been made in HIV therapy. Unfortunately, all segments of society have not equally benefitted from this progress. At the same time that the NA-ACCORD (North American AIDS Cohort Collaboration on Research and Design) data have highlighted the increased life expectancy of HIV-infected patients starting antiretroviral therapy,[1] the WIHS (Women's Interagency HIV Study) data reemphasize that black HIV-infected women are twice as likely to die with AIDS as their white counterparts.[2]

Overall, Latinos and blacks are substantially more likely to present late for care and experience higher morbidity and mortality than other population groups. Persons dying with HIV infection increasingly are women, blacks/African Americans, residents of the US South, and individuals aged 45 years or older. HIV infection remains one of the leading causes of death among persons aged 25 years to 44 years in the United States, particularly among blacks/African Americans.

As shown in Figure 1 (top), although there have been marked reductions in annual mortality from HIV disease in the United States since 1996 among all racial and ethnic groups, the rate in black/African Americans remains strikingly elevated.[3] Figure 1 (bottom) shows the disparity when mortality rates for black men are compared with those for white men by age group.[4]

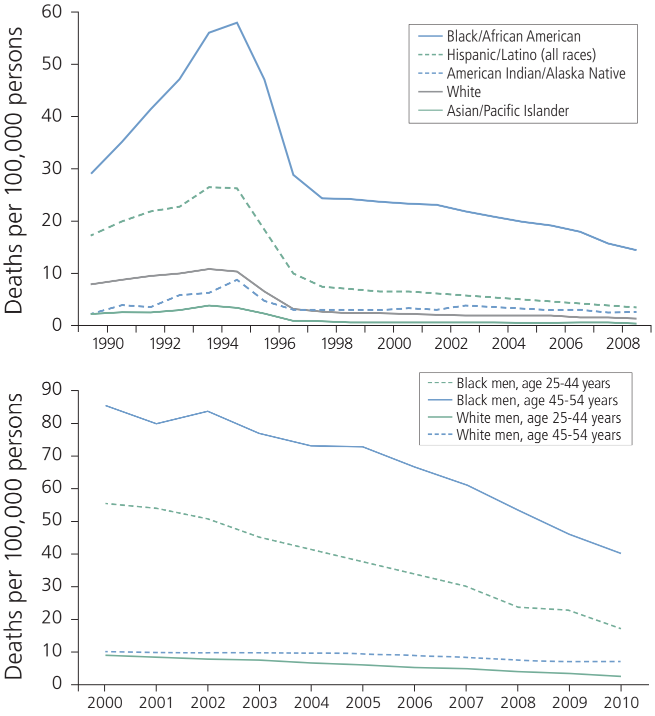

Figure 1. Age-adjusted HIV-related death rates by race and ethnicity (top). Rates are standardized on the age distribution of the US population in 2000. Adapted from National Center for HIV/AIDS.[3] HIV-related death rates in black men and white men by age group (bottom). Adapted from National Vital Statistics System.[4]

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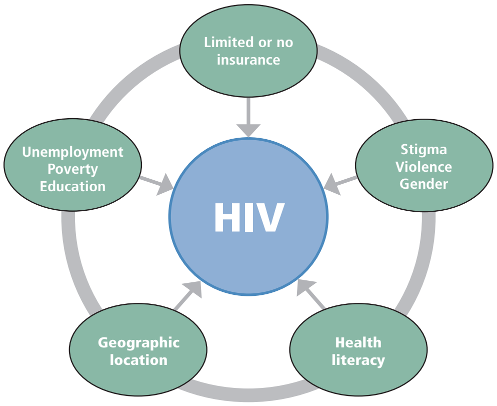

Figure 2. HIV infection: A single factor among many potential socioecologic disparities.

HIV infection presents as a health disparity but is only one disparity among many that affect both the quality and quantity of life among the vulnerable populations in society (Figure 2). These disparities overlap and intersect to present a web of challenges for many racial and ethnic minorities living with HIV infection and those who provide care for them.

Poverty is one such disparity. Poverty rates for blacks and Hispanics exceed the national average. According to National Poverty Center data, 27.4% of blacks and 26.6% of Hispanics are poor, compared with 9.9% of non-Hispanic whites and 12.1% of Asians.[5] Foreign-born noncitizens in the United States also have high poverty rates.[5]

Health illiteracy and limited or nonexistent health insurance coverage negatively impact the management of HIV infection and are particularly relevant to vulnerable and marginalized populations in that health literacy can be correlated with HIV knowledge[6] and HIV treatment adherence.[7] However, the impact of low health literacy can be moderated by self-efficacy[8]—namely, people's belief that they can take control in their lives to improve their circumstances. Among individuals with self-efficacy, the impact of low health literacy is not as profound.

Several large studies on health insurance coverage have demonstrated an association between earlier initiation of antiretroviral therapy[9] and having commercial or private insurance. Although less striking, a similar association has been found between antiretroviral therapy initiation and having Medicare coverage. Individuals enrolled in Medicaid consistently initiated antiretroviral therapy at a more advanced stage of disease, corroborating earlier findings.[9,10] Health insurance coverage is also correlated with employment, and unemployment rates are much higher for blacks and Latinos. The unemployment rate for blacks was twice that for whites in 2012—a ratio that has not changed since the US Beareau of Labor Statistics began reporting unemployment by race in 1972.[5]

Along with poverty, unemployment, underemployment, and limited health literacy, violence must be included as a factor that can negatively affect HIV care. Violence and suicide rates are disproportionately higher in racial and ethnic minority populations. Native Americans have the second-highest rate of suicide across all age groups. Blacks account for 48.7% of homicide deaths, which is the highest rate for any population group, and more than half of these deaths occur in men aged 15 years to 34 years. Native Americans rank second in homicide deaths, followed closely by Hispanics.[11]

In addition to these disparities, many other factors may affect an individual's ability to access and remain in health care, including:[12]

- Stigma
- Homophobia
- Language barriers
- Incarceration
- Shame
- Privacy concerns
- Distrust of practitioners
- Active substance use
- Unstable housing
- Limited education
- Isolation
- Lack of support
- Fear of disclosure
- Mental health status

Moving Beyond the Individual—A Socioecologic Framework

Correcting the disparities in HIV care and the differential outcomes for the marginalized and vulnerable sectors of society will require addressing the larger sociocultural context in which these individuals live. Thus, examining the socioecologic framework in which individuals participate allows for an examination of and accounting for the external factors that influence individuals at interpersonal, organizational, community, and public policy levels—all of which can impact HIV care–seeking behavior, as well as an individual's general knowledge, attitudes, and skills. The socioecologic approach has been particularly useful in addressing health behaviors that are influenced by factors such as culture, trust, and beliefs, with prenatal care and weight loss interventions being prime examples.

Mugavero and colleagues have provided a detailed picture of the socioecologic framework for HIV care in which they demonstrate the complex multilevel factors that can affect an individual's engagement in care (Table).[13] For example, at the individual level, there are numerous factors, such as age, sex, race, and ethnicity, that may predispose patients not to engage or remain in care. But there are also enabling factors that may tend to keep them engaged, including health insurance, transportation, social support, self-efficacy, and resiliency (ie, the ability to navigate barriers inherent to seeking and engaging in care). Relationships with case managers, health care practitioners, and social networks, for example, can facilitate or impede engagement in care.

"Are You Sure I'm HIV-Positive?"

Patient B is a 35-year-old African American man who describes himself as a "player." He also has a known factor VIIa deficiency. Four weeks before presentation to clinic, he was treated for syphilis and was encouraged to undergo HIV testing. His rapid HIV test was positive, as was confirmatory

Table. Sociologic Factors in HIV Care

Policy	Health Care System	Community	Relationships	Individual
■ HIV testing guidelines ■ HIV treatment guidelines ■ Quality measures ■ Best practices ■ Workforce ■ Reimbursement ■ Funding - CDC - Health departments - CMS - SAMHSA - HRSA Ryan White (distribution of funds; ADAP) - Coordination	■ Surveillance ■ Testing services ■ Prevention services ■ Medical services ■ Supportive services ■ Service integration ■ HIV clinic distance ■ HIV clinic culture ■ Appointment availability ■ Medical home	■ Neighborhood ■ Poverty ■ Education ■ Social norms ■ Stigma ■ Employment ■ Corrections facilities	■ Intimate partners ■ Family members ■ Friends ■ Social networks ■ Medical provider ■ Case manager ■ Mental health provider ■ Peer mentor/navigator ■ Relationship factors - Trust - Communication - Longevity - Compatibility	■ Potential predisposing factors - Age - Race - Ethnicity - Sex - Mental health - Substance use ■ Perceived needs - Health benefits - Symptoms - Comorbidities - Past experiences ■ Potential enabling factors - Insurance coverage - Transportation - Housing - Income - Education - Social support - Empowerment - Self-efficacy - Spirituality - Coping skills - Resiliency

ADAP indicates AIDS Drug Assistance Program; CDC, Centers for Disease Control and Prevention; CMS, Centers for Medicare and Medicaid Services; HRSA, Health Resources and Services Administration; SAMHSA, Substance Abuse and Mental Health Services Administration. Adapted from Mugavero et al.[13]

testing. Posttest counseling included a discussion about the meaning of a positive test result, the importance of getting into care, the role of barrier protection in sexual safety, and the need for cleansing of any drug equipment or sex toys. He was given a list of treatment sites, with those closest to his stated address circled. He never showed up at any of the treatment sites—another common scenario.

Engagement in HIV Care

Failure to follow up after HIV testing is a common scenario in the HIV care cascade. As discussed below, several studies have convincingly demonstrated that engagement in HIV care *begins at the testing site.* How closely the HIV counseling, testing, and referral (CTR) experience correlates with subsequent linkage to care appears to be related to the tone and expectation for future engagement in care established during CTR. The Never in Care Project conducted in 5 locales with mature HIV epidemics (New York City, Philadelphia, and sites in Indiana, Washington state, and New Jersey) highlights the importance of this experience.[12] HIV-infected individuals who never sought care beyond testing were predominantly male (71%) and African American (54%), with almost half being younger than 30 years. Dissatisfaction with the CTR experience was a pervasive theme. Some of the factors reported were lack of empathy, insufficient counseling, and incorrect information. Being given the wrong address for a practitioner discouraged some individuals from pursuing care. One 25-year-old African American man stated, "They acted like they could not have cared less. It's a good thing I have support. And if you think this means I'm going to go back and see anyone about this, I won't. No. Never. Never."[12]

The method of referral also had an effect on linkage outcomes. Passive referral in the form of a card, brochure, or verbal direction was often perceived as constituting little or no help. Patients receiving passive referral were less likely to go to a treatment location. Active referral in which the tester made the treatment appointment or accompanied the patient was associated with a feeling of support and a higher likelihood of follow through. One patient reported, "When they did the quick test she gave me her card, she talked to me and my mom then.... Not knowing if I would have that support group, she made herself a support group [for me] until I could get to the [AIDS service organization]."[12] Such challenges are part of the rationale for test-and-treat interventions presently being devised, tested, and implemented in a number of settings.

Practitioner behavior is a crucial piece of the engagement and retention puzzle. A number of earlier studies suggested that antiretroviral prescribing was racially biased,[14,15] but repeat studies have failed to corroborate this finding.[16,17] It is clear, however, that patient trust in the practitioner is an important component of care adherence in some populations, including African Americans,[18] as emphasized by recent data confirming the importance of practitioners to engagement in HIV care.[19] In an urban clinic, more than 1300 patients rated their communication and relationships with their HIV practitioners. Appointment adherence correlated with patients' perceptions that they were being treated with dignity and respect, as well as with the opinion that the practitioner listened to their concerns. Patients also kept more appointments if practitioners explained things in a way that they could understand and took the time to get to know them as individuals. Being involved in decision making was not associated with appointment adherence.[19]

Beyond improving practitioner and patient interactions, other strategies that can help improve engagement and retention in care include:

- *Easing of Structural Barriers*. Small changes, such as increasing clinic hours, ensuring appointment availability, etc.
- *Novel approaches for specific populations.* STYLE (Strength Through Youth Livin' Empowered) is a Health Resources and Services Administration (HRSA)-funded project that uses social media as a way to reach young black and Latino men who have sex with men.[20]
- *Easy, low-effort interventions.* Use of brochures, posters, and messages conveying the importance of regular clinic attendance in an urban clinic yielded modest (7%) but consistent improvement in follow-up.[21]
- *Incentives.* Cab vouchers, grocery cards, other inducements to adhere to appointments.
- *Peer navigators.* Peer navigators have been successfully used in a model to increase access to and retention in dental care through help with care coordination and support.[22]
- *Medical homes.* HRSA is also interested in developing patient-centered medical homes with retention specialists, staff training, and a variety of programs to increase reengagement. In one study, the retention specialist alone was directly responsible for the return of 116 (16.2%) of 716 reengaged patients.[23]
- *Multidisciplinary teams.* Multidisciplinary team approaches have been used for antiretroviral therapy adherence and primary HIV care, with teams often including a case manager, social worker, pharmacist, nurse, and care practitioner.[24]

Moving Forward—What We Need

In the simplest terms, what is needed to enhance linkage from testing into HIV care can be described as the 4 Es: Easy, Evidence-based, Economical, and Effective interventions targeted to specific populations at increased risk for care disengagement, including youth, minorities, and lower-literacy populations.[25] Robust clinical trials of real-world interventions to enhance care linkage, facilitate patient-practitioner communication, build system navigation skills, and encourage reengagement in care for at risk populations continue to be needed, as interventions that work for one population group may not be applicable to another. Enhanced safety nets to quickly identify and engage individuals who do not link to care after testing are needed, as is recognition that, sadly, not everyone can be engaged.

For the HIV practitioner, losing patients despite one's best efforts is an unfortunate and bitter reality. As noted above, patient A refused hospitalization. The practitioner asked the patient's mother to call family members to the office, which led to a gathering of 14 people, including the patient's extended family. Her issues were discussed, and a case manager assured her that her children would not be prevented from seeing her if she were hospitalized. Her mother, who had custody of her children, and her uncle also promised to ensure that her children would be able to visit during her hospitalization. An adherence team member offered to accompany her to the hospital, to which she agreed. Unfortunately, she was so debilitated and emaciated that she was unable to walk, so the practitioner carried her from the room to the waiting stretcher. She was hospitalized and treated for bacterial pneumonia, and antiretroviral therapy and opportunistic infection prophylaxis were initiated. At discharge, her CD4+ cell count was 2/µL and her plasma HIV RNA level was in excess of 375,000 copies/mL.

However, 6 months later, she was nearly unrecognizable—she had gained 20 lbs, her viral load was undetectable, and her CD4+ cell count was 200/µL. She was wearing makeup and appeared to be well on her way to better health. But 8 months later, just 14 months from the time of her last hospitalization, she dropped out of care. Thus, the cycle begins again—a cycle we very much need to stop.

