Barriers to Care among HIV+ Youth

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

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Introduction

In 2005, the Comprehensive HIV Planning Committee of the Houston Ryan White Planning Council commissioned three “special studies” focusing on populations of interest, which were identified based on findings from the 2005 Needs Assessment, and HIV/AIDS surveillance data. The first of the special populations identified by the Committee was HIV positive youth.

The purpose of this study was to better understand the factors that enhance or impede entry (and retention) into care for HIV positive youth. The focus on entry to care was triggered by HRSA’s unmet need initiative, and the Houston Ryan White Planning Council’s efforts to bring HIV+ individuals into medical care. The findings in this study are based on the personal narratives of HIV+ youth living in the Houston EMA. We chose to utilize one on one interviews in order to collect in-depth information not usually captured in quantitative surveys, and to give a direct voice to the experiences of HIV+ youth.

HIV/AIDS among youth in the Houston EMA

During 2004, there were 7,093 living HIV cases (including 796 new HIV diagnoses) and 9,967 living AIDS cases (including 936 new AIDS diagnoses) in the six-county Houston EMA. A total of 229 youth between the ages of 13 and 24 were newly diagnosed with HIV or AIDS. The HIV infection rate among youth is higher than the AIDS infection rate, suggesting an increasing trend in new infections among this population. Youth aged 13 to 24 exhibited increasing infections with more than 2 times more HIV diagnoses per 100,000 than AIDS diagnoses.

Young women, age 13 to 24, were a significantly higher percentage of new HIV infections than women overall. They represented over 45% of new HIV diagnoses and 50% of living HIV/AIDS cases among 13 to 24 year olds.

Of 13 to 24 year old MSMs living with HIV, only 2% are white/Anglo and 10% are MSM of color. Representing 68% of new cases, black youth are disproportionately affected by HIV and AIDS. They are, by far, the largest group infected with HIV disease, comprising 69% of those living with either HIV or AIDS. This compares to 11% for white youth and 20% for Hispanic youth.

2005 Needs Assessment

Youth aged 13 to 24 years constituted only 10% of the total Needs Assessment sample (n=39); however, nearly 60% of those youth reported being out-of-care.

The most frequently identified reasons for being out-of-care:

1. I do not believe I need medical care currently because I am not sick (49%);
2. I do not believe medical care would do me any good (36%); and

3. I was actively using (street drugs or alcohol) (23%).

Out-of-care youth’s ten most frequently identified unfulfilled service needs:

1. Food Bank
2. Health Insurance
3. Primary Medical Care
4. Medical Case Management
5. Utility Assistance
6. Household Items
7. Rental Assistance
8. Nutritional Supplements
9. Housing Related Services
10. Oral Health

Methodology

The findings of this study were based on 23 semi-structured one-on-one interviews with HIV+ youth between the ages of 18 and 24. Although HRSA and HIV/AIDS surveillance data define youth as 13 to 24 year olds, this study limited interviews to youth 18 years and above due to research consent issues for younger participants. Participants received gift cards at the conclusion of each interview. All interviews were conducted in English by the Health Planner in the Ryan White Planning Council Office of Support.

At the onset of each meeting, youth were informed that their participation was completely voluntary and that they could stop the interview at any time. A Research Assent form, containing details of the study and assurances of confidentiality, was reviewed with each participant (see Appendix A). Upon receiving the participant’s assent, a brief one-page questionnaire was administered (see Appendix B).

To further protect confidentiality, first and last names were not collected during the course of the study, participants signed only their initials on the Research Assent and gift card receipt forms, and a unique identification number was assigned to each participant.

Interview items were based on findings from a literature search on access to care among HIV+ youth, and lasted between 30 to 100 minutes. All interviews were recorded using a digital voice recorder, transcribed into Microsoft Word and coded and analyzed using AnSWR, a qualitative analysis program developed by the CDC.

Participants

Twenty-three (N=23) HIV positive youth participated in one-on-one semi structured interviews. Ten (44%) were male and 13 (56%) were female. None of the participants identified as transgender. Ages ranged from 18 to 24 years, with an average age of

20.6 yrs (sd = 2.37). Ethnicity and race were collected as two separate variables. Four (17%) participants identified as Hispanic, 19 (83%) Black, 2 (9%) White and 2 (9%) identified as Other ("Mexican," "Puerto Rican"). Approximately half of the participants identified as heterosexual (n=12; 52%), 6(26%) gay, 3 (13%) bisexual and 2 (9%) preferred not to disclose. None of the participants identified as lesbian.

While the vast majority of participants (n=17; 74%) were not in school, five (22%) participants were full time students and 1 (4%) was a part time student. The majority of participants (n=17; 74%) did not work, one (4%) worked full time, 3 (13%) worked part time and 2 (9%) worked temp or odd jobs. Most participants (n=20; 87%) lived with an average of 3 other people. Five (22%) participants had children (average = 1.2), and three (13%) said their children lived with them.

The average length of time being positive averaged at 2.4 years, though time ranged from 6 years to as recent as 2 months. The average time since last doctor's visit averaged at 41 days, and the majority of participants reported that they were not taking HIV medications (n=14; 64%). Only two participants had private insurance (through family members), 7 (30%) were on Medicaid and 13 (61%) "Other" or "Don't Know." During the course of the interviews, many of these 13 participants reported using the Gold Card or CHIP.

The following table shows the demographic breakdown of the 23 youth participants.

