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"Taking a Half Day at a Time:" Patient Perspectives and the HIV Engagement in Care Continuum

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Abstract

The HIV treatment continuum, or "cascade," outlines key benchmarks in the successful treatment of HIV-infected individuals. However, the cascade fails to capture important dimensions of the patient experience in that it has been constructed from a provider point of view. In order to understand meaningful steps in the HIV care cascade for individuals diagnosed with HIV through expanded, more routine testing, we conducted in-depth interviews ($n=34$) with three groups of individuals: those diagnosed with HIV in the emergency department/urgent care clinic who linked to HIV care and exhibited 100% appointment adherence in the first 6 months of HIV care; those diagnosed in the emergency department/urgent care clinic who linked to HIV care and exhibited sporadic appointment adherence in the first 6 months of HIV care, and; hospitalized patients with no outpatient HIV care for at least 6 months. This last group was chosen to supplement data from in-care patients. The engagement in care process was defined by a changing perspective on HIV, one's HIV identity, and the role of health care. The linkage to care experience laid the groundwork for subsequent retention. Interventions to support engagement in care should acknowledge that patient concerns change over time and focus on promoting shifts in perspective.

Introduction

The HIV treatment continuum, or "cascade," is a dominant paradigm in engagement in care research.[1] This continuum outlines key steps in the successful treatment of HIV-infected individuals, focusing specifically on diagnosis, linkage to care, retention in care, initiation of antiretroviral therapy (ART), and achievement of an undetectable viral load. In recent years, there has been increased emphasis on the continuum given the potential for treatment as prevention, as clinical data demonstrate a dramatically reduced risk of HIV transmission in the setting of virologic suppression.[2] The Centers for Disease Control and Prevention has used the continuum to show that only about 50% of HIV-infected individuals are retained in care.[3] Poor retention in HIV care has been associated with delays in ART initiation, virologic failure, and death.[4–7] Previous research has found that structural factors (e.g., transportation, housing, or insurance), psychosocial factors (e.g., stigma, social support), and clinic factors (e.g., appointment reminders, patient-provider relationships) all affect engagement in care, particularly in populations affected by health disparities.[8–10] However, these factors are frequently cross-sectional correlates,[11–13] and little attention has been paid to how an individual moves through the steps of the cascade over time.

Indeed, the HIV care continuum has been constructed from a provider perspective and does not account for patient experiences. While a useful framework for setting clinical and public health goals, the targets of the continuum cannot be met unless there is a thorough understanding of patient concerns at each step. This point assumes added significance in light of the fact that little is known about patient perspectives in the current era of more tolerable antiretroviral therapy (ART) and "routine" HIV testing. In medical settings, "routine" HIV testing has been defined as a less exceptional fashion of HIV testing, in which patients may receive a new HIV diagnosis while seeking care for other reasons.[14] To our knowledge, there is no qualitative study of the engagement in care experience from diagnosis to linkage to retention for individuals newly diagnosed with HIV via expanded, more routine HIV testing. Qualitative studies of engagement in care are of critical importance because they allow for in-depth exploration of the phenomenon and can expand conceptual understandings. Thus, the objective of this study was to

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understand barriers to and facilitators of engagement in care across the testing/linkage/retention continuum for patients newly diagnosed with HIV via expanded, more routine testing and to supplement this knowledge with the perspectives of patients not currently receiving outpatient HIV care.

Methods

The San Francisco General Hospital is a public hospital that serves many diverse, poor, urban vulnerable populations. The hospital HIV clinic, Ward 86, is one of the oldest and largest HIV clinics in the United States, providing multidisciplinary care to nearly 3000 patients. HIV testing in the emergency department (ED) and urgent care clinic (UCC) is ongoing, and Ward 86 maintains a linkage team to connect patients immediately who test HIV positive in these locations to care.[15,16] The linkage team also helps hospitalized patients who are out of HIV care re-establish care. Through the linkage team and HIV clinicians, we recruited two populations for in-depth, semi-structured interviews: (1) individuals whose HIV diagnosis occurred in ED or UCC at least 6 months prior and who linked to care at Ward 86, and; (2) hospitalized patients with no outpatient HIV care at any facility for at least 6 months. In order to fully understand the range of patient experiences after "routine" HIV diagnosis, we attempted to sample equally for patients who exhibited perfect retention for the first 6 months of clinic care (i.e., no missed or "no show" visits), and patients who missed one or more visits. After obtaining verbal consent, interviews were conducted in English or Spanish in a private room and audio-recorded. Participants also completed a short socio-demographic questionnaire. Interviews lasted approximately 1 h and respondents were reimbursed $30 for study participation. Study data were collected from February 2011 to October 2012. The institutional review board of the University of California San Francisco approved this study.