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References

1. Hogg R, Samji H, Cescon A, et al, for North American AIDS Cohort Collaboration on Res and Design (NA_ACCORD) of IeDEA. Temporal changes in life expectancy of HIV+ individuals: North America [Abstract 137]. 19th Conference on Retroviruses and Opportunistic Infections (CROI). March 5-8, 2012; Seattle, Washington.
2. Murphy K, Hoover D, Shi Q, et al. The association of race with death from AIDS in continuous HAART users: WIHS [Abstract 1045]. 19th Conference on Retroviruses and Opportunistic Infections (CROI). March 5-8, 2012; Seattle, Washington.
3. Mortality slide series. National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. Division of HIV/AIDS Prevention. http://www.cdc.gov/hiv/pdf/statistics_surveillance_HIV_mortality.pdf. Accessed on June 18, 2013.
4. Quick stats: human immunodeficiency virus (HIV) disease death rates among men aged 25-54 years, by race and age group—National Vital Statistics System, United States, 2000-2010. http://jama.jamanetwork.com/article.aspx?articleid=1681429. Accessed on June 18, 2013.
5. Poverty in the United States FAQ. National Poverty Center. http://www.npc.umich.edu/poverty/. Accessed on June 18, 2013.
6. Barragan M, Hicks G, Williams MV, Franco-Paredes C, Duffus W, del Rio C. Low health literacy is associated with HIV test acceptance. *J Gen Intern Med.* 2005;20(5):422-425.
7. Navarra AM, Neu N, Toussi S, Nelson J, Larson EL. Health literacy and adherence to antiretroviral therapy among HIV-infected youth. *J Assoc Nurses AIDS Care.* 2013;doi: 10.1016/j.jana.2012.11.003 [Epub ahead of print]
8. Wolf MS, Davis TC, Osborn CY, Skripkauskas S, Bennett CL, Makoul G. Literacy, self-efficacy, and HIV medication adherence. *Patient Educ Couns.* 2007;65(2):253-260.
9. Schneider G, Juday T, Wentworth C, III, Lanes S, Hebden T, Seekins D. Impact of health care payer type on HIV stage of illness at time of initiation of antiretroviral therapy in the USA. *AIDS Care.* 2013;doi: 10.1080/09540121.2013.774316 [Epub ahead of print].

10. Kahn JG, Zhang X, Cross LT, Palacio H, Birkhead GS, Morin SF. Access to and use of HIV antiretroviral therapy: variation by race/ethnicity in two public insurance programs in the U.S. *Public Health Rep*. 2002;117(3):252-262.

11. Karch DL, Logan J, McDaniel D, Parks S, Patel N. Surveillance for violent deaths—national violent death reporting system, 16 states, 2009. *MMWR Surveill Summ*. 2012;61(6):1-43.

12. Garland PM, Valverde EE, Fagan J, et al. HIV counseling, testing and referral experiences of persons diagnosed with HIV who have never entered HIV medical care. *AIDS Educ Prev.* 2011;23(3 Suppl):117-127.

13. Mugavero MJ, Norton WE, Saag MS. Health care system and policy factors influencing engagement in HIV medical care: piecing together the fragments of a fractured health care delivery system. *Clin Infect Dis.* 2011;52(Suppl 2):S238-S246.

14. King WD, Wong MD, Shapiro MF, Landon BE, Cunningham WE. Does racial concordance between HIV-positive patients and their physicians affect the time to receipt of protease inhibitors? *J Gen Intern Med.* 2004;19(11):1146-1153.

15. Wong MD, Cunningham WE, Shapiro MF, et al. Disparities in HIV treatment and physician attitudes about delaying protease inhibitors for nonadherent patients. *J Gen Intern Med.* 2004;19(4):366-374.

16. Oramasionwu CU, Brown CM, Lawson KA, Ryan L, Skinner J, Frei CR. Differences in national antiretroviral prescribing patterns between black and white patients with HIV/AIDS, 1996-2006. *South Med J*. 2011;104(12):794-800.

17. Oramasionwu CU, Skinner J, Ryan L, Frei CR. Disparities in antiretroviral prescribing for blacks and whites in the United States. *J Natl Med Assoc.* 2009;101(11):1140-1144.

18. Saha S, Jacobs EA, Moore RD, Beach MC. Trust in physicians and racial disparities in HIV care. *AIDS Patient Care STDs.* 2010;24(7):415-420.

19. Flickinger TE, Saha S, Moore RD, Beach MC. Higher quality communication and relationships are associated with improved patient engagement in HIV care. *JAIDS.* 2013;63(3):362-366.

20. Hightow-Weidman LB, Smith JC, Valera E, Matthews DD, Lyons P. Keeping them in "STYLE": finding, linking, and retaining young HIV-positive black and Latino men who have sex with men in care. *AIDS Patient Care STDs.* 2011;25(1):37-45.

21. Gardner LI, Marks G, Craw JA, et al. A low-effort, clinic-wide intervention improves attendance for HIV primary care. *Clin Infect Dis.* 2012;55(8):1124-1134.

22. Rajabiun S, Bachman SS, Fox JE, Tobias C, Bednarsh H. A typology of models for expanding access to oral health care for people living with HIV/AIDS. *J Public Health Dent*. 2011;71(3):212-219.

23. Sitapati AM, Limneos J, Bonet-Vazquez M, Mar-Tang M, Qin H, Mathews WC. Retention: building a patient-centered medical home in HIV primary care through PUFF (patients unable to follow-up found). *J Health Care Poor Underserved.* 2012;23(3 Suppl):81-95.

24. Horberg MA, Hurley LB, Towner WJ, et al. Determination of optimized multidisciplinary care team for maximal antiretroviral therapy adherence. *J Acquir Immune Defic Syndr.* 2012;60(2):183-190.

25. Gilman B, Hidalgo J, Thomas C, Au M, Hargreaves M. Linkages to care for newly diagnosed individuals who test HIV positive in nonprimary care settings. *AIDS Patient Care STDs*. 2012;26(3):132-140.

Top Antivir Med. 2013;21(4):133-137

Peer Navigators Effectiveness in Increasing Linkage and Retention to HIV Care: Best Practices from 13 AIDS United Access to Care Programs

Presented by:

- Erin Nortrup, AIDS United
- Paula J. Lanell, AIDS Action Committee of Massachusetts
- Shannon Hansen, Christie's Place
- Vernita Perry, Institute for Public Health Innovation

aidsunited.org

AIDS United

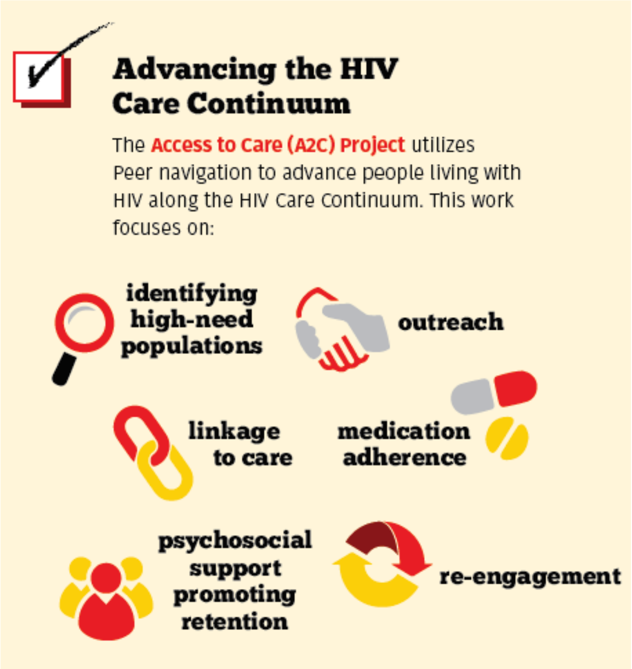
Access to Care (A2C) Initiative

- Twelve innovative, public-private partnerships around the country focused on improving individual health outcomes and strengthening local service systems
- Emphasis on hard-to-reach populations, particularly those living in poverty and those who know their HIV status but are not in care
- Innovative approaches driven by local epidemic and gaps in linkage and retention
- Funded by the Corporation for National and Community Service's Social Innovation Fund and numerous foundations

SOCIAL INNOVATION FUND

AIDS United
EVERY PERSON EVERY COMMUNITY

Access to Care Initiative



Advancing the HIV Care Continuum

The Access to Care (A2C) Project utilizes Peer navigation to advance people living with HIV along the HIV Care Continuum. This work focuses on:

- identifying high-need populations
- outreach
- linkage to care
- medication adherence
- psychosocial support promoting retention
- re-engagement

Retention in Care (RiC) Initiative

- Cohort of seven organizations across the country
- Identify, document and evaluate innovative, emerging or promising program models for improving retention in care.
- National evaluation monitoring improvement in individual health, systems change and cost effectiveness.
- Funded by the M·A·C AIDS Fund

Best Practices: Integrating Peers into HIV Models of Care

- Features ten Peer Navigation programs at AIDS United partner organizations
- Provides guidance on implementing these best practices in your organization

AIDS United

PEER NAVIGATOR PROGRAM BEST PRACTICES CHECKLIST

Providers can use this Peer navigation checklist to assess their organization's program readiness and ensure its comprehensive approach.

☐ **Design and Implement a Structured and Well-defined System that Supports Peer Navigators in the HIV Care Team**
Regardless of the type of care or service setting that Peer navigation services exist within, it is critical to create a system of integration prior to the hiring and arrival of Peers.

☐ **Identify Specific Population(s) to be Served by Peers**
Matching clients with a Peer that has a solid understanding of their barriers and opportunities for optimal health and wellbeing is a key strategy.

☐ **Establish a Standardized Title and Position for the Peer Navigator Within the Integrated Care Team**
Common roles include outreach, linkage, and retention in HIV care and treatment adherence support. Peers in these projects are paid staff rather than volunteers, reflecting a shift in the field in recognizing the role of Peer Navigators as a professional one. Peers offer a unique supportive role due to their shared life experiences with clients. Basic qualifications include emotional and physical readiness for the duties, computer literacy, and a deep understanding of the community being served. Across sites, Peer Navigators are defined as *"medication-adherent role models living with HIV who share the same experiences and community membership and who are trained to provide effective services that increase the linkage, retention, and medication adherence of the people they serve."*

☐ **Establish Protocols and Procedures for Peer Navigation Programs**
It is critical that the *"who" and "how"* of assigning and utilizing Peers is in place at the organization, including Peer priorities and how they will interact with colleagues.

☐ **Train Agency Staff and the HIV Care Team**
Hold organizational meetings to share policies and procedures, including how Peers will complement the team and the organization's mission. Ensure that all staff members are clear on roles and lines of communication with Peers and how to coordinate work across departments. Share the "value added" benefit of Peer Navigators, and provide an opportunity to address staff questions or concerns.

☐ **Implement a System of Open Communication and Coordination With Other Care Team Members**
Team meetings with case managers or social workers are helpful. Peers may need training on meeting procedures and how to present clear and concise client information in this setting. Peers may have access to electronic medical records and may need training on how to utilize these records and help clients do so as well.

☐ **Implement a Competency-Based Training for Peer Navigators and Supervisors**
Competency areas may include: HIV and healthful living, communication skill-building, Health Insurance Portability and Accountability Act (HIPAA), various roles of HIV care team members, health and health care literacy, developing service plans, electronic health records (EHRs), and documentation and local implementation of the Affordable Care Act (ACA).

☐ **Provide Consistent Administrative and Clinical Supervision to Peers**
Have a supervision structure in place with identified staff filling this role. A key to Peer success is the provision of training, guidance, and support in their own self-care as individuals living with HIV/AIDS.

☐ **Create a Documentation System to Describe and Monitor Peer-Client Activities that is Linked to Case Management Records**
Train Peers on how to report data and use critical information to inform the care team of client progress and ongoing needs.

AIDS United

Peer Navigator's Effectiveness in Increasing Linkage and Retention to HIV Care

Paula Lanell

AIDS Action Committee of Massachusetts

AAC Access to Care Model

- LEAP (Learning, Engaging & Advocating *with* Peers)
  - Integrated Advocacy Team (Medical Case Manager – Peer Navigator – Mental Health Clinician – Client)
  - Peers work closely with Medical Case Managers to link, engage and retain clients in care
  - Align all services along the HIV care continuum
  - Collaboration with HIV providers/medical centers
  - Funding through AIDS United to improve linkage, retention and viral suppression

Integrated Advocacy Team

- Medical Case Managers and Peers work closely together to improve the health and self sufficiency of clients.
- Weekly check-ins with Medical Case Managers, Peers & Supervisors
  - Review Individual Service Plan goals and action steps
  - Review client’s upcoming medical appointments and collaborate on accompaniment needs
  - Place calls to clients for appointment reminders and general check-in

Peer Navigator Core Responsibilities

- Medical Systems Navigation
- Appointment Accompaniment
- Support Group Facilitation
- Treatment Adherence Education
- Documentation in Electronic Database
- Outreach to Target Populations
  - Non-US Born (Haitians, Latinos, Africans), people who use drugs, those experiencing homelessness

Criteria & Population

- Newly diagnosed
- Out of care
- At risk of falling out of care
  - Substance Use
  - Homelessness
  - Cultural Issues
  - Stigma

Case Finding & Referrals

- In-Reach
  - Review current caseloads & new intakes to identify clients who are eligible
- Outreach
  - Community - Counseling and Testing sites, programs for people who inject drugs, substance use programs, shelters
  - Connect with local HIV providers informing them of LEAP program
  - Maintain ongoing relationship with local Community Health Center(s)

Strategies for Positively Impacting the Care Continuum

- Weekly meetings with Medical Case Managers and Peers
  - Discuss accompaniment needs and schedule with Peers
  - Discuss clients, focus on those with detectable viral loads
  - Schedule home visits with clients to assess their living environment and possible barriers to adherence

Social and Community Referrals

- SSI/SSDI (Social Security)
- DTA (Department of Transitional Assistance)
- Senior Services
- Mental Health Services
- Food Banks
- Housing Search
- Substance Use Programs (Detox, Methadone, Suboxone, etc.)
- AA/NA
- Other resources as needed…

Peer Training

- Peer Competency Training
- Treatment Adherence “Train the Trainer”
- Organization Wide “Getting to Zero” Trainings

Supervision

- Bi-weekly Administrative Supervision (with direct supervisor)
  - Program/Training Update
  - Data entry review (ETO)
  - Personal check-in
- Monthly Clinical Supervision (licensed clinician) with site team
  - Case Studies – Self Care

Data Collection and Monitoring

- Peers have access to electronic database to collect data and write notes.
  - Peers require a basic level of computer literacy and may need additional training and supervision.
  - Peers are trained in issues around confidentiality, data collection, and progress notes.
  - Supervisor meets with Peers to discuss and review data.