Participant Background Information (N=23)

Characteristics	
Gender	
Male	10 (44%)
Female	13 (56%)
Age	Range 18-24; Avg = 20.6; (sd=2.37)
Age at diagnosis	Range 13-24; Avg = 18.0; (sd=3.18)
Number of years HIV+	Range 0-6; Avg = 2.4; (sd=1.89)
Time since last visit to the doctor	Range = 0-8 months; Avg = 41 days; (sd=70.18)
Taking HIV Medications?	
Yes	8 (36%)
No	14 (64%)
Insurance Status	
Private	2 (9%)
Medicaid	7 (30%)
Other/Don't Know	13 (61%) *(Other = Gold Card, CHIP)*
Hispanic	
Yes	4 (17%)

Characteristics	
Race	
Black	19 (83%)
White	2 (9%)
Other:	2 (9%)
Sexual Orientation	
Heterosexual	12 (52%)
Gay	6 (26%)
Bisexual	3 (13%)
Prefer not to say	2 (9%)
Currently in school?	
Full time student	5 (22%)
Part time student	1 (4%)
Not currently in school	17 (74%)
Job Status	
Work full time	1 (4%)
Work part time	3 (13%)
Temp work/odd jobs	2 (9%)
Do not work	17 (74%)
Live Alone?	
Yes	3 (13%)
No	20 (87%)
- How many?	Range 1-6; Avg = 3.1; (sd=1.76)
Children?	
Yes	5 (22%)
- How many?	Range 1-2; Avg = 1.2; (sd=.44)
- Do they live with you?	Yes = 3 (13%)

* Some categories may not total 23 because demographic information was missing for one participant.

Limitations

It is important to note that interviews were conducted with HIV+ youth, between 18 and 24 years old, who were willing and available to talk about their experiences. None of the participants were infected through perinatal transmission. Additionally, since study recruitment was conducted through service providers, all participants were receiving medical and supportive services at the time of the interview. Therefore, the findings may not fully reflect the experiences of out-of-care HIV+ youth, perinatally infected youth and youth under the age of 18 in the Houston area. These limitations may affect the generalizability of the findings.

In addition to participant names, the names of specific case managers, doctors and service providers have been removed.

Results

Sources of messages about HIV/AIDS

For most participants, sex and STDs – let alone HIV or AIDS – were rarely discussed amongst their families. A few did have parents or family members who provided them with in-depth information about HIV, but the majority of participants stated that issues related to sexuality were rarely discussed amongst their families.

> *"That's one problem we had in our family; we don't have good communication, so we were never able to talk real open about STD's or HIV or drugs at all." (Female, 18)*
>
> *"It wasn't really a talked about situation in our house." (Female, 18)*
>
> *"My house we just never really talked about, about stuff like that." (Male, 19)*

In some cases, sex and STD were mentioned rather than HIV or AIDS:

> *"…my whole family was giving me rubbers. They was like, protect yourself 'cause I don't want you getting pregnant and whatever 'cause they got a lot of disease, but my mama never named them to me." (Female, 18)*
>
> *"…they would say, you know, protect yourself if you're doing it but not any in depth conversation." (Male, 19)*
>
> *"My mom was always telling me use a condom, you know, she's always, you know, I don't want any babies, you know, so always use a condom, you know. She never really like said anything about it. Specifically, it wasn't something that we talked about. She was more worried about the other ones then she was about HIV." (Male, 24)*
>
> *"My mama, she never told me about HIV and if she did I probably wasn't paying attention. She only told me about STD's, Herpes and all that other stuff. She ain't never said nothing about HIV and I never heard of it." (Female, 18)*

School health classes were common sources of information about STDS.

> *"… it was hush, hush. You know, they don't talk about, you know, they talk about typical, gonorrhea and all this. They don't talk about HIV or AIDS. They don't talk about that, you know. They preach abstinence but of course, we're not doing, you know, you know they don't offer condoms. Only you can get condoms in the clinic if you can get in a clinic. But they didn't preach that. We didn't hear about that at school, you know, we heard the typical gonorrhea, chlamydia and all that and stuff but you didn't really hear HIV or AIDS." (Female, 24)*

Some participants said that the messages they got about HIV/AIDS were that it was scary and deadly.

> *"…it was bad, that if you had it you're a bad person and all that." (Female, 18)*
>
> *"it's something you get from, you know, having sex, unprotected and you could die from it." (Male, 22)*

Youth also talked about ignorance and stigma in the community regarding HIV/AIDS.

> *"…everybody say you dirty if you got AIDS." (Female, 18)*
>
> *"… you tell them [that you're positive] and they like, oh, get away from me…" (Female, 18)*
>
> *"…I know ya'll are old and ya'll are set in your ways, and you don't want nobody with HIV to touch y'all or touch your silverware or anything like that because you think you're gonna get it because we done touched your silverware. And no, you're not gonna get it because we touched your silverware." (Male, 24)*
>
> *"You know people think just because you have HIV you're nasty and you're dirty and all this stuff; that's not true…." (Female, 19)*

HIV Testing Experiences

HIV testing sites utilized by participants included clinics (i.e., Planned Parenthood, mobile clinics, Live Clinic, People's Clinic, Houston Area Community Services (HACS), Kelsey Seybold, Montrose Clinic), hospitals (i.e., Ben Taub, Memorial Hermann, City of Houston) and jails/detention centers.

Some youth sought HIV tests as part of normal routine care.

> *"…I knew every year you go your check-up, you know, every year you get a HIV test." (Female, 24)*
>
> *"Oh, I always got tested. We had to all make sure we had, 'cause if you had sex you had to make sure you're healthy…I had gotten like gonorrhea like three times." (Female, 18)*
>
> *"…. my wife. She had said, you know, I'm hungry they have some chips over there let's go get tested and get some food, you know, it was just like, you know, a playful thing, you know let's go get some chips and get some soda and take the test, you know. " (Male, 24)*

The youth who received their diagnoses in hospitals were tested during prenatal care, childbirth or hospitalization.