The study team consisted of HIV physicians and nurses trained in qualitative methods, a medical sociologist, a medical anthropologist, and a clinical psychologist. Guided by two behavioral models that have been used to understand health services utilization, the Behavioral Model for Vulnerable Populations, and the Information, Motivation and Behavioral Skills (IMB) Model, the team developed an interview guide that was organized along the steps of the HIV care cascade but also aimed to understand the HIV illness experience more generally.[17,18] Key points included pre-diagnosis orientation to medical care and HIV; the diagnosis experience; the linkage to care experience; and experiences around keeping appointments. The interview guide was revised in an iterative fashion during the first several interviews to ensure adequate yield and flow of information from participants. Interviews were transcribed (and if in Spanish, translated) verbatim. In addition, field notes documented observations about each participant encounter.

Data analysis drew on general elements of the thematic approach.[19] The first step was familiarization with the data, including reading and summarizing individual interviews as they were transcribed and then comparing across interviews (cross-case analysis). Preliminary codes were generated using both deductive and inductive approaches. The deductive approach, consistent with the work of Miles and Huberman, begins with a conceptual framework that allows researchers to integrate concepts from the existing empirical and theoretical literature into the coding process.[20] The inductive approach, consistent with grounded theory, uses the constant-comparative method to conduct open coding, in which codes arise from careful reading of the text.[21] We employed a grounded theory approach in order to allow participants to identify important points not evident in existing conceptual frameworks. Codes were refined through practicing on a selection of transcripts, and new codes were created as necessary. The final codebook had 50 codes in addition to 4 temporal overlay codes (pre-diagnosis, diagnosis, immediately post-diagnosis, ongoing). Two analysts independently coded five transcripts and discussed discrepancies until $>90\%$ agreement was reached. Atlas.ti was used to code the interviews and to pull all text associated with a code across interviews. Selected codes were read aloud in a series of analysis meetings to help collate codes into potential themes. In a second stage of analysis, we employed elements of narrative analysis and phenomenology. Narrative analysis seeks to determine the important points of a particular story in contrast to the segmentation of text created by coding, while phenomenology attempts to understand the meaning of the lived experience.[22,23] As such, we sought to understand the role of the themes we identified in patient experiences of care. Illustrative quotes were selected to exemplify themes and demonstrate their relevance to the research question.

Results

Participant characteristics

Participants ($n=34$) were evenly divided between the well-engaged [i.e., those who had missed no primary care appointments in the first 6 months of clinic care ($n=11$)], more sporadic users [i.e., those who had missed one or more primary care visits in the first 6 months of clinic care ($n=13$)], and the out of care ($n=10$). Of the participants whose HIV was diagnosed in the ED or UCC ($n=24$), the median time since diagnosis at study participation was 24 months (range 6–62 months). The median age was 47 years (range 25–61 years). Participants were mostly male (Table 1) and men who have sex with men (MSM), and were 60% racial/ethnic minorities. With regard to the out-of-care group, the median time since HIV diagnosis was 14 years (range 2–29 years), and the median time since last HIV care was 10 months (range 6 months to 12 years). The median age was 50 years (range 42–57 years) and participants were fairly balanced between male/female and white versus African-American race (Table 1).