Benefits of Peer Work

- Motivate behavioral change through shared experiences and histories.
- Reduce barriers that impact health and HIV treatment adherence.
- Enhance the work that Medical Case Managers are already providing clients by offering a unique perspective.
- Establish an honest, trusting relationship with clients
  - Clients often share personal information with peers that they may not with their providers.

Peer Navigator Quote

“I feel that my past challenges and related trauma made my life ***great*** because it now helps people who are in the same or similar situations.”

~Mayra~

Questions?

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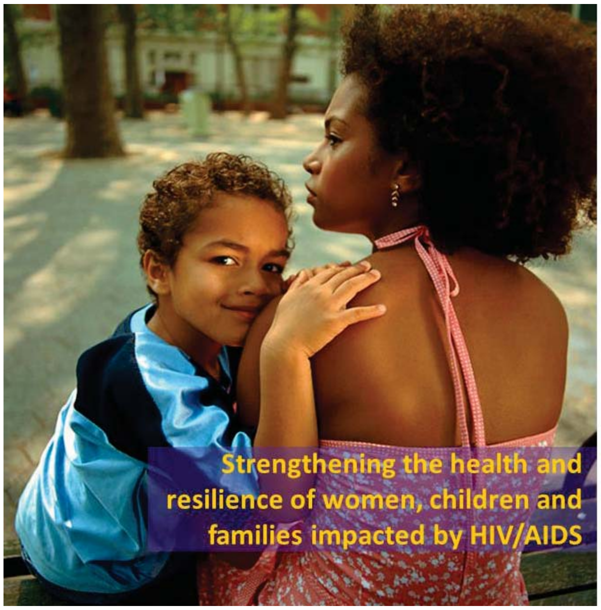
THANK YOU!!

Christie's Place

Transforming lives since 1996™

Shannon Hansen, MSW

Program Director



Strengthening the health and resilience of women, children and families impacted by HIV/AIDS

CHANGE for Women

Coordinated HIV Assistance and Navigation for Growth and Empowerment

- Improve timely entry, access to and retention in HIV care for women living in San Diego County, with an emphasis on the underserved communities of Latina and African American women.
- Increase women's utilization of HIV medical care and treatment.
- Improve communication and health system navigation between clients and medical providers.
- Build and support the capacity of partner organizations to integrate peers into their multidisciplinary health care teams.
- Create Center of Excellence in Women's HIV Care & Research
- Bridge the gaps between HIV, immigration and social justice

Target Population

- HIV+ women who are newly diagnosed
  - *up to six months*
- HIV+ women who have never been in care
- HIV+ women who have fallen out of care
  - *unmet need definition = no care for 12 months or longer*
- HIV+ women who are sub-optimally engaged in care
  - *Sub-optimal defined as failing to have two visits two months apart within a six month period*

Peer Program Model

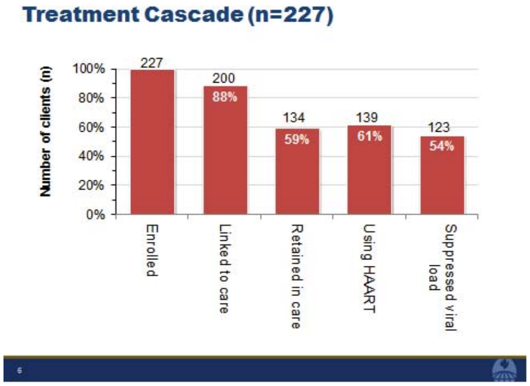
- Evolutionary process
- Evidence based approach
- Essential members of care team
- Location, location, location
- Integration and replication with clinical partner care team(s)

Implementing Best Practices

- Readiness
- Defined populations
- Recruitment
- Clear roles and expectations
- Training and development
- Supervision and support
- Care coordination
- Evaluation
- Sustainability

Consistent Administrative and Clinical Supervision

- On-boarding
- Supervision
  - Weekly 1:1 Clinical Supervision
  - Case Consultation
  - Treatment Team Meetings
- Performance monitoring
- Continuous staff development



Qualities of a Trauma-Informed System of Care

- Intentionality
  - Purposeful efforts towards creating and sustaining healing and growth
- Mutuality
  - *"Healing happens in relationship."*
  - Reciprocal connections which foster increased understanding and shared learning
- Commonality
  - *"We all have a story."*
  - Life experiences shape our perceptions of ourselves and others
- Potentiality
  - Positive change is possible for all (individuals, organizations, & communities)

Office on Women's Health, 2013

Unexpected Challenges

- Acceptance and validity
- Role ambiguity
- Client "ownership"
- Acuity level of clients
- Systems limitations
- Sustainability in a healthcare reform landscape

Successes

- Individual level health outcomes
- Systems level change
- Cost effectiveness

TRAINING FOR COMMUNITY HEALTH WORKERS

LESSONS LEARNED

Vernita Perry
Community Health Worker
Institute Of Public Health Innovation

INSTITUTE OF PUBLIC HEALTH INNOVATION

Institute for Public Health Innovation is a unique non-profit resource that builds partnerships across sectors and cultivates innovative solutions to improve health and well-being for all people and communities throughout the District of Columbia, Maryland, and Virginia.

IPHI's work emphasizes building community capacity so all individuals and population groups can achieve the best possible health and quality of life.

POSITIVE PATHWAYS PROGRAM

Community Health Workers

May 2011 - Present

Positive Pathways, an initiative of the Washington AIDS Partnership and the Institute for Public Health Innovation, assists HIV-positive African Americans living in the District of Columbia to access and effectively benefit from HIV medical care, with a particular focus on women and their partners.

A group of trained community health workers (CHWs), who can be identified as part of or from the same communities are placed in clinical and non-clinical settings.

COMMUNITY HEALTH WORKER

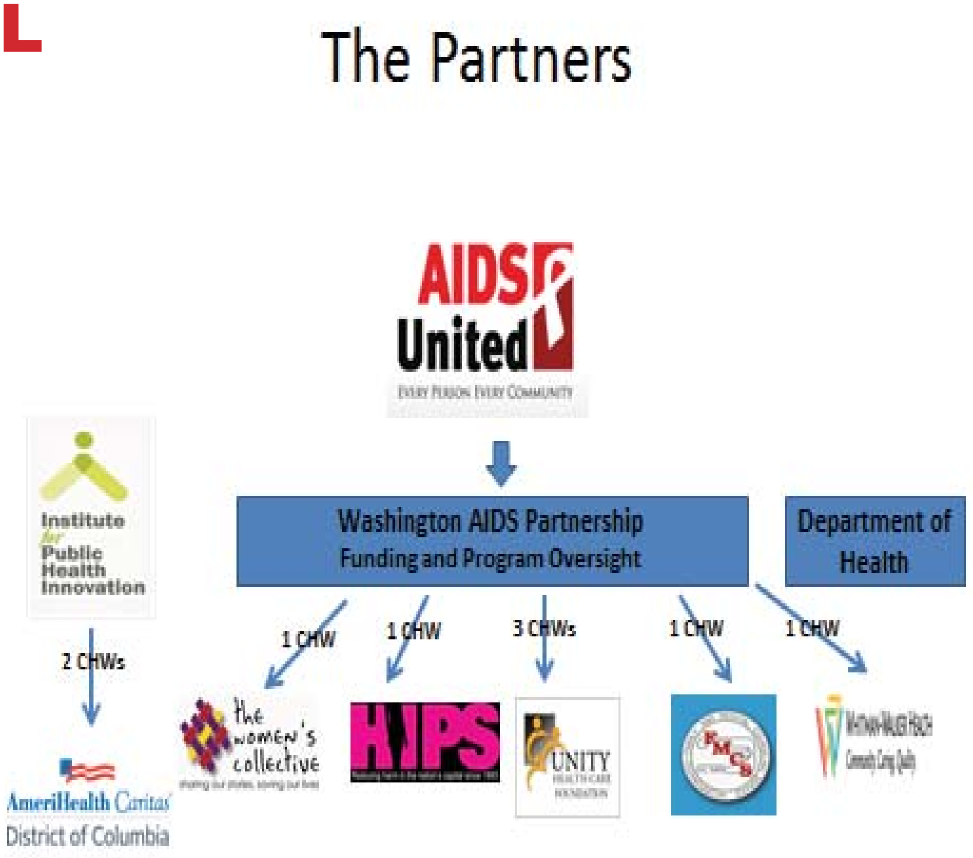
According to the American Public Health Association, a CHW is defined as a **frontline public health worker** who is a **trusted member** of and/or has an unusually close understanding of the community served. This trusting relationship enables the worker to serve as a **liaison/link/intermediary between health/social services and the community** to facilitate access to services and improve the quality and cultural competence of service delivery. A community health worker also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy.

OUR ACTIONS

WE:

- **Serve members who live in the District in Wards 1 through 8**
- **Identifying out-of-care HIV-positive individuals**
- **Work with members who are newly diagnosed**
- **Building peer-based trust**
- **Educate individuals about living with HIV**
- **Address barriers to care**
- **Linked them care**
- **Providing personalized assistance in navigating the health care systems**
- **Support them through the early part of their medical care**
- **Teach and show them how to be retention in care.**

MODEL



The Partners

CHALLENGES AND SUCCESSES

CHALLENGES

- Case management support
- Consistence and supportive supervision
- Limited resources
    - For clients: housing, jobs, and transportation
    - For CHWs: full excess to medical records

SUCCESS

Medical and non medical sites are hiring CHWs not just a grant

Higher CD4

Lower viral suppression

Retention in care

COMPETENCY-BASED TRAINING FOR PEER NAVIGATORS AND SUPERVISORS

- 8 months in Community College
- 40 hours in HIV training
- 8 hours Monthly Continuing training
- Yearly three day retreat of training

IPHI COMMUNITY HEALTH WORKER TRAINING COURSE OUTLINE -- INITIAL 80-HOUR CORE TRAINING

Health Equity 101

Perspective Transformation

Communication

Introduction to the CHW Role: CHW History, Roles, Skills, Tasks

Outreach & Advocacy

Multiculturalism and Vulnerable Populations

Teaching and Motivating

Health Education & Prevention

Data Collection & Medical Record Review

CHW Legal & Ethical Issues

Health Core (40 hours)

COMPETENCY-BASED TRAININGS FOR PEER NAVIGATORS CONTINUING TRAINING (ETC.)

Self-care
Mental Health and HIV
Boundaries
Communications
Drug addiction and HIV
Motivational Interviewing
Portability and Accountability Act (HIPAA),
Various roles of HIV care team members,
Health and healthcare literacy,
Developing service plans,
Electronic health records (EHRs), and
Documentation and local implementation of the Affordable Care Act (ACA).

Questions?

Thank You!

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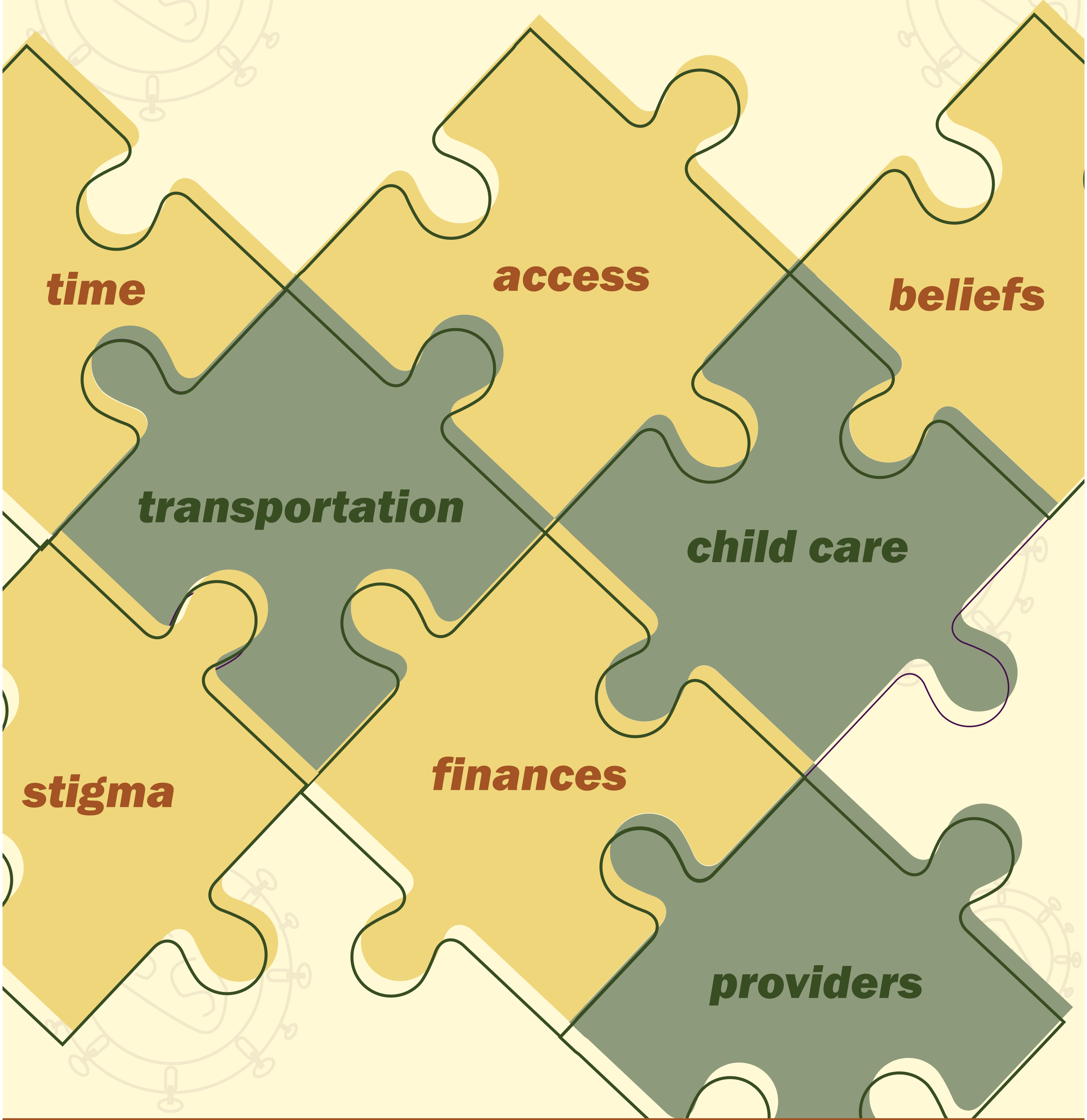
RETENTION IN HIV CARE:

A CLINICIAN'S GUIDE TO PATIENT-CENTERED STRATEGIES

NOVEMBER 2013



HIV PROVIDER REFERENCE SERIES

A PUBLICATION OF THE MOUNTAIN PLAINS AIDS EDUCATION AND TRAINING CENTER

MountainPlains
AIDS EDUCATION AND TRAINING CENTER

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The human immunodeficiency virus (HIV) is a sexually transmitted and blood borne retrovirus that causes immune deterioration, chronic disease, and early mortality. More than 1.2 million people are currently living with HIV infection in the United States. An estimated 18% of people living with HIV (PLWH) have not been diagnosed and, despite effective treatment, only 33% of PLWH are receiving routine HIV care (Crowley & Kates, 2013). This is unfortunate, as patients who keep regular clinic visits live longer and have healthier lives than those who do not. The maximum benefits of antiretroviral therapy are derived when PLWH are diagnosed and receive care early in the course of the disease. In addition to the obvious personal health benefits for individual patients, PLWH who are engaged in care are less likely to transmit the infection to others (Cohen et al., 2011).