> *"Because the doctor was wondering why I was having so many miscarriages and so he just put the test. That was one of the tests he wanted to run." (Female, 23)*
>
> *"Oh, I had when I was pregnant and my baby died and that's how I found out 'cause they gave me a test," (Female, 18)*
>
> *" I was pregnant and, I guess it was mandatory that when you're pregnant you have to get one." (Female, 18)*
>
> *"…my knees were hurting and he tested my t-cell lymph nodes, said they were swollen and felt a couple different areas like under my arm pits and he suggested I get tested..." (Male, 22)*
>
> *"I just gotten sick and they couldn't figure out what was wrong with me and I ended up having to take one." (Male, 22)*

Other youth were tested following partner notification or blood donation.

> *"….a lady from high school said I had a note from the Texas Health Department saying call immediately. It was posted on my mail box and posted on my apartment door. So I called the woman…as soon as possible and she say…she say I'm sorry to tell you this but…you been named by someone that have it, that you should get checked immediately." (Female, 19)*
>
> *"I used to donate plasma…and I think I went one day to donate and they gave me this piece of paper stating that I need to go get checked, so I went and got checked and that's how I got referred…" (Female, 22)*

In most cases, participants tested outside of the jail system received referrals to case manager or a public clinic during their post-test counseling sessions. However, the youth did not seem to feel the post-test info was very useful.

> *"They just gave me papers so I can take to [a public clinic] and that's all they said. " (Male, 18)*
>
> *"Well they give me that; I can go and get treated at this clinic…I can go get treated there and that was it. They gave me some 1-800 numbers to call if I needed somebody to talk to about it. That was it." (Male, 20)*
>
> *"They really didn't give me any information. I didn't start getting information until I got with the people I'm with now. She just was, she just basically did the testing…." (Male, 19)*

A few participants reported negative experiences after receiving their diagnoses.

> *"…they referred me to this counselor and she was like well, do you understand what HIV is and…you know, talking to me like I'm slow but then she, she went like if you had kept your legs closed then you wouldn't be in this predicament." (Female, 24)*
>
> *"The director or whatever, he was, I just didn't like his attitude. He seemed like, you know, kind of like treated like you was diseased animal, you know, just the way he talked to you, his body language, he didn't care like he wouldn't try to help you, you know. He just give you all this information and then you sort it out it was like no comfort. When you hear something like that, you know, you want comfort, you know, you don't want sternness. " (Male, 24)*

Family Support

Approximately half of the participants received positive support from family members, particularly their mothers, and disclosures to romantic partners were always positive. Other participants had not disclosed their status to their family members, or were met with silence and/or denial. Only a few participants reported negative or violent reactions from relatives.

> *"My family be doing talking trash to me, doing me wrong, but then I got to tell my family what if the shoe was on the other foot, what if you have HIV and I didn't, you know what I mean, what if the shoe was on the other foot; how would you like at them tables 'cause you wouldn't want me saying that type of stuff to you so why would you say that type of, that, that hurting things to me?" (Male, 20)*
>
> *"My mama, she cried but she took care of me at that time but then she start changing on me. She didn't put me out she just started changing on me like being mean..." (Female, 18)*
>
> *"…my mama girl friend beat me and left a little, what you call, a hickey on my head and I was bleeding everywhere so she told me to pick that blood up around her children." (Female, 18)*
>
> *"…my daddy they know about it too and his wife tell me not to eat off the same plate as their children or nobody else. " (Female, 18)*

Personal Reactions

Personal reactions to being diagnosed varied among the participants. Some reacted with extreme depression and self-isolation.

> *“I didn't believe, I was like, uh-uh, you wrong. “ (Female, 18)*
>
> *“…kind of feel like I let myself down and other people around me.” (Male, 19)*
>
> *“Suicide. I think about that all the time, I think about it…I cry and it hurt just to think about it and it really do, just to think about it.” (Female, 18)*
>
> *“…when I first caught this virus, I used to hide from people. I used to not want to come outside and play with my friends. I used to stay inside and hide and my mama used to come in my room and say, why you hiding? 'Cause I don't want my friends to laugh at me.” (Female, 18)*
>
> *“…every time I think about it, it scares me, it makes me cry…” (Female, 18)*
>
> *“…I really didn't think I could make it. I didn't know if I was gonna wake up the next day….” (Female, 18)*
>
> *“I cried myself to sleep like and I just like really couldn't believe that I had that. I didn't want to believe it but I know that it was true...” (Female, 19)*
>
> *“I thought people wouldn't want be around me.” (Female, 19)*
>
> *“I think like my whole world, just like turned up side down, it was like, just, I can't even explain it, I was like so shocked and scared and worried and the angry and upset and frustrated and like just confused, you know, what the hell I was gonna do, I didn't know where I was going…I was like homeless so that added to the problems...” (Male, 24)*
>
> *“I don't even talk about it. You know. The only time you know I think about it is when I start getting sick and then I get like depressed” (Male, 22)*
>
> *“…when they first told me I had HIV I thought I was just, well that's the end of my life” (Female, 22)*
>
> *“That's like the hardest thing I deal with day by day, my depression.” (Female, 22)*

Other participants responded positively to their diagnoses, viewing their HIV status as part of a larger purpose in life. It should be noted that these participants were actively involved in a youth support group.

> *“I wasn't ashamed. It helped me to bring out what used to be me and you know I used to have a picture say this used to be me before I got positive and this is me now. But it's different. It's a difference in my soul and difference in my being.” (Female, 24)*