Patient concerns

We found that patient concerns across the care continuum could be organized into four broad topic areas: (1) physical/medical; (2) psychological [e.g., shock, depression]; (3) social [e.g., support, disclosure, stigma]; and (4) administrative [e.g., access to care, care navigation]. For all patients, HIV diagnosis initiated a new narrative with regard to identity. However, as patients moved through the steps of the continuum, their prioritization of concerns was not static. Some patients initially prioritized physical/medical concerns, while other patients focused more on psychological or social concerns. All patients had to learn and manage the administrative aspects of care to stay engaged in care. Below we outline key

Table 1. Participant Characteristics (n=34)

	Diagnosed in ED/UCC (n=*24*)	*Out-of-care* (n=*10*)
Age (median, range)	45 (25–61)	50 (42, 57)
Gender		
Male	20 (83%)	6 (60%)
Female	3 (13%)	3 (30%)
Transgender (MTF)	1 (4%)	1 (10%)
Race/ethnicity		
White	9 (37%)	4 (40%)
African-American	4 (17%)	5 (50%)
Hispanic	8 (33%)	1 (10%)
Asian-American	3 (13%)	0 (0%)
HIV risk factor		
MSM	13 (55%)	6 (60%)
Heterosexual	7 (29%)	2 (20%)
IDU	2 (8%)	2 (20%)
Not sure	2 (8%)	0 (0%)
Time since diagnosis (median, range)	2 years (6 months–5 years)	15 years (2–30 years)
Missed visits in first 6 months of care		
None	11	N/A
At least one	13	N/A
Time out of care (median, range)	N/A	9 months (6 months to 12 years)

themes at each step of the continuum. In addition, we discuss disclosure, social support, and fear of stigma in a separate section, as these themes pertain to all steps of the care cascade.

Pre-diagnosis orientation to care and HIV

Though the HIV care continuum begins at the time of HIV diagnosis, pre-diagnosis perceptions of medical care and HIV may influence subsequent engagement in care. We found that individuals diagnosed with HIV in the ED/UCC were not engaged in primary care prior to diagnosis and had tended to seek medical care only for acute symptoms or STD testing, viewing interactions with medical providers as necessary only to obtain medications or in emergencies. Some individuals reported always having felt healthy and saw no need to see a physician on a regular basis. Others stated that they believed they did not have access to medical services, despite living in a city with a safety net program to encourage preventive care. Participants described how HIV providers helped reframe this orientation to medical care, specifically communicating that consistent, ongoing care was available and had the potential to maintain good health, in addition to managing symptoms or providing medications. Similarly, an individual's pre-diagnosis knowledge of and familiarity with HIV appeared to shape feelings towards HIV care, as did experiences with HIV-positive individuals. Nearly all participants voiced awareness that people with HIV are frequently stigmatized, and this awareness of HIV stigma was a powerful driver of their response to HIV diagnosis.

Diagnosis

HIV diagnosis caused participants to revise previously held ideas about themselves and the disease in light of new information they received from health care providers or from their own research. The way participants understood what was happening to them (e.g., fear, a sense of inevitability) helped inform the choices they made around medical care, especially since in our dataset the response to HIV diagnosis was characterized by a fear of death. As such, participants noted the importance of immediate education about HIV and HIV treatment and indicated that they found comfort in a discourse of HIV as a chronic illness as opposed to a terminal one.

> *Dr. H. who became my primary care physician, he told me if you do the right things you can live a long time, you know, by taking your meds and everything. So that was quite reassuring. I was hoping he would say that because I didn't want to die.* (60-year-old well-retained white heterosexual man)

Other participants found that they could intellectually acknowledge this discourse, but emphasized that the diagnosis experience was still a significant emotional stress, particularly with regard to feeling betrayed by one's partner and deeply worried about stigma.

> *I was just breaking up with him. Everything was a shocker because I broke up with him the week before…he's on the East Coast now. I was just alone. You had all these doctors saying the same thing, "Oh, we have this medicine now versus 20 years ago." It's like, "Okay, I understand, I hear you saying it but you don't know exactly how I feel unless you feel it. Oh, HIV is the basically the new diabetes now. We can treat it." That's great but you're not going to feel like how you're telling me to feel if you don't have it.* (27-year-old African-American woman with sporadic attendance)

Many participants described a period of depression and isolation after HIV diagnosis yet they still linked to care, noting that they received psychological support and referrals to psychiatric services by accessing HIV care. Reassurance that physical symptoms could be alleviated was also remarked upon as an important part of the diagnosis experience, as many participants were diagnosed in the context of other serious illnesses.

Linkage to care

The linkage to care experience was often described as instrumental in laying the groundwork for subsequent engagement in care, as it provided the opportunity for patients to be oriented to care, meet and build trust with providers, and address psychological and social needs more thoroughly. Participants expressed appreciation of kindness on the part of clinic linkage personnel, particularly empathy without judgment, and they appeared to value the efforts made by linkage staff to thoughtfully match them to an HIV provider.