In newly diagnosed patients who receive HIV care, mortality is twice as high for those who miss a clinic visit within the first year of diagnosis (Mugavero et al., 2009). Appointment non-adherence has been associated with virologic failure (failure to reach undetectable levels), clinical disease progression (including AIDS-defining illnesses), and death (Giordano et al., 2007). Clearly, retention in care depends on successfully connecting to an HIV clinic and being actively engaged in care, but this is not an all or nothing process, as many patients cycle in and out of treatment.

Individual and structural barriers can keep patients from fully engaging in care. Individual barriers may include:

- Healthcare beliefs (such as not perceiving the need for care)
- Not liking the care provider
- Not feeling well enough to come to clinic
- Feeling well (healthy) and not understanding the need for regular HIV care even when feeling well
- Forgetting clinic appointments
- Substance abuse and mental health problems
- Perceived homophobia, racism, discrimination, stigma
- Insufficient financial resources and/or lack of insurance
- Housing issues
- Fears related to treatment
- Competing time demands such as work and other appointments

- Limited access to transportation
- Family responsibilities and/or the need to care for others that may supersede self-care
- Language and/or literacy barriers

Structural barriers may include:

- Inconvenient clinic hours, especially for patients who work
- Clinics that are not located on easily accessible public transportation lines
- Cycling in and out of prison
- A long wait time from making an appointment to the actual clinic visit, especially for first clinic appointments
- Culturally insensitive treatment
- Language barriers (lack of multi-lingual providers at clinic)

Linkages to care and retention in care will become even more important as the number of new patients in need of HIV treatment increases. Increases are expected in response to:

- Centers for Disease Control and Prevention HIV testing recommendations that advocate opt-out testing of everyone ages 13 to 64 (CDC, 2006),
- U.S. Preventive Services Task Force recommendations to screen all patients ages 15 to 65 as well as older and younger people at increased risk for HIV (Moyer, 2013),
- Roll-out of the Affordable Care Act (Martin & Schackman, 2012), which will increase access to health care, and
- The National HIV/AIDS Strategies (Office of National AIDS Policy, 2010).

Retention in care can be improved through the use of a variety of tactics, such as:

- Providing comprehensive and easy-to-access services, including case management
- Decreasing structural barriers at clinics, including expanded appointment times for working patients, one-stop care, and transportation vouchers
- Creating a clinic environment that is friendly and welcoming to patients
- Providing basic HIV education
- Teaching patients the skills that will help them be successful in care
- Develop an understanding of MSM and gay men, and how sexuality and race impact interactions with providers

THE CLINIC ENVIRONMENT

A warm and welcoming clinic environment requires teamwork. Everyone, including the receptionist who greets patients at the front desk, the medical assistant who takes vital signs, the clinician who provides medical care, the social worker or case manager who helps patients navigate the clinic system, and, in effect, anyone who has patient contact, has an important role in helping patients feel cared about and cared for. There are many ways to create a clinic culture that is inviting. In fact, it can be as simple as:

- Greeting patients by name.
- Saying, "Thanks for coming in today. It's good to see you."
- Treating each patient as an important individual.

TAILOR MESSAGES TO THE PATIENT

Every patient is different and you need to adjust your approaches and messages to each one. It may help to consider the following groups of patients.

New patients need to feel welcome and to learn about the importance of establishing routine care. Things you can say to new patients:

- "Welcome to our clinic. If I can do anything to help you, please let me know."
- "It is very important to keep your appointments. If you can't come in, please let me know and I will help you schedule a new appointment."
- "People with HIV who come to their appointments do better than those who don't. I look forward to seeing you on a regular basis."
- "It is important for you to keep your appointments so we can work together to keep you healthy."
- "If you come to your appointments regularly, we have a better chance of managing your HIV so that you don't get sick."
- "It is important that I see you regularly to ensure that there are no problems with your health or your medications."

Inconsistent attenders who do not regularly show up for appointments can frustrate providers and clinic staff. It is important to provide education and support to these patients. Try some of these messages:

- "We have good evidence that people with HIV who come to their appointments do better than those who don't. When you miss your appointments, we can't work together to keep you healthy."
- "You deserve the best care possible, but when you miss appointments I can't monitor your labs and adjust your treatment if there are problems."
- "You have an important role in keeping yourself healthy. When you don't come in, it is more difficult to act as partners in your care."

It is easy to ignore ***established patients*** who consistently keep their clinic appointments, but they deserve reinforcement for being conscientious. Give them positive messages:

- "Welcome back. How are you doing?"
- "Thanks for keeping your appointment. It is good to see you again."
- "You do such a good job of keeping your appointments. It makes it easier for us to work together to keep you healthy."
- "You're doing well and I know it is—in part—because you've been coming in so regularly."
- "We are a team, and when it comes to your health, you're the most important player."

FOCUS ON THE PATIENT'S STRENGTHS

Strengths-based approaches emphasize the patient's skills, abilities, and self-efficacy; they minimize problems, deficits, and helplessness. Focusing on strengths improves the provider-patient relationship, teaches the patient to advocate for him/herself, decreases denial, and limits resistance to care. When patients understand their strengths, they are better able to set personal goals and develop plans to reach those goals. Make use of both formal (substance abuse/mental health treatment, case management, transportation support, housing assistance, etc.) and "natural" or informal resources already in the patient's life (job, family, friends, partners, personal motivation). Strengths-based care uses the following strategies:

Emphasize strengths and base goals on past successes

- "How have you solved this problem in the past?"
- "What skills and resources do you use to solve other problems in your life?"

De-emphasize the patient's account of things s/he's done wrong

- "We all make mistakes. That's how we learn. The important thing is that you're here today."
- "You made a mistake, but I think you are being too hard on yourself."
- "Sometimes mistakes provide a learning opportunity. What can you do differently next time?"

Use affirmations to acknowledge personal effort

- "By coming to your appointments, you're helping to create a healthier life for yourself. You can feel proud of this."
- "I know that you are a smart, resourceful person with the ability to overcome problems related to your care."

Reframe negative and erroneous statements into positive/neutral and more appropriate assertions

- If the patient says, "I can never keep my appointments. I mess up every thing I do," you might want to respond
  - "You're here today, and that's a great start."
  - "We can work together to develop a system to help you get to the clinic."
- If the patient says, "I didn't come to my last appointment because I felt good. There's no point in coming when I don't feel sick," you might want to respond:
  - "It's very important to come in even when you feel well."
  - "Keeping your appointments can help you stay healthy."
- If the patient says, "I hate coming to the clinic, because it reminds me that I have HIV, which is so depressing," you might say:
  - "It's true that HIV is a chronic illness that will require some changes on your part, however, it's important to remember that people who keep their clinic appointments and are active in their care can live long, healthy lives, and you can too. It's good that you're here today."
  - "When you come to the clinic we can work together to make sure you stay as healthy as possible."

Patients are resilient. People constantly adapt and evolve; they are capable of affecting their environments and circumstances, not simply reacting to them. Despite their problems, the patients you work with are survivors, each with unique strengths and skills. Offer hope:

- Help patients create personal meaning that incorporates optimism about the future.
- Let the patient know you believe in him/her, even when s/he doesn't yet share that confidence.

THE IMPORTANCE OF EDUCATION

Patients need to know about their health problems and develop the skills necessary to engage in care. Often we expect patients to do things, but they don't understand why or they don't have the skills to meet our expectations. It will help if your patients know the basics about HIV infection and how being engaged in care can make a difference in disease progression. They will also need to develop skills in the following areas: Getting Organized, Communicating with Providers, and Problem Solving. (See Appendices.)

Clinicians are often too busy to provide education in the depth necessary to make real differences in their patients' lives, so it is important to get case managers, social workers, nurses, peer navigators, patient educators, and other clinic staff involved in the teaching process. You may want to consider this sequence of events:

- Assess the patient's learning needs to determine the areas that require focused education.
    - ▫ Clinicians will often be the first to recognize a problem. When you see a need for education, determine (a) if the problem can be quickly addressed (in which case, it should be addressed immediately with a brief message or piece of information) or (b) if it needs more in-depth teaching (in which case, it is appropriate to refer the patient to a staff member who knows how to provide the needed education). Clinicians can help facilitate this process by making statements such as, "I would like for you to spend some time talking to our health educator. He can help you learn how to solve problems like the one you just described."

  - ▫ Staff members who are responsible for teaching patients the skills that will help them stay in care should initiate education with a more in-depth assessment of the problem area(s). (See Appendices.)
- Develop a plan to deliver the education. Teaching can be delivered individually in one-on-one sessions or in small groups. If the patient is willing, it may help to include significant others in education sessions.
- Allow sufficient time to cover the identified needs; more than one session may be required.
- Follow up after teaching. Plan a session to determine if the patient has additional questions, learning needs, and/or misconceptions that need to be corrected. If you have taught a skill to the patient, ask for a demonstration of the learning. For instance, if you taught a patient to use a calendar, ask her to show you where she entered her next appointment on her calendar.

PRACTICAL TIPS

- Motivation is a complex topic, and beyond the scope of this pocket guide, but we know that people are often motivated by both self-serving (personal gain) reasons and by altruistic (socially conscious) reasons. Providers can use knowledge of these motivators to strengthen retention in care messages. Remember that different motivators work for different people at different times depending on the context of the individual’s situation.
  - ▫ To reinforce the self-serving motivator, use statements such as:
    - “Coming to all of your clinic visits will help you stay healthy.”
    - “I’m sorry this drug is causing side effects, but we can work together to help you feel better.”
    - “Keeping your viral load low is the best way for you to stay healthy and live longer.”
  - ▫ To reinforce the altruistic motivator, use statements such as:
    - “Your family/partner needs you to stay as healthy as possible.”
    - “It will be easier to contribute to your job/family when you feel well.”
    - “Keeping your viral load low decreases the risk of giving HIV to your sex partner(s).”

- Be culturally appropriate:
    - ▫ Honor differences in languages, social customs, spiritual traditions, and health/illness beliefs
    - ▫ Use materials that address culture in an appropriate manner
    - ▫ Use easy-to-understand language
    - ▫ Provide translation services
- Offer referral to ancillary services that can address specific patient needs such as substance abuse, mental health, transportation, and housing
- See newly diagnosed patients as soon as possible after an HIV diagnosis to emphasize the need to engage in care and to stay in care
- Use a system of reminder calls (personal calls are preferable to automated calls, when possible)
- Follow up with patients who have missed a clinic appointment, and reschedule as soon as possible

REMEMBER . . .

Health care providers can help patients develop skills to enhance retention in HIV care. It is worth the effort. Help your patients by:

- Acknowledging that change occurs slowly and that every small step is a success
- Bearing in mind that it can difficult (but certainly not impossible) to change long-standing behaviors
- Using affirmations and empathy to demonstrate sincere caring and increase patient trust
- Encouraging the patient when problems occur and celebrating successes as they happen

Assessment. Ask questions specific to HIV biology and treatment to determine if there are gaps in the patient's information. Sample questions:

- "Tell me what you know about your lab work."
- "What is a good viral load?"
- "What does it mean when your CD4 cell count goes below 200?"

At the least, the patient needs to have a working knowledge of the following information.

Information for the Patient

CD4+ T lymphocytes are white blood cells (WBCs) that are responsible for initiating and maintaining the immune responses that help you fight off infections.

- HIV targets these cells and kills them. Your body can make new cells to replace the cells that have died, but over time HIV kills more cells than your body can replace.
- The lower your CD4+ T cell count, the weaker your immune system and the greater the likelihood you will develop an opportunistic disease and/or a life-threatening condition.
- One goal of therapy is to keep your CD4+ T cell count high.

The viral load is a measure of how many viruses can be found in your blood.

- An undetectable viral load indicates that the virus cannot be found in your blood by the lab tests that are currently available. It does not mean that the virus is not there; it is, however, an indication that the viral load is too small to detect.
- The lower the viral load, the better your clinical outcome AND the lower your risk of transmitting HIV to a sexual or drug-using partner.
- Another goal of therapy is for you to have an undetectable viral load.

Basics of treatment:

- The better you adhere to your treatment, the better chance you have of staying healthy.
- If you have side effects to your medications, talk to your care provider. Side effects make it harder to take your medications as prescribed, but your provider can help you deal with side effects so that you stay on your treatment.

Staying in care can make a difference in your health:

- Patients who attend clinic appointments regularly are more likely to maintain healthy lab values.
- Patients who attend clinic appointments regularly are more likely to get the help they need to deal with problems as they emerge.
- Patients who attend clinic appointments regularly are more likely to adhere to their medications.

TEACHING TOOLS: ORGANIZATION SKILLS

Assessment. Ask questions specific to how the patient usually stays organized. Sample questions:

- "How do you usually remember things?"
- "What are your biggest problems when it comes to keeping your clinic appointments?"
- "What helps you remember to take your medications?"
- "Tell me how you keep track of your important paperwork. How is that system working for you?"

If the assessment reveals that the patient has problems getting organized, the following information may be useful. *Note: Have the patient practice/demonstrate using a calendar and/or file folder during the teaching session.*

Information for the Patient

Most patients use a calendar to keep track of important dates and appointments. You need to decide what kind of calendar works best for you – a small pocket-sized calendar? the calendar on your cell phone? Remember that calendars work best if you have them with you most of the time. Use your calendar effectively:

- Put all clinic appointments in your calendar as soon as you make them
- Use extra pages in your calendar to take notes and list questions
- If you use a paper calendar, carry a pen or pencil so you can write things down as they occur

In addition to your calendar, you can be better organized by:

- Deciding which activities are most important and doing them first
  - ▫ Make a list of things you need to do and number them in order of importance.
  - ▫ Check off each item as you complete it.

- Keeping health information in one place.
    - A multi-pocket file folder works well for this.
    - Make tabs for lab work, appointments, education materials, documents you need for social services, and other important papers.
    - Make it a habit to take your folder to clinic visits in case you need any paperwork.