> *"…I use that HIV thing for a motivation…as a blessing and a guidance for others, you know, to help other people." (Female, 24)*
>
> *"…to me its like, its in my blood it's not me, it's me, it's my name, you know what I'm saying, but it's me, it's not, it's not….it's inside my blood, my blood red, it's just something I got, it's not going to define me…" (Female, 18)*
>
> *"…I wasn't worried about it because if God puts it in my hands and says I want you to have this so you can go and tell your story to people, then that's His calling, there's nothing I can do for that. And that was His calling, I ended up getting it, but it's not a death sentence to me at all. It's more of a now you have something to go and tell people." (Male, 24)*
>
> *"It's not a death sentence – look at me, I'm happy, I'm go lucky. You never see me in my room going I can't do nothing because I have HIV, I might as well sit here and let it take over me. Oh, no no no. I done have too many friends, people I've known throughout the years who get it and do that, sit back and I'm just gonna let it take over me, there's nothing I can do. Yeah, there's something you can do. Get up and be yourself. Go, go out and have some fun. You just a regular person. You just have a sickness. It's the same thing for people with high blood pressure, they don't sit there and say well I'm gonna let this blood pressure take over and let it kill me. No. Go out and have fun. Go do what you're supposed to be doing. Live your life like you're living it, like you lived it before you found out. That's how I am, I'm living my life like I did before I found out. Ain't nothing's stopped from what I used to do." (Male, 24)*

Entry into Care

Virtually all participants reported seeking medical care no more than three weeks following their diagnosis. Only one participant was not immediately connected to medical care due to a miscommunication with her case manager. Youth who were diagnosed in hospitals or prison systems received immediate medical care, and those diagnosed in clinics or other testing sites sought medical care within a few days to three weeks following their diagnoses.

In most cases, participants were referred to specific medical care sites by their testing sites. In some cases, hospital staff contacted specific case managers, who then arranged transportation for the youth to and from a public clinic. Other youth reported local resource directories as very helpful referral sources.

Although all of the study participants were receiving medical care at the time of the interview, several reported going in and out of care in past years. Denial, pride, drug abuse, being busy and simply "not wanting it" were reasons for "falling" out of care.

> *“…I guess in between all that time I was in denial…I would act like I didn't know what was going on with me sometimes.” (Female, 18)*

> *“…in the back of my mind I knew I had it but I just didn't, I was, I was living with my pride, you know, I mean, how would that look I'm going to the clinic, ‘hey yo man, I'd like to checked up on my HIV positive’, you know, I mean, that's, HIV is, that's a big worry, even though it's small that's a big word to some folks and that's a hard word, you know, that's what, I mean, that's what I was looking at my pride, you know.” (Male, 20)*

> *“I started going back to drugs and stuff, so my main concern was not my health anymore basically, so I just stopped going to the doctors and I would go, I would go only when I didn't feel, when I felt like weak or something you know, I would tell my mama I think I need to go get my labs done so I could see that I'm not going into 200 or something, you know. That, that was the only other time I was concerned.” (Female, 18)*

> *“…I was working and going to school and it got really busy and hectic and I just forgot all about the appointments. I done forgot that, like I was really sick…” (Female, 18)*

> *“I wasn't getting help because I didn't want it. I mean, at that time I didn't want it you know, I knew people to go to, you know. I had already met people to go to but it was my choice not to go back to them, you know.” (Female, 18)*

During the interview, participants were asked to give their opinions on why some HIV+ youth might not be receiving adequate levels of appropriate medical care. Responses fell under three categories. Some participants felt that the cost of medication was to blame for inadequate levels of care among HIV+ youth.

> *“I think it's because they either first, they don't have Medicaid or they can't afford it.” (Female, 19)*

> *“…us youth around here we, you have majority that's living like very poor and they can't afford medicines like that and it's hard to get help. So I think that's like basically their problem.” (Female, 18)*

A few participants felt that the attitude of doctors played a role.

> *“…some doctors might not want to be around HIV person.” (Female, 18)*

And other participants felt that the onus of receiving adequate medical care fell on the HIV+ youth. They suggested that youth might feel scared, in denial, concerned about confidentiality or simply not interested in seeking care.

> *"…young people aren't getting enough medical care because they don't feel there's any hope or they just gave up because there's no cure." (Male, 22)*
>
> *"Denial and they can't tell people. Some of them, you know, they probably on their parent's insurance and they just can't get up and go to the doctor." (Male, 19)*
>
> *"I'm thinking it's because sometimes they just don't want to come out and say they're HIV positive, so maybe they're not doing what they need to, to get the care that they want, or that they need. Because I believe, everywhere you go, you're gonna find doctors who go beyond that level to help HIV+ youth, just like they'd try to help the HIV+ adults, so I wouldn't necessarily put it on the doctors, I would put it on the youth…they need to carry out the initiative to go out and find some ways to get to doctors offices, to get the medical attention that they need…if you can't get your mom to take you, then get on the bus. That's all you have to do, get on the bus. I mean, we're in the city of Houston, Houston has one of the largest HIV/AIDS resources in the United States. So really, there is no excuse for youth in the City of Houston to say that they're not getting no medical attention because it's here. I'm getting it. It's really here. It's youth that really need to step up and do what they need to do." (Male, 24)*

Service Providers

Participants were asked to describe traits of an "ideal" Case Manager. By far, most said they desired from their case managers a genuine sense of concern, friendliness and willingness to help.

> *"Every time I tell her I need something she try her best for me to get it." (Female, 23)*
>
> *"Just a cool person…Just someone I could, like just to talk to…you know, someone I could talk to and relate to." (Male, 19)*
>
> *"Somebody that tries to help me, somebody who honest that they gonna try to help me get on my meds and stuff like that and someone who cares about me." (Male, 18)*
>
> *"Someone caring, someone that you can talk to not as a friend, well yes, as a friend, a mother, a counselor. I'm not looking for a friend but I want somebody to confide in. If I really have something on my, on my chest that I really need to tell someone and I don't want to tell my parents or my mom or my girlfriend or anything, I can come to you and I know you'll keep it confidential or you'll try to talk to me to help me out about it…I would want a social worker that will treat me the same way as they want to be treated, put it that way. I just want respect and*

> *understanding between each other. You understand where I'm coming from; I understand where you coming from." (Female, 22)*

Based on the interviews, it appeared that there were three programs that worked collaboratively to coordinate entry into and retention in care for youth. These three programs consisted of a particular public clinic and two local agencies. A common "entry to care" scenario involved the participant being referred to the particular public clinic following diagnosis. Prior to, or during, the participant's first visit to that public clinic, a youth-designated case manager on site would meet with them and coordinate his or her medical and supportive care. This case manager would also connect the participant with one or both of the local agencies. One of the local agencies provided case management and a youth support group for all youth up to 24 years of age. The other agency provided case management only targeted to young MSM of color. There seemed to be a high level of coordination amongst these three agencies, and appeared seamless to the youth.