> *A: She's like, "Well it's time for you to get a doctor, a regular doctor." They were like, "Do you want a woman, man, gay?"*
>
> *Q: Oh, they asked all that?*
>
> *A: They asked me what kind of doctor do you want—who are you going to be comfortable with. I said, "I want the best doctor that you give me. I don't care if it's a woman or man."* (32-year-old well-retained Latino MSM)

Another participant recalled how linking to HIV care helped her find support that she lacked in other areas of her life.

> *So it was just a waiting game, basically trying to get my health back in order, trying to stay focused and not be depressed, like how I was. Because I've had nights where I just sit down and start crying. My mom keeps telling me, "There's no pity party, there's no pity party," but I keep telling her, "Okay, I didn't put this on myself. I just need somebody to understand what I'm going through." And that's why I hooked up with C.* (nurse practitioner) *because the same ladies she sees, they're going through something too. At first I didn't want it because it's a constant reminder that I am sick but it's a relief to be around somebody who knows how you feel.* (27-year-old African-American woman with sporadic attendance)

Since many participants seemed to lack strategies for handling the psychological stress of the diagnosis, the linkage experience was crucial in building trust and making them feel they could rely on the clinic and its providers. This participant added:

> *The compassion that they give me is like family, you know. Like they fill that void, that's why I don't even look for it from my family because they're there. Like yeah it's their job but they care for me. They'll call me even when I'm at work and say, "Hey how you doing? I know it's tough, but hey we got you taking a half day at a time."*

This participant appeared to find it meaningful when her providers acknowledged that living with HIV is difficult and gave her a strategy for coping (i.e., "taking a half day at a time.")

Indeed, a key aspect of the linkage experience was when providers established a timeline in which return to physical and emotional health was possible. One participant emphasized how it important it was to remind patients that how they feel physically or emotionally at the time of diagnosis is not how they will always feel.

> *One of the things that he said to me early, early on was that you're going to be aware one day of how much energy you have compared to what you were. That's when you know you're going to be on the mend. And one day I was just walking down the street and and I was like, wow, I don't have to stop! I don't have to sit. And that was kind of the light bulb he gave to me. He was very encouraging. He wasn't condescending.* (43-year-old Latino MSM with sporadic attendance)

Similarly, patients noted the need to familiarize themselves with administrative aspects of care, such as scheduling appointments and planning transportation. Participants described how helpful the linkage team was in orienting them to the clinic and how personal connections with linkage team members helped them learn how to make appointments, get blood drawn, and use urgent care. This familiarity with clinic resources appeared to lead to greater comfort when accessing them.

Retention in care

A changing perspective helped define the retention in care experience, as individuals who were retained in care described five key shifts in perspective that occurred over time: (1) the realization that concerns at the time of diagnosis could recede over time; (2) acceptance of HIV as a chronic illness and the creation of routines to support good health; (3) assumption of responsibility for one's health in a shared fashion with medical provider; (4) acknowledgment that fewer provider appointments are necessary over time; and (5) the desire to become an expert guide for other newly diagnosed individuals.

One participant narrated how the fear of death and other co-morbidities at the time of diagnosis became less prominent for him as time passed.

> *I became isolated, certainly depressed, and then as you get more information and actually start believing being told, "Well, you won't quote/unquote die of AIDS, you'll die of something else." Then as I got more knowledge that people in my situation can have kidney problems, liver problems, osteoporosis earlier than we would had we not had the disease, which me being a worrier, makes me very nervous…It took me about a year before I started realizing that days have gone by that I didn't think about that. I used to think about it every day. Now it'll go multiple weeks before anything comes to mind.* (61-year-old well-retained white MSM)

Consistent with other literature, nearly all participants cited appointment reminders as facilitators to keeping appointments and lack of clinic staff to consistently answer and return phone calls as a barrier to retention in care.[24] Patients described having to navigate administrative aspects of the health care system without becoming overwhelmed in order to remain in care. However, participants also described the creation of their own systems to manage appointments and maintain health.

> *There's a lot of appointments in the first year, between social works and other government agencies where I had sources for benefits. So my calendar was pretty full the first year. I immediately created a calendar for myself on the computer and have maintained it ever since.* (48-year-old white MSM with sporadic attendance)

Another participant emphasized the importance of a daily routine.