TEACHING TOOLS: COMMUNICATION SKILLS

Assessment. Ask questions specific to how comfortable the patient feels discussing concerns with his/her care provider. Sample questions:

- "When you have questions about your health care, how do you get them answered?"
- "Are you comfortable talking to your care provider? If not, please tell me about that."
- "Have you had questions that you were too embarrassed or uncomfortable to ask your provider? What do you do when you have those kinds of questions?"

If the assessment reveals communication problems, the following information may be useful. Note: One of the best ways to teach communication skills is to practice with the patient.

Information for the Patient

Your providers want to hear your questions and concerns, so it is important for you to talk to them. Tell them how you are doing and about any problems you are having, especially when you develop new symptoms or problems taking your medications. Here are some ideas on how to communicate better with your provider. They are easy to remember if you think ABCC:

Ask Questions. You need to know about your treatment and your provider is the best person to teach you about your care. You might have questions like these:

- "How long do I have to take this new medication?"
- "What does my CD4 count mean?"
- "Why do I need another blood test?"

Be Prepared. It isn't always easy to remember the things you need to talk about, so plan ahead for your clinic visit.

- Write questions down (use your calendar, a notebook, or a section of your file folder) and bring them to appointments.
- Keep a list of all of your medications and bring the list to your appointments.
- Bring a list of problems, new symptoms, and other things you want to talk about to your appointments.

Communicate Concerns. It is not unusual for people with HIV to worry about their care, and it helps to discuss these things with your provider. For instance, you may have some of the following concerns:

- "I am afraid of the side effects of these medications."
- "Sometimes I feel so tired and sad."
- "My job makes it hard to keep my clinic appointments."

Clarify. Sometimes your provider will say things that you don't understand. When that happens, some patients are intimidated. They may think, "I don't understand what my doctor is saying, but I don't want to seem stupid, so I just smile and nod, even if I have no idea what she wants me to do." A better way to handle this would be to say:

- "Can you find another way to explain that to me?"
- "So are you saying . . . (and restate what s/he just said in your own words)?"
- "I still don't understand why I need to take all of these pills."
- "What do you mean when you say that I need an assay? I never heard of that."

TEACHING TOOLS: PROBLEM SOLVING SKILLS

Assessment. Ask questions specific to how the patient usually solves problems. Sample questions:

- "What problems most affect your ability to keep your clinic appointments? How have you resolved those problems in the past?"
- "Tell me about a time when you were able to figure out what to do about a problem."
- "Tell me about a time when you just couldn't find a solution to a problem."

- “Remember the last time you missed an appointment? What was going on then?”
- “I’m glad you are here for this appointment. Tell me how you made that happen.”

If the assessment reveals that the patient needs help with problem solving, the following information may be useful. Note: Trust patients to create their own unique solutions. You may have ideas or suggestions, but the answers people come up with for themselves enhance their sense of self-efficacy and are usually the solutions that will work best for them.

Information for the Patient

It is not unusual for people with HIV infection to have problems keeping their appointments – sometimes life just gets hectic. It helps to have a system for thinking about ways to solve your problems. We call this system the 3 Os:

The first step is to state your problem clearly. For instance: “I can’t come to my appointment because I don’t have anyone to take care of my baby.”

Once you know what the problem is, you can work your way through the 3 Os:

Options: Think of different ways to solve the problem.

- “I could ask my mother to watch the baby.”
- “I could ask my neighbor to watch the baby.”
- “I could take the baby to the appointment with me.”

Outcomes: What are the expected outcomes to each option?

- “If I ask my mother, she will watch the baby but I will get a lecture about how it is my responsibility.”
- “If I ask my neighbor, she might watch the baby but I will have to babysit her kids in exchange.”
- “If I take the baby with me, she might cry and fuss but she might also sleep through the appointment.”

Order: Decide what to do first.

- Of all the ways to solve the problem, which would work best for you? Which is the easiest or least risky?
- If that option doesn’t work, what is your next best choice?

Let's look at another problem. Remember to state your problem clearly. For instance: "I'm afraid to tell my boss that I need time off to go see the doctor."

Once you know what the problem is, work your way through the 3 Os:

Options: Think of different ways to solve the problem.

- "I could call in sick on the days that I have an appointment."
- "I could ask someone to cover for me and just leave for a couple of hours."
- "I could take vacation time."
- "I could tell my boss why I need to be gone and see what happens."

Outcomes: What are the expected outcomes to each option?

- "If I call in sick, I will have to take the whole day off and it will use up my sick leave pretty quickly."
- "If I ask someone to cover for me I wouldn't have to use my sick leave, but they might start asking questions about my health and if the boss finds out I might get fired."
- "If I take vacation time no one would know what I was doing, but I would use a lot of vacation time to go the clinic."
- "If I tell my boss she might be sympathetic, but she could also find a way to fire me."

Order: Decide what to do first.

- "Of all the ways to solve the problem, which would work best for you? Which is the easiest or least risky?"
- "Which solution would you like to try first?"
- "If that option doesn't work, what is your next best choice?"

Aziz, M., & Smith, K.Y. (2011). Challenges and successes in linking HIV-infected women to care in the United States. *Clinical Infectious Diseases, 52*(Suppl. 2), S231-S237. doi:10.1093/cid/ciq047

Centers for Disease Control and Prevention. (2006). Revised recommendations for HIV testing of adults, adolescents and pregnant women in healthcare settings. *Morbidity and Mortality Weekly Report*, *55*, 1-17.

Christopoulos, K.A., Das, M., & Colfax, G. (2011). Linkage and retention in HIV care among men who have sex with men in the United States. *Clinical Infectious Diseases*, *52*(Suppl. 2), S214-S222. doi:10.1093/cid/ciq045

Cohen, M.S., Chen, Y.Q., McCauley, M., Gamble, T., Hosseinipour, M.C., Kumarasamy, N., . . . Fleming, T.R. (2011). Prevention of HIV-1 infection with early antiretroviral therapy. *New England Journal of Medicine*, *356*(6), 493-505. doi:10.1056/NEJMoa1105243

Craw, J.A., Gardner, L.I., Marks, G., Rapp, R.C., Bosshart, J., Duffus, W., . . . Schmitt, K. (2008). Brief strengths-based case management promotes entry into HIV medical care: Results of the Antiretroviral Treatment Access Study-II. *Journal of Acquired Immune Deficiency Syndromes*, *47*(5), 597-606.

Crowley, J.S., & Kates, J. (2013). *Updating the Ryan White HIV/AIDS Program for a new era: Key issues and questions for the future.* Retrieved from http://kaiser-familyfoundation.files.wordpress.com/2013/04/8431.pdf

Few, T.E. (2012). *Engaging men who have sex with men in care*. Retrieved from http://blog.aidsetc.org/engaging-men-who-have-sex-men-msm-care

Flickinger, T.E., Saha, S., Moore, R.D., & Beach, M.C. (2013). Higher quality communication and relationships are associated with improved patient engagement in HIV care. *Journal of Acquired Immune Deficiency,* online ahead of print. doi:10.1097/QAI.0b013e318295b86a.

Gardner, L.I., Marks, G., Craw, J.A., Wilson, T.E., Drainoni, M.L., Moore, R.D., . . . Giordano, T.P. (2012). A low-effort, clinic-wide intervention improves attendance for HIV primary care. *Clinical Infectious Diseases, 55*(8), 1124-1134. doi:10.1093/cid/cis623

Giordano, T.P., Gifford, A.L., White, A.C., Suarez-Almazor, M.E., Rageneck, L., Hartman, C., . . . Morgan, R.O. (2007). Retention in care: A challenge to survival with HIV infection. *Clinical Infectious Diseases*, *44*, 1493-1499. doi:10.1086/516778

Mallinson, R.K., Rajabiun, S., & Coleman, S. (2007). The provider role in clinical engagement in HIV care. *AIDS Patient Care and STDs*, *21*(Suppl. 1), S77-S84. doi:10.1089/apc.2007.9984

Martin, E., & Schackman, B.R. (2012). What does U.S. health reform mean for HIV clinical care? *JAIDS*, *60*(1), 72-76. doi:10.1097/QAI.0b013e31824c0dd4

Moore, R.D. (2011). Epidemiology of HIV infection in the United States: Implications for linkage to care. *Clinical Infectious Diseases*, *52*(S2), S208-S213. doi:10.1093/cid/ciq044

Moyer, V.A. (2013). Screening for HIV: U.S. Preventive Services Task Force recommendation statement. *Annals of Internal Medicine*, on-line ahead of print. doi:10.7326/0003-4819-159-1-201307020-00647

Mugavero, M (2012). *Improving retention in HIV care: Which interventions work?* Retrieved from http://www.medscape.com/viewarticle/770596

Mugavero, M.J. Lin, H.Y., Willig, J.H., Chang, P.W., Marler, M., . . . Saag, M.S. (2009). Failure to establish HIV care: Characterizing the “no show” phenomenon. *Clinical Infectious Diseases*, *48*, 248-256. doi:10.1086/595705

Mugavero, M.J., Norton, W.E., & Saag, M.S. (2011). Health care system and policy factors influencing engagement in HIV medical care: Piecing together the fragments of a fractured health care delivery system. *Clinical Infectious Diseases*, *52*(Suppl 2), S238-S246. doi:10.1093/cid/ciq048

Mugavero, M.J., Raper, J.L., Reif, S., Whetten, K., Leserman, J., Thielman, N.M., & Pence, B.W. (2009). Overload: Impact of incident stressful events on antiretroviral medication adherence and virologic failure in a longitudinal, multisite human immunodeficiency virus cohort study. *Psychosomatic Medicine*, *71*(9), 920-926. doi:10.1093/cid/ciq048

Office of National AIDS Policy. (2010, July). *National HIV/AIDS strategy for the United States.* Retrieved from http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf

Rapp, R. C. (2007). The strengths perspective: Proving "my strengths" and "it works." *Social Work*, *52*(2), 185-186.

Saleebey, D. (2009). *The strengths perspective in social work practice* (5th ed.). Old Tappan, NJ: Pearson.

Redko, C., Rapp, R.C., Elms, C., Snyder, M., & Carlson, R.G. (2007). Understanding the working alliance between persons with substance abuse problems and strengths-based case managers. *Journal of Psychoactive Drugs*, *39*(3).

Wohl, A.R.,Galvan, F.H., Meyers, H.F., Garland, W., George, S., Witt, M., . . .Lee, M.L. (2011). Do social support, stress, disclosure and stigma influence retention in HIV care for Latino and African American men who have sex with men and women? *AIDS and Behavior*, *15*(6), 1098-1110. doi;10.1007/s10461-010-9833-6

Zaller, N.D., Fu, J.J., Nunn, A., & Beckwith, C.G. (2011). Linkage to care for HIV-infected heterosexual men in the United States. *Clinical Infectious Diseases,* *52*(S2), S223-S230.

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Access to HIV Care among Transgender and Gender Non-Conforming People in Houston

A Special Study of the Houston Area Ryan White Planning Council
Approved March 14, 2013

BACKGROUND

The Houston Area Ryan White Planning Council is responsible for designing HIV care, treatment, and support services for people living with HIV/AIDS in the Houston Eligible Metropolitan Area (EMA). The Planning Council uses several sources of information in order to meet this mandate, including epidemiological profiles, service-utilization reports, and a community-wide needs assessment of HIV-positive individuals conducted every three years. When specific populations are underrepresented in current data sources, the Planning Council may also commission a special data collection effort, or *Special Study*, to fill data gaps.

In 2012, the Planning Council released its comprehensive HIV prevention and care services plan for the Houston Area. In it are the specific HIV-infected populations in the Houston EMA with insufficient data for assessing their current level of access to HIV services. In response, the Planning Council commissioned a series of Special Studies to gather data on each underrepresented group. This article presents the results of the Planning Council's first Special Study in the series, focused on transgender and gender non-conforming people living with HIV/AIDS in the Houston EMA.

INTRODUCTION

Transgender individuals are among the highest risk for HIV infection in the U.S. today. [1] Moreover, the challenges often faced by transgender individuals in regards to discrimination, stigma, lack of resources, and other social determinants can make it difficult for them to access HIV services.[1] One study of transgender people living with HIV/AIDS showed a statistically lower rate of HIV treatment when compared to nontransgender people.[2] For these reasons and others, transgender communities are a high priority for HIV prevention, linkage, and retention in care efforts both nationally and in the Houston EMA.[3]

However, relatively little is known about the specific needs, gaps, and barriers to HIV care among transgender people in the Houston EMA. Transgender individuals are less than 1% of all Ryan White HIV/AIDS Program clients in the EMA,[4] and only 22 transgender-identified individuals participated in the EMA's most recent community-wide needs assessment of people living with HIV/AIDS.[5] This Special Study sought to describe the HIV service utilization patterns of transgender people living with HIV/AIDS in the Houston EMA, including socio-economic or behavioral factors that may be influencing their use of services, and to establish baselines for core HIV prevention and care indicators, including linkage to care and unmet need.

METHODS

Participants were self-selected, self-identified transgender HIV-positive adult residents of the Houston EMA. Because many individuals may not identify with the term "transgender," inclusion screening questions used the broader terminology of "transgender or gender non-conforming" and offered both a definition of the term and examples along a broad continuum of gender expression. The text for the transgender inclusion screening question for the study was: [6]

> **"Do you consider yourself to be transgender or gender non-conforming in any way?**
> Transgender/gender non-conforming refers to people whose gender identity or expression is different, at least part of the time, from the sex assigned to them at birth

on their birth certificate. Below are some examples of people who might consider themselves transgender:

- MTF (male to female)
- FTM (female to male)
- Part time as one gender/part time as another
- Transgendering
- Transsexual
- Cross dresser
- Androgynous
- Drag performer (queen or king)
- Genderqueer
- Genderfluid
- Feminine male
- Masculine female
- Third gender
- Two spirit

Please check one:

☐ Yes, I consider myself to be transgender or gender non-conforming in some way
☐ No. If no, please do NOT continue with the survey"

In addition, following national recommendations, [1] the two-step data collection method of asking sex assigned at birth and current gender expression was also used. Sexual orientation identification was also asked separately.

Our primary data collection method was a survey that addressed three overall topics: HIV diagnosis and linkage to care; HIV service needs, gaps, and barriers; and social determinants. Demographics were also collected. To participate, individuals could self-administer surveys online, in hard-copy by mail, or in hard-copy in-person at designated survey sites; they could also complete surveys via staff interview by telephone or in-person. Two trained interviewers conducted the surveys. Recruitment occurred through social promotion (i.e., flyers and postcards at bars, clubs, community centers, clinics, community-based organizations, and housing complexes), social media, staff promotion, and word of mouth. Surveys were voluntary and anonymous, and all participants were offered a $20 gift card. Surveys were collected from August 27, 2012 through December 13, 2012.