It was also clear that two specific case managers located at the particular public clinic and a local agency played an especially integral role in helping youth enter into care. These case managers work hand-in-hand, and rarely was one case manager's name mentioned without the other. The youth under their care often described them as a pair.

> *"You know them two…they're a good team and I like that. That's a good team 'cause they, they, they conference on things, they talk about patients that don't want to show up or don't want to come to the doctor, you know. They, they talk about it, you know, I mean, they, they a good team. They kind of like a Shaq and Kobe. A good thing." (Male, 20)*

Every youth under the care of these case managers spoke of them very highly. They clearly valued not only the services provided by the case managers, but also the individual level of care and concern they received.

> *"…if I saw anybody who was just diagnosed and under the age limit I would refer them to [the Case Manager] because when I say that she is awesome, I say it from the bottom, not 'cause I like her, but from the bottom of my heart because she has done things that she didn't have to do, and that I have never seen anybody do." (Female, 24)*
>
> *"…she tell you what you need to be told and she helps you when you need to be helped." (Female, 24)*
>
> *"She act your second mama. She is there. She is good support. She should get like award or something 'cause she's really good. You call like 2 o'clock in the morning and just, man, you could talk to her all the time." (Female, 18)*
>
> *"I didn't want to really go to [a public clinic]…she was telling me if you want me to I'll take you, she'll take you to [a public clinic] and get you information. She*

> *driving out her car. I don't think they pay her for that for her niceness. She drives out there on North Side, you know what I'm saying, so she cool, 'cause she cares. She really cares. She invite you to her church, she care, she really care…she ain't doing it for profit or kudos, she doing from her heart, so she's real like that." (Female, 18)*
>
> *"…you can call her and talk to her about any problem. If she can help you, she will try her best to help you. If she can't she'll tell you she can't help you right then and, but she will try her best to help you…" (Male, 20)*
>
> *"…she look out for us. She make sure we have our best, she look over us like we her own kids." (Female, 18)*
>
> *"I never tell her when the appointments, she just finds, magically finds out herself, and she meets me up there. All I see is her sitting there before I get there." (Female, 18)*
>
> *"[Case Manager A] know we young but [she] can relate to our level and that what make her so special because she can relate. She can relate to us; she can relate to everybody in her group…I give her the utmost respect, you know, because a lot of things…she shouldn't have to do, but I mean, she go out of her way to do 'em, you know what I mean, 'cause it's not that because that's her job, it's that because she, she want to see us get better in life…and even though some of us mess up, you know, some of us mess up, some of us don't mess up, you know what I mean, she still, even if we do mess up she still there, know what I'm saying, with an open hands, open arms, she still there. " (Male, 20)*

Participants were also asked to describe traits of an ideal doctor. Common themes were patience, good listener, friendly, knowledgeable, caring, open, trustworthy and non-judgmental. Participants who were very satisfied with their current doctor referred to him/her as examples.

> *"…when I talk to her she doesn't interrupt me…she lets me get it all out, you know, so, I mean, that's what I look for, you know. " (Female, 18)*
>
> *"…you feel like you can talk to her about anything." (Female, 23)*
>
> *"She actually listens." (Female, 18)*
>
> *"Knowledgeable, caring and understanding; understand the person where they coming from." (Female, 18)*
>
> *"…they don't talk to you like you're beneath them. They talk to you like you're a human being and, you know, that's respect for you, you know. " (Male, 20)*

> *"…they show that they really care, I mean, they're not just kind of doing because it's a job, that they really genuinely really care about each person." (Male, 20)*
>
> *"When they be kind, courteous to their patients. Make their patients feel good about themselves. Help their patient out by you know, if their patient tell 'em like something they need refer them to somebody they know that could help them out with that issue." (Female, 18)*
>
> *"Her qualities is she doesn't look at us like, oh my god they have this, or oh my god they're young and they're just dumb and stupid because they have HIV now, no she doesn't look at us like that…she tries to help us out whenever we need help. She will always overstep her boundaries to get us help. She will. She will always overstep her boundaries to get us help. And whenever we need her, she's just a phone call away because we all have her cell phone number too. Most doctors won't even go that far to give you their cellphone numbers, she has given every single one of us her cellphone number, so we all have ways to get in contact with her whenever we have problems or questions or anything. And other qualities about her, she's caring, she's very caring. She's very caring. She loves the field she's in, and she loves dealing with her patients." (Male, 24)*
>
> *"…somebody who you feel like you can see very easily and also treat you like you're a member of the family or has a…personable relationship with you, a very familiar relationship; spends more time with you…" (Male, 24)*
>
> *"…they actually care about me and try to help me." (Female, 19)*
>
> *"…she's always trying to call me and check on me so…makes me happy that somebody cares." (Female, 18)*
>
> *"She explains everything and goes through everything and like she, she told me when I first met her she was like, now you're gonna have to listen to me and you're gonna have to just sit there and listen and if I keep repeating myself it's because you need to know, and every time she said something or she repeats everything she says like three or four times, and it's like okay I finally understand you can stop repeating yourself. But, it's good she's like that..." (Female, 19)*
>
> *"Someone who is warm, down to earth, someone that…I don't have to actually necessarily look at them as the doctor, I can look at them as someone who can help me, and that is easy to talk to about the situation and is non-judgmental." (Male, 22)*
>
> *"If they act like they on your level, they really understand you….more a friendship form than medically….." (Male, 22)*

In addition to case managers and doctors, participants also described traits of an ideal HIV/AIDS agency. The most common trait was friendly staff. The vast majority of participants utilized medical and supportive services at a public clinic, and most rated their experiences there as very positive.