> *I wanted to make sure I developed a routine that would help me. So my routine every day was to take my meds, have breakfast, take a walk down the hall a few times, then take my shower. It was important for me to do things to make myself feel good—to make myself active as much as I could.* (60-year-old well-retained white heterosexual man)

Participants also mentioned taking a more active role in their health care over time. At the beginning of the HIV care experience, participants acknowledged deferring to provider knowledge and judgment. As participants learned more about the disease over time, they seemed to come to a process of shared decision-making with providers.

> *Boy, at that time (of diagnosis) it was sort of like you could lead me by the nose. They said go upstairs, I went upstairs. They said, "This is the doctor," and it was just "Okay." Now I'm at a point where perhaps people should be all the time. I disagree with what my doctor is saying and I'm like, "Well, no I don't want to take that," or "No, I asked you for this information and you're telling me this and I really want this information." That's the way I am now, but in the beginning I just sort of handed myself over, "You people know what's going on, I don't."* (61-year-old well-retained white MSM)

Another participant added:

> *They're kind of directing where it's going but at the same time I have control over it. So if they tell me something and it doesn't seem like something I want to do, I'll go read about it, and then I'm like, okay, yes or no.* (25-year-old well-retained Latino MSM)

Participants noted that when providers establish a timeline for treatment, it should include anticipating a period where fewer appointments are necessary; otherwise, this spacing out of appointments can be experienced almost as a personal rejection. One participant who had transitioned to less frequent appointments because he was doing well said:

> *I asked him, "Are you cutting me loose?" Because he didn't want to see me anymore. Initially I was coming every 4 weeks, then it was every 2 months, now it's every 4 months. He doesn't want to see me until the end of the year and I'm just like, "You're cutting me loose?"* (laughs) *Right? You get attached to these people.* (43-year-old Latino MSM with sporadic attendance)

This participant went on to outline how positive aspects of the patient–provider relationship were also experienced outside of scheduled appointments, such as the provider's responsiveness to e-mail.

> *So I would type him and I don't know if the man ever sleeps or not but literally within hours my phone would buzz and it was him responding to me. So that makes me feel really good.*

In general, accessibility and genuine concern on the part of providers seemed to make participants feel connected to the clinic and that they were receiving compassionate care.

Finally, when participants felt they had gained enough knowledge to be of value to other patients, they expressed a desire to serve as an expert guide to their peers by providing education and support. This confidence in care helped characterize the experience of well-engaged patients.

> *If I had a friend who was now just diagnosed I think I would take the day off and come with him the first day here and show him where everything is.* (49-year-old well-retained white MSM)

Out-of-care experience

All but one of the out-of-care participants had been in outpatient HIV care previously. They expressed valuing and appreciating their prior HIV care. In fact, many did not seem to view themselves as out of care.

> *I don't have no problem with Ward 86. I was never gonna leave Ward 86. They stay on their jobs and let me know when I miss my appointments. They cuss me out once they get me over there and they get me in their traps and it's like doomsday* (chuckles). *I like it because they treat me like family. They go out of their way. M.* (provider) *has come to my house to see me. I know she cares – that's how mad she gets at me."* (54-year-old African-American heterosexual woman)

For these patients, the categorization of "out of care" did not appear to fit their experience, in part because their perception of time seemed different. For example, a participant last seen a year ago still viewed himself as in care. In addition, participants acknowledged well-documented barriers to keeping appointments, such as substance use, lack of transportation, loss of private health insurance, and family caregiving responsibilities.[25] However, an important theme that emerged was that participants did not make conscious decisions to stop coming to appointments. Rather, they simply had competing priorities, or, at times, no stated reason.

> *I don't have trouble scheduling them, I just got trouble keeping them* (laughs). *That's all. Keeping appointments, yeah, I let them slide on by* (laughs). *Oh, I don't feel like going today to no doctor's appointment. I just don't feel like it. But I'm gonna start going. I'm gonna start going to my appointments regularly and everything.* (42-year-old African-American MSM)

Though it was not the most common experience, two participants did describe making conscious choices to temporarily disengage from care. These choices involved weighing the physical and emotional costs required to stay in care against a quality of life when not in care. One participant described how he felt when, after having an undetectable viral load for 10 years, he decided to stop antiretroviral medication.