This study was intended to be descriptive in nature; therefore, no sampling methods or control groups were used. Participation was non-identifying, and the results are self-reported. Data collection methods and survey questions were reviewed and approved by an advisory committee of transgender-identified community members, leaders, and gatekeepers as well as researchers with experience studying transgender populations (See Acknowledgments). Survey Monkey was used for data storage; and analysis was conducted in Microsoft Excel. Consistent with a descriptive study, no statistical tests were performed, and it is unknown if the comparisons presented here are significant.

SAMPLE

(See Table 1) A sample of 135 transgender or gender non-conforming people living with HIV/AIDS in the Houston EMA is included in this analysis.[7] Forty percent (40%) of the sample was natal males with a primary full-time current gender expression and/or identity of female (MtF), and 8% was natal females with a primary full-time current gender expression and/or identity of male (FtM) (a ratio of 5:1). An additional 37% had part-time discordant natal sex and current gender expression and/or identity, and 14% had concordant natal sex and current gender expression and/or identity, though still identified as transgender or gender non-conforming. The average age of the sample was 40 years (standard deviation = 10.8; range = 19 - 63).

The sample was comprised of 77% African Americans, 17% White, non-Hispanics, 8% Hispanics, and 4% other, which is an overrepresentation of African Americans (and an underrepresentation of other racial/ethnic groups) when compared to current HIV/AIDS prevalence in the Houston EMA.[8]

The majority of the sample had at least a high school diploma or GED (69%), while 31% reported less than a high school education, which is 1.6 times higher than the percent reported by the general population of people living with HIV/AIDS in the Houston EMA (19%). At 47%, the sample reported more disability than the general HIV-positive population (39%) and only slightly less full- or part-time employment (16% vs. 18%). The percent of respondents living in their own home or apartment (38%) was 2.0 times less than the general HIV-positive population (77%), and the percent living in a group home for people who are HIV-positive (30%) was 2.3 times higher (13%). No-one in the sample reported living in a shelter, car, or on the street.

TABLE 1-Demographic Comparison of Participating Transgender People Who Are HIV Positive (n=135) and the General HIV-Positive Population in the Houston Area

	Transgender Participants	General HIV+ Population
Transgender Identification		
Natal male/female expression (MtF)	40%	--
Natal female/male expression (FtM)	8%	--
Part-time male/female	37%	--
Non-variant	14%	--
Age, mean (sd)	40.2 (10.8)	44.7 (10.0) [a]
18-24	9%	3%
25-44	47%	44%
45+	44%	54%
Race/Ethnicity		[b]
White, non-Hispanic	17%	25%
African American	77%	50%
Hispanic	8%	23%
Other	4%	2%
Education		[a]
Less than high school	31%	19%
High school diploma/GED	58%	38%
Technical degree or above	11%	42%
Employment Status		[a]
Employed FT/PT	16%	18%
Temporary/seasonal/contract	5%	5%
Student	8%	--
Retired	4%	3%
Unemployed	28%	35%
Disabled/not working	47%	39%
Housing Status		[a]
Own house/apartment	38%	77%
With friends/family	25%	--
Group home	30%	13%
Shelter, car, street	0%	11%
Combination/changes often	7%	--
Incarceration History	20%	19%[a]
Years of HIV Diagnosis (sd)	12.2 (8.2)	11.2 (7.3)[a]

[a] 2011 Houston Area HIV/AIDS Needs Assessment, April 2011 (n=924). Conducted in the Houston Eligible Metropolitan Area (EMA) of Chambers, Fort Bend, Harris (including the City of Houston), Liberty, Montgomery, and Waller Counties

[b] Texas eHARS (as of 12/31/2011). Jurisdiction is Houston EMA

Twenty percent (20%) of the sample reported being released from a correctional facility in the last 12 months, which is comparable to the general HIV-positive population in the Houston EMA (19%).

The average length of HIV diagnosis in the sample was 12 years (standard deviation = 8.2; range = 0 - 30) with 8% diagnosed for one year or less.

RESULTS

HIV Testing, Diagnosis, and Linkage to Care

The first topic we wanted to address through this study was what motivates transgender people in the Houston EMA to test for HIV and where they test. In our sample, the most commonly-cited reason for testing was feeling sick (25%), followed by receiving an HIV test as part of a routine health check-up (21%). Three percent (3%) of the time the reason for testing was the recommendation of a medical provider, and another 3% was in response to community advertising, The most common location for HIV testing was a dedicated HIV clinic (34%), followed by an ER or hospital (17%). Thirteen percent (13%) said they were tested at a health department, and 9% were tested in jail or prison.

Because treatment for HIV can extend life expectancy and quality of life for those infected, length of time for linkage to care post-diagnosis and current care status are used as indicators of community health related to HIV both nationally and locally.[3,9] At the time of this study, baselines were missing for both of these measures for the transgender population in the Houston EMA. Therefore, the next topics we sought to address in the study were linkage to care and patterns of care. We asked respondents when they first saw a doctor for HIV following their diagnosis (either within three months or more than three months, per the federal benchmark[9]) and if they were currently meeting the national definition of being in care, which is defined as completing at least one of the following in the last 12 months: (1) seen a doctor for HIV, (2) taken HIV medications, (3) had an HIV viral load test, or (4) had a CD4 count test.[10]

(See Table 2) The majority of the transgender people in this study was linked to care within three months of their HIV diagnosis (76%). This percentage is comparable to current estimates for the Houston EMA as a whole (77%), [11] though lower than both local and national goals.[3,9] For those in the sample who did report delayed care, the most commonly-cited reason was denial about being HIV-positive (80%). However, 16% of the time the reasons were lack of knowledge about where to go for HIV services, fear about how the medical staff would react to their gender variance, and fear about how other clients would react. Twelve percent (12%) of the time the reason for delayed care was having to disclose their gender variant status to providers and staff.

TABLE 2-Linkage to Care among Participating Transgender People Who Are HIV Positive (n=133) Compared to the General HIV-Positive Population in the Houston Area and Local and National Goals

	Transgender Participants	General HIV+ Population[a]	Goal[b]
Linked to HIV Care within 3 Months of Diagnosis	75.9%	77.4%	85.0%

[a]Texas Department of State Health Services, 8/20/12
[b]National HIV/AIDS Strategy for the United States (July 2010); Houston Area Comprehensive HIV Prevention and Care Services Plan (2012 – 2014)

The majority of the people in this study was also currently in care (97%). This percentage far exceeds estimates for the general HIV-positive population in the Houston EMA (75%).[12] This is most likely a bias in our sample, rather than a true unmet need result, due to study recruitment taking place at HIV clinics and HIV group homes. Therefore, no additional analysis was performed on this data point.

HIV Care Service Utilization, Barriers to Care, and Service Needs

(See Table 3) Another topic we wanted to explore in this study was the use of specific HIV care, treatment, and support services by transgender people in the Houston EMA. To do this, we

TABLE 3-HIV Care Services Used and Barriers Reported by Participating Transgender People Who Are HIV Positive (n=132) in the Houston Area

Service Category (in order)	Reporting Use of Service # (%)	Service Category (in order)	Reporting Barrier to Use # (%)
Primary HIV care	113 (85.6)	Oral health care	28 (21.2)
Transportation	76 (57.6)	Primary HIV care	23 (17.4)
Case management	64 (48.5)	Case management	23 (17.4)
Oral health care	60 (45.5)	Transportation	18 (13.6)
Mental health counseling	59 (44.7)	Medical nutritional therapy	15 (11.4)
Medical nutritional therapy	51 (38.6)	Mental health counseling	13 (9.8)
HIV medication assistance	46 (34.8)	Legal services	8 (6.1)
Substance abuse treatment	28 (21.2)	Health insurance assistance	7 (5.3)
Health insurance assistance	25 (18.9)	Hospice care	7 (5.3)
Legal services	21 (15.9)	HIV medication assistance	6 (4.5)
Day treatment	19 (14.4)	Day treatment	6 (4.5)
Language services	14 (10.6)	Substance abuse treatment	4 (3.0)
Hospice care	9 (6.8)	Language services	4 (3.0)

asked each respondent if, in the past 12 months, they had used each of the services that the Planning Council had prioritized for funding through the Ryan White HIV/AIDS Program and if they had experienced any difficulties accessing each of the services, regardless of recent use. Primary HIV care (86%), transportation (58%), and clinic-based case management (49%) were the most used services in past 12 months. The services cited most often as having difficulties to access were oral health care (21%), primary HIV care (17%), and clinic-based case management (17%). These findings are consistent with the general population of HIV-positive people in the Houston EMA.[13]

(See Table 4) Specific barriers faced by this population when seeking HIV services were also explored. When asked what barriers, if any, respondents had faced at any time since their diagnosis, the most commonly-cited was lack of transportation (44%). Also high on the list was being treated poorly by staff due to gender variance (29%), lack of funds to pay for services (28%), and denial about being HIV-positive (24%). In addition, 19% of respondents reported lack of provider familiarity with transgender needs as a barrier to care. Twenty-two percent (22%) reported no barriers. When compared to

TABLE 4-Most Commonly-Cited Specific Barriers to HIV Care Reported by Participating Transgender People Who Are HIV Positive (n=105) Compared to the General HIV-Positive Population in the Houston Area

Specific Barrier Experienced (in order)	# (%) Reporting	Rank among General HIV+ Population[a]
No transportation	46 (43.8)	6
Treated poorly by staff due to being transgender	30 (28.6)	--
No money, the services cost too much	29 (27.6)	11
Fear or denial about being HIV-positive	25 (23.8)	14
Wait times for services were too long	20 (19.0)	3
Hard to get an appointment for HIV services	20 (19.0)	5
Providers are not familiar with transgender needs	20 (19.0)	--
A problem with drugs or alcohol	18 (17.1)	--
Lack of housing	18 (17.1)	--
Felt fine, not sick, "didn't think I needed HIV care"	16 (15.2)	--
HIV care a low priority	16 (15.2)	--
No Barriers Experienced	30 (22.2)	--

[a] 2011 Houston Area HIV/AIDS Needs Assessment, April 2011 (n=924). Ranking is for core and support services combined; no distinction between type of service was made in our study.

the general population of HIV-positive people in the Houston EMA, some differences emerged.[14] For example, while lack of transportation is the highest ranking barrier to HIV care among our sample (when barriers existed), it ranked sixth among the HIV-positive population as a whole. Similarly, lack of funds ranked third in our sample (when barriers existed) yet eleventh among all HIV-positive persons in the Houston EMA.

This section of our survey also asked respondents if more or different services are needed by transgender people living with HIV/AIDS in the Houston EMA to more effectively manage HIV disease. The top five categories of responses were: (1) more housing, including rental assistance and shelters for transgender persons, (2) more transportation services, (3) assistance with basic needs such as food and clothing, (4) support groups for transgender persons, and (5) employment assistance for transgender persons.

TABLE 5-Comparison of Risk Behaviors and Co-Morbidities among Participating Transgender People Who Are HIV Positive and the General HIV-Positive Population in the Houston Area

	Transgender Participants	General HIV+ Population[a]
Risk Activities, last 6 mo.		
Sex with someone known to be HIV+	39%	30%
Anonymous sex partner	30%	16%
Sex bartering	15%	6%
Shared needles/injection equipment	3%	1%
Had sex with known needle-sharer	5%	--
Condom Use		
No condom at last sexual activity	26%	30%
Does not *always* use condoms	60%	50%
Diagnosed with STD, last 6 mo.	13%	--
Mental Health Concern, last 30 days	70%	63%
Anger management	26%	24%
Anxiety	54%	52%
Depression	62%	--
Fear of leaving the home	6%	--
Wanting to harm themselves	17%	9%
Attempt at self-harm	6%	--
PTSD	6%	--
Mental health concern requiring medication	44%	27%
Experience with Discrimination		
Been treated differently	84%	--
Been denied services	17%	--
Been asked to leave a public place	16%	--
Experience with Violence		
Verbal harassment/taunts	60%	--
Threats of violence	36%	--
Physical assault	30%	--
Sexual assault	23%	--
Rape	16%	--

[a] 2011 Houston Area HIV/AIDS Needs Assessment, April 2011 (n=924)

Risk Activities, Co-Morbidities, and Discrimination History

Multiple national studies of transgender people and two studies conducted in the Houston community[15, 16] have suggested that risk behaviors for HIV transmission are common in the transgender population as are other health concerns such as depression or substance abuse that can hinder the ability to access and maintain HIV care. We wanted to assess the frequency of these types of behaviors among HIV-positive transgender persons in the Houston EMA as well (See Table 5).

In our sample, sexual activities known to increase HIV transmission risk were reported more often than in the general HIV-positive population in the Houston EMA,[13] with one exception. In our sample, a slightly lower percentage of respondents reported no condom during their last sexual activity (26%) than did the population as a whole (30%). However, a higher percentage of our respondents (60%) reported not *always* using condoms during sexual activity than did the general population (50%). Also of note, 13% of our sample reporting being diagnosed with an STD other than HIV in the last six months.

Results related to co-occurring concerns were varied. A higher percentage of the respondents in our sample (70%) than in the general HIV-positive population in the Houston EMA [13] reported having a least one mental health concern in the past 30 days; however, comparable and lower percentages reported a concern with alcohol use or drug use, respectively. Of note, however, is the difference in frequency of *type* of mental health concern reported. Among the HIV-positive transgender persons in our sample, 17% reported wanting to harm themselves compared to 9% of the general HIV-positive population. Moreover, 44% of our sample reported having a mental or emotional problem severe enough to require prescription medication compared to 27% of the general HIV-positive group.

Lastly, our study also sought to describe the local transgender HIV-positive population's experience with gender variant-related stigma, discrimination, and violence. The results were high, with 84% of respondents reporting receiving differential treatment in public due to gender variance, including 16% who reported being asked to leave a public place. In addition, 60% of respondents reported being harassed or taunted due to their gender variant status, 36% reported being threatened with violence, and 30%, 23%, and 16% reported being the victims of physical assault, sexual assault, and rape, respectively, at some time in their lives.

LIMITATIONS

There are limitations to this study. Respondents were self-identified and self-selected according to provided definitions of inclusion criteria. Though the broad scope terminology utilized at screening may have produced a more inclusive sample of respondents, the lack of a random sample, sampling frame, control group, and statistical testing lessens the study's generalizability, and results may not be fully representative of the study population as a whole. To mitigate this limitation, comparisons have been provided between study results and those found in larger samples. Respondent self-selection can also result in duplication as do some of the recruitment methods used in the study, such as incentives and word of mouth promotion. A data matching protocol was applied post-data collection in order to reduce potential duplication. Another limitation is the use of mixed-methods for data collection, which resulted in both self- and interviewer-administration of the survey tool. While this approach may have reduced barriers to participation in the study, it may also have lessened the accuracy of the survey instrument and produced variability between respondents. Data collected by the tool were also self-reported, and confirmation was not possible due to study design. As a result, there is no way to validate the individual experiences described by respondents, and the results presented here should not be interpreted or used as verification of service delivery or health outcomes.