> *"I like the way the clinic is, the way the clinic run, you know, it's either with the nurses and the cashier, you know, they talk to you real nice…It's really, it's real wonderful. It's real site, a real good site." (Male, 20)*
>
> *"…they nice and stuff.   They treat you well. The doctors, the nurses are all nice. Nobody has a attitude, so it's really okay with me 'cause nobody don't treat you bad, make you feel down about yourself." (Female, 18)*
>
> *"…they nice, they have a lot of stuff that you can do that they give out. A lot of stuff like clothes, food, stuff. They like every month, like whatever holiday, they always have something for the patient that come here, it's free. Medication's free." (Female, 18)*
>
> *"I just want to have one doctor where I can just stick to one and that doctor will know what's going on with me instead of starting all over with another doctor and trying to communicate trying to have like, like a friendship with her instead of having to start all over and having different doctors." (Male, 18)*
>
> *"I thought it was going to be a lot of sickly people and a lot of people in very, very bad situations I had to be around a lot of people on drugs and every thing like that, but it really wasn't like that at all. I was comfortable with the person I was working with. She made sure that, you know, I did every thing correctly and, you know, I was, everybody was very nice. Everyone greeted me with a smile, warm smile; it was a great, you know, process." (Male, 22)*
>
> *"I loved it there because it, everyone seemed helpful…everyone had a smile, they actually had me smiling and I felt, I felt horrible yesterday." (Female, 22)*
>
> *" Everyone there helped me out. Everyone there has happy faces, their attitudes are nice, then everyone is up to par even if you go there feeling like you're down. You're not going to leave like that. Somebody gonna make you laugh before you leave." (Female, 22)*
>
> *"I went from the first floor to the second floor, moved all around the second floor, moved back down to the first floor, went to the pharmacy and left. That's just how quick it was." (Female, 22)*
>
> *"I have fun when I go there." (Male, 22)*

However, some participants were not comfortable with the size of a public clinic, its designation as an HIV-specific site and inconsistency of providers.

> *"I haven't a stable doctor ever since I started with [a public clinic]…it's been different doctors. It hasn't been the same." (Male, 18)*

> *"[a public clinic] was a little bit too big and busy." (Female, 18)*

> *"I wouldn't want to see people look, seeing me and then after that they might say something to one of their friends, I saw this, this person at [a public clinic] and then the person tell the other person and it's going, everybody's going to know and I don't want that. 'Cause you know, somebody will say something to a friend and they gonna find out about you and I don't want that." (Male, 18)*

> *"…if they're just a HIV clinic you automatically linked if you're in the area that you have HIV so, you know, I just better going to just a regular hospital then to go somewhere like that." (Male, 22)*

Many participants attended one or both youth support groups offered at a public clinic and a local agency. When asked to describe what they valued about those support groups, participants emphasized the importance of the "safe space," confidentiality, openness and peer support they received through the groups. Several participants also described the groups as a "family."

> *"…it's been so confidential…what I say stays in there, and from what I see too, so, I mean, it's a…safe box that can always come to, you know, if I'm having trouble at home or something or something I can't talk about at home I can come here and talk…" (Female, 18)*

> *"…to have a safe haven, you know, it's a difference that's unexplainable…" (Female, 24)*

> *"Everybody is voicing their opinion and everybody comments and everybody tries to help you. If I bust out crying they gonna get up to console me, comfort me..." (Female, 24)*

> *"You know, we help each other, we real positive role model to each other, you know, we help and we push and we motivate each other, so you know if they hear somebody that's gonna motivate them and help them and show them, they'll go to the doctor." (Female, 24)*

> *"…what I like about it is you can come express your feelings and you can cry and you can do anything, everybody will support you and everybody will be there to help you 'cause we all in the same situation. " (Female, 19)*

> *"…I rather would be around people that are diagnosed like me because they can understand where I'm coming from. They can understand my pain." (Female, 22)*

> *"…we're a family. We all consider ourselves family." (Male, 24)*

> *"… I felt depressed at the beginning 'cause I felt like I was by myself, but once the class had ended I felt, I felt good. I felt real good. I felt like I was around people that I had known for years…I felt like I was around another family." (Female, 22)*

Service Needs

These support groups were targeted to youth up to 24 years old. When asked about the importance of age-specific services, participants had mixed responses. While age may not be a universally valued factor in choosing and utilizing services, it is important to many of study participants. Unsurprisingly, the majority of study participants who attended the support groups favored services that targeted youth.

> *"I feel more comfortable here because I'm gonna listen to somebody who's my age." (Female, 18)*
>
> *"I feel comfortable with them 'cause they around my age group but I know that I'm not really like the only one that's eighteen that's HIV positive. For about half of the people is eighteen years old. So I really feel comfortable around them, like, if I was around the older age group; they're like, I think they look at me as I been too young to be having HIV and that be like; I don't know if they'd try to put me down but if I, I didn't know that everybody probably be like looking at me or whatever, like why's that little girl up in here? Like she's usually like too young to be going through what she's going through." (Female, 19)*
>
> *"It would be good for youth to have their own group, because some youth don't want to be in front of more older adults to tell them anything because I think it's a trust issue, I guess, because I can sit there and tell anybody about anything, but then there are some things that I won't tell an adult, but I'll tell somebody around my own age. Because if you tell an adult, sometimes if you tell an adult something, they'll look at you crazy because either they don't know what you're talking about, or they don't think that you should even be talking like that, or whatever, you know, they have their own agenda." (Male, 24)*

Other study participants stated that age did not play a role in their satisfaction with services – many stated, "age does not matter to me."