> *Not having to wake up and swallow those pills—yeah, I felt great. It was like being at Disneyland for a couple of years, pretending like I just didn't have this disease anymore.* (48-year-old African-American MSM)

However, this participant emphasized that he always planned to go back onto antiretroviral therapy. He wanted to travel overseas and viewed his interruption in care as temporary. Another participant said he decided to try alternative medicines for a period of time, but he too acknowledged the benefits of antiretroviral treatment.

Antiretroviral therapy and virologic suppression

Some out-of-care participants described experiences with side effects from antiretroviral medication that led to social discomfort and limited functionality (e.g., diarrhea). Others were unfamiliar with current treatment options. For retained patients, favorable changes in HIV lab results such as CD4 cell count and viral load due to antiretroviral treatment were referenced as motivations to come to appointments. However, few patients acknowledged prevention benefits to virologic suppression and those who did were not certain of these benefits.

> *And now of course there are people who say, "Because the meds keep our viral load undetectable we can all go out and have sex without any protection because the odds of us transmitting are very, very low." That's probably something that's still on my tape. I don't believe it. I mean, even if it's true I don't want to take a chance.* (61-year-old well-retained white MSM)

A participant who had not recently been in care echoed this thinking.

> *I mean, I wouldn't lose my life on this but I've heard that men with undetectable HIV viral loads have not passed the virus on.* [42-year-old white man (out of care)]

Disclosure and social support

In our dataset, there was no clear pattern between disclosure and engagement in care, though concerns about disclosure were clearly an important part of the HIV illness experience. Some individuals who had not disclosed their HIV diagnosis to anyone or who had negative disclosure experiences were retained in care, while those who had worked as HIV-positive activists were out of care. Similarly, disclosure assumed different meanings for different people with regard to maintaining or forming social connections. Some participants chose not disclose their HIV status at all or to disclose strategically to friends or family but not sexual partners. Some participants disclosed to primary partners but more strategically to friends or family. For other participants, particularly women and heterosexual men, lack of disclosure tracked with a fear of rejection and a sense of social isolation, as these participants indicated that they could not initiate relationships with new romantic partners or friends and be accepted as an HIV-positive individual. Newly diagnosed individuals did state that they benefitted from referral to clinic and community resources for social support, though participants mentioned that simply having an outlet for social connection was in some ways more important than focusing on HIV.

> *Because it's a relief to see other people in my situation who can understand but it's a downer because it's like, "Oh, we're all in here, we all have HIV, we are HIV/AIDS." And, "Oh, wow, your story is just like mine." It's that constant reminder that we're going through this, we're going through that. "I'd rather, 'Hey, we're all here but we're at Great America," instead of sitting down in the circle reminiscing on how we caught it and how we're dealing with it.* (27-year-old African-American woman with sporadic attendance)

The importance of social activity was echoed by newly diagnosed participants who felt they had a fair amount of support around their HIV diagnosis.

> *When I go rafting it's going to be exciting. I don't have a bucket list but I'm going to do a reverse bucket list. I'm going to write on it that I've already done it. STOP AIDS has a paintball thing. I never in my life shot paintball, I was running around getting shot, hurting, black and blue marks like a son of a gun. I had the most fun I've had in 15 years. Of course that's going to help me. So doing social things, though it sounds, you know. It's affirming, it's energizing, it's realizing I'm alive because sometimes with HIV you don't feel alive.* (61-year-old well-retained white MSM)

Discussion

In this qualitative study examining patient experiences at different steps of the HIV care continuum, we found meaningful steps in the process of engaging care that are not evident in the current provider-defined paradigm. These results are particularly significant because this is the first study to look at the testing/linkage/retention continuum from the perspectives of individuals "routinely" tested for HIV in an era of efficacious and tolerable antiretroviral therapy. For these individuals, the engagement in care experience was defined by a changing perspective on HIV, one's HIV identity, and the role of health care in the HIV illness experience. Well-engaged patients voiced active participation in their health care through shared decision-making with providers and creation of health routines, and these patients wanted other newly diagnosed individuals to benefit from their care and treatment knowledge. In short, care was viewed as central to one's well-being and it became an ongoing priority. The linkage to care experience was a crucial facilitator of this type of retention, as it provided the opportunity to be oriented to the administrative aspects of HIV care, build trust with providers, and obtain psychological and social support, particularly through referral to community resources. Linkage staff also guided participants through the process of obtaining public insurance and/or medication coverage, which helped alleviate fears about the inability to pay for care. Given the high level of unmet need for supportive services among HIV-infected individuals, further study of this type of guidance may be warranted.[26]