DATA SUPPLEMENT—FOCUS GROUP RESULTS

Three focus groups were held in October 2012 to complement the quantitative results of this Special Study. The goal of the focus groups was to better understand the perspectives of HIV-positive transgender clients in the Houston EMA in regards to their HIV status and to hear directly from clients about opportunities for improving the HIV system of care. A total of 14 self-identified and self-disclosed transgender HIV-positive individuals participated in the series. Key themes from their discussions are described below.

Gender variance is perceived as having greater stigma than HIV. Focus group participants were asked to describe what daily life is like as a transgender identified person living with HIV. For most participants, being gender variant was a greater source of concern than being HIV-positive. Said one participant, "that's a worse stigma, [being] gay or transgender, than the disease itself." According to focus group participants, this often results in transgender people isolating themselves from the public and from needed HIV services out to fear of others knowing they are transgender. Explained a participant, "A lot of transgender people are afraid to come out. A lot of them feel fear [about] how they're going to be received."

The HIV medical home is an effective model for transgender clients. Because many transgender identified persons may be fearful of public reaction, an HIV medical home or "one-stop-shop" was cited as a preferred model for HIV care for this population, and a dedicated HIV clinic was identified as the preferred type of provider. According to focus group participants, fear about disclosure of and/or differential treatment due to being gender variant or HIV-positive is a main reason why transgender people are out of care. Explained a participant, "They say, if they go to the doctor and see someone they know, they will tell their business. At [an HIV clinic], everybody is the same. They already know." Said another participant, "They [the HIV clinic] deal with one situation, HIV…you walk in, and everyone's going through the same thing." A third participant noted, "When you go to an [HIV clinic], they give you the same treatment. They are going to treat you with respect." In addition, HIV clinics that "cater to" transgender clients were also praised, with one participant describing them as "wonderful."

Increased capacity for serving gender variant clients remains a system wide need. Participants in all three groups described repeated interactions with HIV providers who were "insensitive" to their transgender status, particularly in regards to pronoun usage and name. Explained one participant, "You know [your client] is a male, but she's dressed as a female. But, the first thing that comes out of your mouth is 'excuse me, *sir,* can I help you.' That makes the client uncomfortable. There's no way I can discuss my problems, concerns, needs, frustrations when you've just disrespected me." Participants had the overall impression that staff at HIV clinics are hired without regard to their experience working with transgender clients.

Discrimination appeared to be more pronounced in the broader social service community than in the HIV services arena. Said one participant, "It is easier for [non-transgender people] to walk up and get services, like shelter. Even going to certain clothing closets. They said you can only get male clothes. I don't dress as a man, so why should I get male clothing?" Training on client-centered pronoun usage, name usage, and improving the gender variant sensitivity of policies and procedures were all identified as potential solutions. When describing a positive experience regarding pronoun usage following a change in policy, one participant said, "It's not something you're already used to. It's something that somebody had to tell you [to do]."

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REFERENCES

1. Centers for Disease Control and Prevention (CDC), *HIV Infection among Transgender People*, August 2011.
2. Melendez, RM et al., "Health and Health Care among Male-to-Female Transgender Persons Who Are HIV Positive," *American Journal of Public Health*. June 2006, Vol 96, No. 6.
3. Houston Area Ryan White Planning Council and Houston HIV Planning Group. Houston Area Comprehensive HIV Prevention and Care Services Plan (2012 – 2014). May 21, 2012.
4. Harris County Public Health Services, Ryan White Grant Administration. Total number of net unduplicated clients served in calendar year 2011 by the Ryan White HIV/AIDS Program Part A, B, State Services and Minority AIDS Initiative (MAI). Run 4/12/12. Source: Centralized Patient Care Data Management System
5. Houston Area Ryan White Planning Council, 2011 Houston Area HIV/AIDS Needs Assessment, April 2011.
6. This text was modeled on terminology used in the National Transgender Discrimination Study (See Grant, JM et al., *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey*. Washington: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011).
7. Unique identifying information was not collected on survey respondents, and surveys could be completed without in-person contact with an interviewer as well as through self-administration. This created the potential for duplicate respondents and for survey completion by individuals who did not meet screening criteria. Various de-duplication and authentification methods were applied throughout the study, and only results from the subsequent data set are presented here. A total of 142 surveys were completed; and 135 were determined to be non-duplicates meeting the screening criteria.
8. Living HIV/AIDS cases in the Houston EMA as of December 31, 2011. Source: Texas eHARS.
9. National HIV/AIDS Strategy for the United States (July 2010).
10. Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB)
11. Texas Department of State Health Services. New Dx Cases with Met Need But No Linkage to Care Dates, 2011.
12. Texas Department of State Health Services. Number & Proportion of PLWHA with Unmet Need for Medical Care by EMA/TGA, 2011
13. Respondents in the community wide needs assessment of the general HIV-positive population in the Houston EMA were asked to indicate if they "had difficulty" accessing core medical and support services funded by the Ryan White HIV/AIDS Program. Core medical services that respondents reported most often as having "some difficulty getting" were oral health care (29%), HIV medication assistance (20%), clinic-based case management (18%), and primary HIV care (17%). Source: Houston Area Ryan White Planning Council, 2011 Houston Area HIV/AIDS Needs Assessment, April 2011.
14. When respondents in the community wide needs assessment of the general HIV-positive population in the Houston EMA indicated difficulty accessing core medical or support services funded by the Ryan White HIV/AIDS Program, they were subsequently asked what specific barrier they encountered. Most commonly cited barriers were (1) lack of knowledge about where services are offered, (2) lack of knowledge about how to access services, (3) wait times, (4) ineligibility for services, (5) difficulty making or keeping appointments, (6) transportation, (7) paperwork, (8) inconvenient location, (9) poor treatment by agency staff, (10) perception of ineligibility for services, (11) inability to pay for services, (12) fear of disclosure of status, (13) language barriers, and (14) denial about being HIV-positive. Source: Houston Area Ryan White Planning Council, 2011 Houston Area HIV/AIDS Needs Assessment, April 2011.
15. Risser, A, et al., "Sex, Drugs, Violence, and HIV Status Among Male-to-Female Transgender Persons in Houston, Texas." *Intl. J. of Transgenderism* 8:2/3: 67-74 (2005).
16. Padgett, P. and Risser, J."Transgender HIV behavioral survey (thbs): Pilot study in Houston, TX." Unpublished manuscript. The University of Texas School of Public Health, Houston, TX, 2010.

Affirmative Care for Transgender and Gender Non-Conforming People:

Best Practices for Front-line Health Care Staff

NATIONAL LGBT HEALTH
EDUCATION CENTER
A PROGRAM OF THE FENWAY INSTITUTE

Affirmative Care for Transgender and Gender Non-Conforming People:

Best Practices for Front-line Health Care Staff

INTRODUCTION

Front-line staff play a key role in creating a health care environment that responds to the needs of transgender and other gender non-conforming people.[1] Like all individuals, transgender people appreciate friendly and courteous service. However, transgender individuals also have unique needs when interacting with the health care system. First and foremost, many transgender people experience stigma and discrimination in their day to day lives, and particularly when seeking health care. As a result, many fear they will be treated disrespectfully by health care staff, which can lead to them delaying necessary health care services. In addition, the names that transgender people use in their daily lives often do not match the names on their health insurance and medical records. Due to this, mistakes can easily be made when coding and billing for insurance, as well as when talking with patients.

Issues and concerns from transgender patients often arise at the front desk and in waiting areas because those are the first points of contact for most patients. However, these issues are almost always unintentional and can be prevented by training all staff in some basic principles and strategies. This document was developed as a starting point to help train front-line health care employees to provide affirming services to transgender patients (and all patients) at their organization.

WHAT'S INSIDE

- **Part 1** provides background information on transgender people and their health needs.
- **Part 2** provides tips and strategies to improve communication and create a more affirming environment.

HOW TO USE THIS DOCUMENT

There is no set way to use this document, but here are some suggestions:

- Include this document in orientation packets for new hires. Provide a brief verbal introduction to the document and why it is included.

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[1] For the purposes of brevity, we use "transgender" throughout this document. However, the information in this document can be applied to all gender non-conforming people. For definitions of transgender and gender non-conforming, see "Definitions and Terms" on pages 2–3.

- Host a mandatory training on transgender identity and health at your organization, or require staff to watch the webinar "Meeting the Health Care Needs of Transgender People," which describes the information in this document: www.lgbthealtheducation.org/training/webinars.
- Hold a discussion afterwards and distribute this document.
- Encourage staff to post the Best Practices Sheet (included on the last page of this document) near their work station.

Part 1: Gaining a Better Understanding of Transgender People

WHAT DO WE MEAN BY TRANSGENDER?

Different people have different ideas about what the term transgender means. Most describe a transgender person as someone who feels strongly that their gender is not the same as the sex they were assigned at birth. Transgender people feel and express their gender in many different ways. Many transgender people feel they were born as the wrong gender; for example, people born with the outward manifestations of a female who feel very strongly that they are a male. Some transgender people feel they are both female and male, or neither male nor female, but somewhere along the spectrum of male and female. These feelings begin very early in life for many, and later for others.

Most transgender people will dress and behave in a way that matches their inner sense of gender. For example, people born male who feel their true gender is female may grow their hair long and start wearing dresses and makeup. A person who feels they are neither male nor female may dress and do their hair in a way that is not traditionally male or female. Transgender people often change their name to match the gender they feel. They often want people to call them by the pronouns that feel right to them (e.g. he/him, or she/her). Some, but not all, change their bodies to more closely resemble how they think of themselves by getting medical (hormone) and surgical treatments. As is true for all people, it is very important for transgender people's mental health and well-being to be able to live the way they feel about their gender, and to be accepted for who they are.

DEFINITIONS AND TERMS

There are many terms used by transgender people to describe themselves and their communities. Many will change the way they describe themselves over time. In addition, terminology also changes over time. Here, we offer some common definitions. However, keep in mind that each person may not identify with these terms or definitions. It is best to give all patients an opportunity to provide information on how they want to be recognized when seeking care.

Gender Identity: A person’s internal sense of being a man, woman, both, or neither. Gender identity usually develops at a young age.

Gender Expression/Role: The way a person acts, dresses, speaks and behaves in order to show their gender as feminine, masculine, both, or neither.

Birth Sex: The sex (male or female) assigned a child at birth, based on a child’s genitalia.

Transgender: People whose gender identity is not the same as the sex they were assigned at birth.

Gender Non-Conforming: People who express their gender differently than what is culturally expected of them. A gender non-conforming person is not necessarily transgender (for example, a woman who dresses in a masculine style but who identifies as female; a boy who likes to play with girl dolls but identifies himself as a boy, etc.).

Transition/Gender Affirmation Process: For transgender people, this refers to the process of coming to recognize, accept, and express one’s gender identity. Most often, this refers to the period when a person makes social, legal, and/or medical changes, such as changing their clothing, name, sex designation, and using medical interventions. This process is often called **gender affirmation**, because it allows people to affirm their gender identity by making outward changes. Gender affirmation/transition can greatly improve a transgender person’s mental health and general well-being.

Female-to-Male (FTM) or Transgender Man: A person born with female genitalia at birth who feels they are male/a man and lives as male/a man. Some will just use the term male.

Male-to-Female (MTF) or Transgender Woman: A person born with male genitalia who feels they are female/a woman and lives as female/a woman. Some will just use the term female.

Transsexual: A term used to describe a subset of transgender individuals who have transitioned to the opposite sex, often but not always through a combination of hormonal therapy and sexual reassignment surgery.

Genderqueer: A relatively new term, genderqueer is used by some individuals who do not identify as either male or female; or identify as both male and female.

Trans: Abbreviation for transgender.

Sexual Orientation: Sexual orientation is about how people identify their physical and emotional attraction to others. It is not related to gender identity. Transgender people can be any sexual orientation (gay, lesbian, bisexual, heterosexual/straight, no label at all, or some other self-described label).

Terms to Avoid!: The following terms are considered offensive by most and should not be used: she-male, he-she, it, tranny, “real” woman or “real” man.

WHAT DO WE KNOW ABOUT TRANSGENDER PEOPLE AND THEIR HEALTH NEEDS?

There has been very little research on transgender people and their health needs. However, from what has been studied, we do know that they experience a great deal of misunderstanding, rejection, and discrimination, all of which can lead to poor health outcomes.

Below is a summary of some of the research that has been collected on transgender people. Learning about the challenges of being transgender can increase awareness and sensitivity towards this population.

I AM: TRANS PEOPLE SPEAK VIDEO SERIES

I AM: Trans People Speak (transpeoplespeak.org) is a website which features brief videos of transgender people of all ages, ethnicities, and backgrounds. These videos offer a way to get to know the diversity of expressions and experiences of transgender people, and also show how transgender people are just like everyone else.

HOW MANY PEOPLE IDENTIFY AS TRANSGENDER?

The answer to this question is not known because very few surveys ask about gender identity. One study that used data from Massachusetts and California estimated that 0.3% of the U.S. population may be transgender.[2] Some have argued that this number is probably low. In comparison, this same study estimated that around 3.5% of the population identify as gay, lesbian, or bisexual.[2] Research has also shown that about 60–76% of transgender people have had hormonal therapy, and about 20–40% have had some surgery to help their bodies match their gender identity.[3,4] The decision of whether to have medical or surgical treatment is based on personal choice for some; others would like to get treatments but cannot afford the cost (most insurance policies do not offer coverage).

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2 Gates, G. *How many people are lesbian, gay, bisexual, and transgender?* The Williams Institute, April 2011. Available at: williamsinstitute.law.ucla.edu/wp-content/uploads/Gates-How-Many-People-LGBT-Apr-2011.pdf

3 Grant J, Mottet LA, Tanis J, et al. *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey.* Washington: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011. Available at: www.thetaskforce.org/downloads/reports/reports/ntds_full.pdf

4 Xavier J, Honnold JA, Bradford J. *The Health, Health-Related Needs, and Lifecourse Experiences of Transgender Virginians.* Virginia HIV Planning Committee and Virginia Department of Health, 2007. Available at: www.vdh.virginia.gov/epidemiology/diseaseprevention/documents/pdf/THISFINALREPORTVol1.pdf

DISCRIMINATION AND HEALTH DISPARITIES

The majority of transgender people experience various forms of harassment and discrimination in their daily lives. Research has shown that up to 78% of transgender people were harassed in school, and 57% experienced rejection from their families.[3] Many have been taunted, refused service, and physically attacked in public areas like hotels, restaurants, buses, etc.[3,4] Because of discrimination, transgender people are much more likely to be homeless, unemployed, and low income.[3,4] Trying to cope with all of these issues can affect the health and well-being of transgender people. For example, transgender people have higher rates of alcohol use, drug use, and suicide attempts[3,4] (one survey found that 41% had attempted suicide)[3]. In order to survive, some transgender women turn to sex work, which greatly increases their risk of HIV and other STDs, as well as the potential for experiencing gender-based sexual and physical violence.[3,4,5]

BARRIERS TO HEALTH CARE

Transgender people face many barriers to receiving quality care. Sadly, many transgender people avoid seeing a medical provider because they fear they will be discriminated against, humiliated, or misunderstood. For example, one large study of transgender people found that 28% had postponed necessary medical care when sick or injured, and 33% delayed or did not try to get preventive health care due to discrimination by health care providers.[3] There is also a scarcity of health professionals who are trained in transgender medical and behavioral health care. Fifty percent of transgender people report having to teach their doctors about transgender care.[3]

In addition, many transgender people lack health insurance.[3,4] This is often because employers won't hire them or families reject them. Even with insurance, transgender people encounter barriers. For example, many insurance policies do not cover medical treatments for gender affirmation; and many policies will at least initially deny routine preventive care for body parts not consistent with a person's gender identity (for example, a transgender man with "male" on his insurance may be denied coverage for a Pap smear).