> *"it doesn't matter what age they are or anything like that. I sit in the room with anybody as long as you treat me the same way you want to be treated. It doesn't matter what age they are because you'd be surprised an old person can be a happy spirit as a young person." (Female, 22)*

When asked about needs not being met, participants listed housing, job assistance, rental assistance and day care. Participants also expressed a desire for more flexible eligibility requirements for services, more youth programs, community education and easier entry into care.

> *"…my one wish would be to have no requirements for medication; just sign up and you'll get service the next day. My second wish is that anyone that's sick and need, really need them, that they shouldn't be turned down, they should be, like I said before, get help. Basically, it really don't, I don't really need a second or third wish 'cause my main wish is no requirement that you should help them with no turn downs." (Female, 18)*
>
> *"if anything should change, it would be to come up with more youth programs for the city of Houston, because then it would make every youth in here not be afraid to go ahead and take that test…" (Male, 24)*
>
> *"…it'll be nice if they find a place, somebody tells you that you're positive, you immediately get them into counseling, you immediately try to help them, immediately try to offer them some assistance. That, that time is really the most critical time because they get to thinking crazy… " (Female, 24)*

Transportation is a frequently identified barrier to care in the Houston EMA; however, fewer study participants listed transportation as a barrier than expected. Many credited the bus passes and cab assistance provided by various organizations. A few reported that their case managers drove them to and from medical appointments. Two participants said their case managers would drive 45 minutes each way to accompany them to appointments.

> *"…there's not a huge barrier now because I was recently given the little bus card which is very handy now, so I'm making it around on the bus..." (Male, 22)*
>
> *"…they have vouchers where you can catch the bus or they have cabs can pick you up take you to places…and even your doctor's appointment when you need them." (Female, 19)*
>
> *"…I'm riding the bus just like everybody else. And if you can't get your mom to take you, then get on the bus. That's all you have to do, get on the bus." (Male, 24)*
>
> *"[this program] was more helpful to me because they actually provide transportation and so that was our big thing so I think that's why we just really went for this program and didn't go for other ones…" (Male, 19)*

Still, participants acknowledged that without such assistance from these agencies, transportation would be a much larger issue. When asked about the hardest thing about finding services in Houston, one youth replied, "Getting there. Basically getting there." (Female, 19).

> *"I had to ride like four different buses just to get here. I don't think I'd be able to make it and I probably wouldn't be able to make some of my clinic appointments either if I didn't have the cab service…." (Female, 18)*

Conclusion

Based on the findings in this study, several themes emerged regarding entry to, and retention in, care among HIV+ youth. Satisfaction with service providers, the existence of a support network of some kind and access to transportation resources stood out as major factors influencing how HIV+ youth experienced care. And while not all youth reported age as an important factor in choosing services, youth-specific support groups were extremely important sources of emotional and peer support for many participants.

It is again important to note that interviews were conducted with HIV+ youth, between 18 and 24 years old, who were willing and available to talk about their experiences. None of the participants were infected through perinatal transmission. Additionally, since study recruitment was conducted through service providers, all participants were receiving medical and supportive services at the time of the interview. Therefore, the findings may not fully reflect the experiences of out-of-care HIV+ youth, perinatally infected youth and youth under the age of 18 in the Houston area. These limitations may affect the generalizability of the findings.

A number of participants reported that the first time they learned the facts about HIV/AIDS was after receiving their diagnoses. Many did not discuss issues of sex, STDs or HIV/AIDS with their families – and they did not feel susceptible to HIV. This suggests the need for additional prevention education efforts targeted to youth.

HIV testing sites were the first point of entry for most participants, which suggest that immediate linkage into medical care are crucial at time of diagnosis.

In a study by Flicker, et al (2005), youth identified a wide range of emotional response to their HIV status; however feelings of isolation, loneliness and hopelessness were dominant. According to Stein and Rotheram-Borus. (2004), coping styles among HIV positive youth were characterized as passive, depressive withdrawal, escapist and positive. Personal reactions to their HIV status varied among the participants from extreme depression and isolation to believing their HIV status was part of a larger purpose in life. Some participants responded positively to their diagnoses. It should be noted that these participants were actively involved in a youth support group. These findings suggest that mental health services and treatment education are important in helping with feelings of depression or hopelessness following diagnosis.

Virtually all participants reported seeking medical care no more than three weeks following their diagnosis. Youth who were diagnosed in hospitals or prison systems received immediate medical care, and those diagnosed in clinics or other testing sites sought medical care within a few days to three weeks following their diagnoses.

In most cases, participants were referred to specific medical care sites by their testing sites. In some cases, hospital staff contacted specific case managers, who then arranged transportation for the youth to and from a public clinic. Other youth reported using resources books as referral resources.

Although all of the study participants were receiving medical care at the time of the interview, several reported going in and out of care in past years. Denial, pride, drug abuse, being busy and simply “not wanting it” were reasons for “falling” out of care.

During the interview, participants were asked to give their opinions on why some HIV+ youth might not be receiving adequate levels of appropriate medical care. Responses fell under three categories. Some participants felt that the cost of medication was to blame for inadequate levels of care among HIV+ youth. And other participants felt that the onus of receiving adequate medical care fell on the HIV+ youth. Some said that some youth may feel scared, are in denial, concerned about others finding out or simply not interested in seeking care.

Service Providers

Participants were asked to describe traits of an “ideal” case manager. By far, most said they desired from their case managers a genuine sense of concern, friendliness and willingness to help.

Based on the interviews, it appeared that there were three programs that worked collaboratively to coordinate entry into and retention in care for youth. These three programs consisted of a particular public clinic and two local agencies. A common “entry to care” scenario involved the participant being referred to the particular public clinic following diagnosis. Prior to, or during, the participant’s first visit to that public clinic, a youth-designated case manager on site would meet with them and coordinate his or her medical and supportive care. This case manager would also connect the participant with one or both of the local agencies. One of the local agencies provided case management and a youth support group for all youth up to 24 years of age. The other agency provided case management only targeted to young MSM of color. There seemed to be a high level of coordination amongst these three agencies, and appeared seamless to the youth.