Due to these barriers, some transgender people try to provide for their own care using the Internet, friends, and other non-medical people in their social circle. They may get unauthorized and potentially dangerous hormones, silicone (for implants) or silicone injections to enhance their appearance,

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[5] Clements-Nolle K, Marx R, Guzman R, Katz M. HIV prevalence, risk behaviors, health care use, and mental health status of transgender persons: implications for public health intervention. *Am J Public Health*. 2001 Jun;91(6):915-21.

and other treatments from these sources. This may lead to higher risks of illness and injury, further complicating already poor access to care.[3,4]

Although accessing care is obviously very difficult for many transgender people, the good news is that when transgender people **are** able to access the health care necessary to affirm their gender, they typically function much the same as everyone else in both their personal and professional lives. For example, 78% of transgender people who underwent gender transition reported they felt more comfortable at work, and their job performance greatly improved. [3]

Part 2: Transgender-Affirming Customer Service Strategies in Health Care

INTRODUCTION TO CUSTOMER SERVICE STRATEGIES

Every single interaction counts for a transgender person in a health care setting. Front desk and other front-line staff play a critical role in helping transgender people feel welcome and get the health care services they need. The following section offers strategies for working with transgender patients based on the customer service principles of communication, open-mindedness, responsiveness, accountability, reliability, and respect. Examples and scripts are included.

ADDRESSING PATIENTS

It is not always possible to know someone's gender based on their name or how they look or sound. This is the case for all people, not just transgender people. When addressing patients we don't know, we can accidentally call them by the wrong gender, causing embarassment. One way to prevent this mistake is by addressing people without using any terms that indicate a gender. For example, instead of asking "How may I help you, sir?" you can simply ask, "How may I help you?" You can also avoid using "Mr./Mrs./Miss/Ms." by calling someone by their first name (if this is an acceptable practice in your organization) or by using their first and last name together. You can also avoid using a person's name by tapping the person on the shoulder and saying, for example, "Excuse me, we're ready for you now. Please come this way."

It is also important to avoid gender terms when talking to others about a patient. For example, rather than saying "he is here for his appointment," or "she needs a follow-up appointment," you can say "the patient is here in the waiting room," or "Dr. Reed's 11:30 patient is here." You can also use "they" instead of "she" or "he". For example, you can say: "they are here for their 3 o'clock appointment." **Never,** however, refer to a person as "it."

In addition, recognize that avoiding gender terms is important both *in person* and *on the phone*.

USING PREFERRED NAMES AND PRONOUNS

As discussed in the first section, many transgender people change their name and gender to better match their gender identity. Some people change them officially on their legal documents, and some do not (for various reasons). Either way, it is recommended that health care organizations have a system that allows patients to input their preferred name, gender, and pronouns into registration forms and other relevant documents. This allows all staff to see the patients' preferences, and to use them consistently. Creating such a system is helpful for non-transgender patients too, since some patients might prefer to use nicknames or middle names, etc. To learn about suggestions for how to do this, see the section: **Helpful Resources**.

If your organization does not collect this information, it is acceptable to politely ask a person what name they prefer to use. For example, you can say "I would like to be respectful—how would you like to be addressed?" or "What name would you like me/us to use?" Once a patient has given a preferred name, it is very important for staff to use this name in all interactions. Not using the patient's preferred name can cause embarrassment and confusion. For example, imagine how a transgender man would feel if a medical assistant called into the waiting room and asked for "Jennifer Smith" rather than "John Smith".

Similarly, it is important to always respect the gender identity of a patient by using the patient's preferred pronouns (e.g., he/him/his, she/her). Think about how a transgender woman would feel if she overheard someone refer to her with a male pronoun, as in "his insurance has changed." Most transgender men and women prefer that others use the pronoun that matches their gender identity. However, as mentioned previously, only use gender pronouns if you are certain of the patient's gender identity and/or preferred pronouns. Otherwise, it is better to avoid using pronouns and other gender terms. In some circumstances, it is okay to ask about pronouns politely and in a private area, where others cannot overhear, so as not to embarrass or "out" the patient.

WHAT TO DO WHEN THE NAME AND GENDER ON RECORDS DO NOT MATCH

In settings that require insurance or use of third-party payors, transgender patients often have a name and gender on record that do not match their preferred name and gender. Changing one's name and gender on identity documents and insurance records can be a complicated and lengthy process. Moreover, it can be difficult for transgender patients to get certain medically necessary treatments if the gender on their insurance does not match their anatomy (for example, a male-to-female transgender client requiring a PSA test can be denied coverage if her gender is recorded on insurance as female). It is important, therefore, that staff members are prepared for this possibility, and can ask for information without embarrassing or "outing" the patient.

In a situation where a patient's name or gender does not match their insurance or medical records, you can ask: "Could your chart be under a different name?" or "What is the name on your insurance?" You can then cross-check identification by looking at date of birth and address. Never ask a person what their "real" or "legal" name is. Patients may feel offended because these terms assume that their preferred names are not "real". Further information on ways to address these issues can be found in **Helpful Resources**.

APOLOGIZING FOR MISTAKES

Clearly, it is not always possible to avoid making mistakes, and simple apologies can go a long way. If you do slip, you can say something like: "I apologize for using the wrong pronoun/name. I did not mean to disrespect you."

PRACTICING

Making changes in your speech can be a challenge at first. Most of us have learned to use gender terms like "ma'am" and "sir," in order to be polite. However, eventually most people will find it becomes more natural to speak using these new tools. Practicing with your colleagues may be helpful. You may also find it helpful to post the Best Practices sheet (found at the end of this document) near your work space.

MAINTAINING A RESPECTFUL WORKPLACE CULTURE

Below are additional tips for creating a transgender-affirming culture at your workplace.

Stay relaxed and make eye contact: Speak with transgender patients just as you speak with all of your patients.

Avoid asking unnecessary questions: People are naturally curious about transgender people, which sometimes leads them to want to ask questions. However, like everyone else, transgender people want to keep their medical and personal lives private. Before asking a transgender person a personal question, first ask yourself: *Is my question necessary for their care or am I asking it for my own curiosity?* If for your own curiosity, it is not appropriate to ask. Think instead about: *What do I know? What do I need to know? How can I ask for the information I need to know in a sensitive way?*

Do not gossip or joke about transgender people: Gossiping about someone's transition, or making fun of a person's efforts to change their gender expression, for example, should not be tolerated. In addition, only discuss a patient's transgender identity with those who need to know for providing appropriate and sensitive care. This is consistent with policies concerning discussion of all patients.

Continue to use a patient's preferred name and pronoun, even when they are not present: This will help maintain respect for the patient and help other staff members learn the patient's preferences.

Create an environment of accountability: Don't be afraid to politely correct your colleagues if they use the wrong names and pronouns, or if they make insensitive comments. Creating an environment of accountability and respect requires everyone to work together.

CASE SCENARIO

This page offers an example of a positive client interaction. The scenario is between Claire Brooks, a transgender woman, and Danielle Colatino, a front desk receptionist. Claire's birth name was Charles, and her birth sex was male. When Claire first started going to her health center, she was still using the name Charles and expressing her gender as male, even though she always felt female. Over the last few months, she has begun the gender affirmation process and is now asking people to call her Claire. Her primary care provider is aware that Claire is transitioning, but Claire's medical records, registration, and insurance forms remain under the name Charles Brooks, and her sex is listed as male.

When Claire comes in for an appointment, she approaches Danielle at the registration desk:

Danielle: Good afternoon. How may I help you?

Claire: Hello. I have an appointment with Dr. Brown at 2:30.

Danielle: Your name please?

Claire: Claire Brooks.

Danielle: Thank you. I'm sorry but I don't have you listed here. Might your appointment be under a different name?

Claire: Oh yes. It is probably under Charles Brooks. I've changed my name recently, but I guess it isn't in the records yet.

Danielle: Okay, it must not be. I have the appointment under Charles. Just to be sure we are using the right records, would you mind giving me your birthdate and current address?

Claire: Sure. It is November 12, 1987. I live at 10 Maple St. in Durham.

Danielle: Great. And are you still with the same insurance?

Claire: Yes I am.

Danielle: Okay, thank you. I will put a note in here that your preferred name is now Claire. I will let Shavonne, the medical assistant know, and also Dr. Brown. For billing purposes, the insurance records will need to remain under Charles unless you make the change yourself. Unfortunately, they won't let us do that for you but Shavonne can refer you to a website on how you can make that change. Do you have any questions?

Claire: No, that's fine. Thank you.

Danielle: Have a nice day.

REFLECTION QUESTIONS

- Can you picture yourself in this scenario?
- What might be different in your practice?
- What complications might arise and how would you address them?

ORGANIZATIONAL STRATEGIES FOR CREATING A TRANSGENDER-AFFIRMING ENVIRONMENT

There are several steps that management at health care organizations can take to support front-line staff in creating an environment of care that allows transgender people to feel safe, included, and welcome. Here are some suggestions:

- Have a system to track and record preferred gender, name, and pronoun of all patients. Organizations that have Electronic Health Records (EHRs) can standardize the use of the notes field to document preferred name and pronoun for all patients. If EHRs are not in place, a name alert sticker can be used to flag the patient chart.
- Include "gender identity and expression" in your non-discrimination policies. Post those policies.
- If possible, have single-occupancy bathrooms that are not designated as male or female. If you do not have this option, consider putting full-length doors on your stalls. If neither of these options is possible, have a policy that allows transgender patients to use the bathroom that matches their gender identity.
- Provide annual trainings in transgender cultural competency for staff. Train all new staff within 30 days of hire.
- Have clear lines of referral for complaints and questions from both staff and patients.
- Appoint a staff person responsible for providing guidance, assisting with procedures, offering referrals, fielding complaints.
- Have procedures in place that hold staff accountable for making negative or discriminatory comments or actions against transgender people.

HELPFUL RESOURCES

GENERAL INFORMATION ON TRANSGENDER HEALTH CARE

- World Professional Association for Transgender Health Standards of Care: www.wpath.org
- Center of Excellence for Transgender Health Primary Care Protocols: www.transhealth.ucsf.edu
- Vancouver Coastal Health: Guidelines for Transgender Care: www.transhealth.vch.ca/resources/careguidelines.html
- The Fenway Guide to LGBT Health, American College of Physicians: available on amazon.com
- Transgender Law Center: Health Care Issues: www.transgenderlawcenter.org/issues/health

INSURANCE AND BILLING INFORMATION

- Medicare Benefits and Transgender People: www.transequality.org/Resources/MedicareBenefitsAndTransPeople_Aug2011_FINAL.pdf
- Human Rights Campaign: Finding Insurance for Transgender-Related Healthcare (list of links to the carriers' websites where major guidelines for transgender-related treatments are openly available): www.hrc.org/resources/entry/finding-insurance-for-transgender-related-healthcare
- Department of Veteran's Affairs Directive: Providing Health Care for Transgender and Intersex Veterans: www.va.gov/vhapublications/ViewPublication.asp?pub_ID=2416

STRATEGIES FOR COLLECTING AND DOCUMENTING GENDER IDENTITY, PREFERRED NAMES, AND PRONOUNS IN REGISTRATION FORMS

- Center of Excellence for Transgender Health protocol: www.transhealth.ucsf.edu/trans?page=protocol-intake
- The Fenway Institute: How to Gather Data on Sexual Orientation and Gender Identity in Clinical Settings: www.lgbthealtheducation.org/wp-content/uploads/policy_brief_how_to_gather.pdf.

RESOURCES FOR PATIENTS ON CHANGING NAME AND GENDER ON LEGAL DOCUMENTS

- The Name Change Project from the Transgender Legal Defense and Education Fund: www.transgenderlegal.org/work_show.php?id=7
- Massachusetts Transgender Political Coalition: www.masstpc.org/publications/
- Transgender Law Center: www.transgenderlawcenter.org
- Health Care Rights and Transgender People: www.transequality.org/Resources/HealthCareRight_UpdatedAug2012_FINAL.pdf

RESEARCH ON TRANSGENDER HEALTH

- National Transgender Discrimination Survey: www.thetaskforce.org/downloads/reports/reports/ntds_full.pdf
- National Transgender Discrimination Survey Report on Healthcare: www.transequality.org/PDFs/NTDSReportonHealth_final.pdf
- Clements-Nolle, K., Marx, R., and Katz, M. (2006). Attempted Suicide Among Transgender Persons: The Influence of Gender-Based Discrimination and Victimization. Journal of Homosexuality, 51(3), 53-69.

WHERE TO FIND TRAININGS ON TRANSGENDER HEALTH CARE

The following organizations offer trainings on transgender health:

- The National LGBT Health Education Center: www.lgbthealtheducation.org
- Center of Excellence for Transgender Health: www.transhealth.ucsf.edu
- Massachusetts Transgender Political Coalition: www.masstpc.org/projects/trainings.shtml
- Callen-Lorde Community Health Center: www.callen-lorde.org/transgender-health-training

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Post this sheet on your wall or desk as a helpful reminder.

Best Practices for a Transgender-Affirming Environment

BEST PRACTICES	EXAMPLES
When addressing patients, avoid using gender terms like “sir” or “ma’am.”	“How may I help you today?”
When talking about patients, avoid pronouns and other gender terms. Or, use gender neutral words such as “they.” *Never* refer to someone as “it”.	“Your patient is here in the waiting room.” “They are here for their 3 o’clock appointment,”
Politely ask if you are unsure about a patient’s preferred name.	“What name would you like us to use?” “I would like to be respectful—how would you like to be addressed?”
Ask respectfully about names if they do not match in your records.	“Could your chart be under another name?” “What is the name on your insurance?”
Did you goof? Politely apologize.	“I apologize for using the wrong pronoun. I did not mean to disrespect you.”
Only ask information that is required.	Ask yourself: What do I know? What do I need to know? How can I ask in a sensitive way?

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