It was also clear that two specific case managers located at the particular public clinic and a local agency played an especially integral role in helping youth enter into care. These case managers work hand-in-hand, and rarely was one case manager’s name mentioned without the other. The youth under their care often described them as a pair.

Participants were also asked to describe traits of an ideal doctor. Common themes were patience, good listener, friendly, knowledgeable, caring, open, trustworthy and non-judgmental. Participants who were very satisfied with their current doctor referred to him/her as examples.

In addition to case managers and doctors, participants also described traits of an ideal HIV/AIDS agency. The most common trait was friendly staff. The vast majority of participants utilized medical and supportive services at a public clinic, and most rated their experiences there as very positive. However, some participants were not comfortable with the size of a particular public clinic, its designation as an HIV-specific site and inconsistency of providers.

Many participants attended one or both youth support groups offered at a public clinic and a local CBO. When asked to describe what they valued about those support groups, participants emphasized the importance of the "safe space," confidentiality, openness and peer support they received through the groups. Several participants also described the groups as a "family."

Service Needs

The support groups were targeted to youth up to 24 years old. When asked about the importance of age-specific services, participants had mixed responses. While age may not be a universally valued factor in choosing and utilizing services, it is important to many of study participants. Unsurprisingly, the majority of study participants who attended the support groups favored services that targeted youth. Other study participants stated that age did not play a role in their satisfaction with services – many stated, "age does not matter to me."

When asked about needs not being met, participants listed housing, job assistance, rental assistance and day care. Participants also expressed a desire for more flexible eligibility requirements for services, more youth programs, community education and easier entry into care.

Transportation is a frequently identified barrier to care in the Houston EMA; however, fewer study participants listed transportation as a barrier than expected. Many credited the bus passes and cab assistance provided by various organizations. A few reported that their case managers drove them to and from medical appointments. Two participants said their case managers would drive 45 minutes each way to accompany them to appointments.

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APPENDIX A

RESEARCH ASSENT FORM

Barriers to Care Among HIV Positive Youth in the Houston Area

A. PURPOSE AND BACKGROUND

The Houston Ryan White Planning Council is conducting a research study to help understand the experiences of HIV positive youth (ages 18-24) when accessing medical care. You are being asked to participate in this study because you are an eligible youth.

B. PROCEDURES

If you agree to be in the study, the following will happen:

1. You will be asked to complete a brief one-page questionnaire about your basic background and demographic information. It should take approximately ten minutes to complete the questionnaire.

2. You will be interviewed by Jen Haejin Kim, Health Planner for Ryan White Planning Council Office of Support. The interview will cover various topics related to your experiences as an HIV+ youth. The interview will be recorded, and is expected to last about 60 minutes.

3. These research activities will be done at various agencies and/or other agreed upon locations, and will take a total time of about one and a half hours.

4. Data collected from the questionnaires will be entered into a database for summary purposes. No identifying information will be collected on the questionnaires or stored in any database. All participation is confidential. All interviews will be transcribed and stored as word processing files. No identifying information will be included in the transcripts.

5. At the completion of this study, you are welcome to request copies of the final report and any presentations.

6. If at any time during the questionnaire and/or interview you would like to stop participating, just let Jen Haejin Kim know.

C. RISKS/DISCOMFORTS

1. Some of interview questions or topics may make you uncomfortable or upset, but you are free to decline to answer any questions you do not wish to answer or to leave the interview at any time.

D. BENEFITS

There will be no direct, immediate benefit to you from participating in this study. However, the information that you provide may help planning bodies, service providers and health professionals better understand the experiences HIV+ youth face when accessing medical care.

E. COSTS

There will be no costs to you as a result of taking part in this study.

F. PAYMENT

You will receive $30 in Wal-Mart gift cards for your participation in the study. You will receive the gift cards after completion of both the questionnaire and the interview.

G. QUESTIONS

If you have any questions or concerns about participation in this study, feel free to contact:

Jen Haejin Kim, MPH
Health Planner
(713) 572-3729 – voice
(713) 841-0738 – pager
Jennifer_Kim@itc.co.harris.tx.us

H. CONSENT

PARTICIPATION IN RESEARCH IS ALWAYS VOLUNTARY. You are free to decline to be in this study or to withdraw from it at any point.

You may also withdraw your authorization (consent) for this study by contacting Jen Haejin Kim to inform her of your decision.

If you wish to participate in this study, you should sign below. You will be given a copy of this consent form to keep for your records.

____________	________________________________
Date	Subject's Signature for Consent
____________	________________________________
Date	Signature of Person Obtaining Consent

APPENDIX B

Gender:	☐ Male ☐ Female ☐ Transgender
Age:	_______________
Are you Hispanic?	☐ Yes ☐ No
Race:	☐ Black ☐ White ☐ Asian ☐ Native American/Pacific Islander ☐ Other:__________________________
Sexual Orientation:	☐ Straight ☐ Gay ☐ Bi ☐ Lesbian ☐ Prefer not to say
Are you currently in school?	☐ Yes, I'm a full-time student ☐ Yes, I'm a part-time student ☐ No, I am not currently in school
Job Status	☐ Work full-time ☐ Work part-time ☐ Temp work/Odd Jobs ☐ Do not work
Do you live alone?	☐ Yes ☐ No How many people do you live with? _______
Do you have any children?	☐ Yes How many?_____ Do they live with you? _____ ☐ No
What is your Zip Code?	__________________
What kind of insurance do you have?	☐ Private ☐ Medicaid ☐ Other:______________ ☐ Do not know
How old were you when you were diagnosed?	____________________
When was the last time you saw a doctor?	___________________________
Are you currently taking any HIV medications?	☐ Yes ☐ No