One of the most important findings of this study was that patient concerns change over time, suggesting that interventions to support engagement in care should acknowledge this temporality and focus on promoting shifts in perspective. Without tailored intervention, individuals can get "stuck" at one step in the continuum. In the Centers for Disease Control Never in Care project, individuals who had never engaged in HIV care uniformly associated HIV with death and HIV care only with feeling sick or needing medication.[27,28] In our study, fear of death was certainly a potential barrier to engagement at the time of diagnosis but immediate education by the linkage to care team and other providers allowed it to recede with time. While successful navigation of early steps of the care continuum may bode well for subsequent steps, it is worth noting that this may not always be the case. For example, the desire to address physical concerns may cause patients to engage in care immediately but a lack of psychological or social support may cause them to drop out of care at a later point in time.

The idea of turning points in the incorporation of HIV/AIDS identity into the self is not new, though early studies described immersion in an HIV-positive community as central to this process.[29,30] Certainly, as in other studies, the HIV

Table 2. Potential Areas for Intervention Development

Framing the journey	• Setting expectations at time of diagnosis/linkage, specifically around the physical and psychological illness/health trajectory • Defining the role, content, and frequency of primary care and other kinds of appointments • Developing a common vocabulary for monitoring progress
Deepening clinic-based aspects of linkage to care	• Familiarizing new patients with the clinic • Thoughtfully matching patients and providers • Supporting the navigation of bureaucratic aspects of care
Developing clinic-level resources for disclosure and social support	• Hosting disclosure workshops • Ensuring systematic referrals not only to HIV support groups but also to social activities in the community, both HIV and non-HIV related

diagnosis experience caused a "biographical disruption" for many of our participants, in which they struggled to form a cohesive sense of self and feared how others might perceive them.[31,32] For our participants, there was no obvious relationship between disclosure and engagement in care, and we found that participants could develop a medical HIV identity (i.e., seek HIV care), without developing a positive view of this identity or integrating it with a social HIV identity. However, positive experiences with disclosure helped participants to identify as an HIV-positive person, while feared or actual negative experiences with disclosure clearly affected their psychological well-being. Similarly, we found no obvious relationship between level of social support and engagement in care. Regardless of the level of social support an individual reported, participants welcomed community resources for social activities, including non-HIV related social activities. Since a key step of engagement in care for "routinely" tested patients appears to involve providers helping to redefine patient perceptions of what medical care can accomplish, the integrated and active offer of resources for disclosure and social connection could allow the HIV care site to support more than just the biomedical patient experience.

Though our interviews with individuals who had been out of care for at least 6 months were conducted to supplement our understanding of patients engaging in care, a fascinating finding in this group was that these individuals did not necessarily view themselves as out of care. Participants were often unaware of provider-defined parameters for being "in care" and at times did not realize that their status had changed to "out of care." This disconnect between patient and provider perspectives merits further study and points to the need to develop patient-centered definitions of engagement in care. Similar to another study of hospitalized out-of-care patients, our study found that participants tended to view past HIV providers favorably.[33] However, it is important to note that hospitalized patients may be inclined to view providers in a positive light, as they are currently receiving care for acute health issues. A study of out-of-care individuals recruited from the community found deliberate avoidance of care due to distrust of medical providers.[34] We found that participants could value one or more of the benefits of medical care without prioritizing appointment attendance. Most participants did not narrate conscious decisions to go out of care; those who did either made calculated choices to disengage for quality of life reasons or to pursue an alternative treatment.

A general limitation of this study is that the individuals diagnosed via "routine" testing had all successfully linked to care and were recruited from a clinical setting. However, we sampled for those with missed visits, as well as those with perfect appointment adherence. Moreover, this approach allowed us to assess facilitators as well as barriers. Participants were asked to recall their diagnosis and linkage experience, raising the question of whether they might have had different perspectives if interviewed in the context of a longitudinal study. However, the median time since diagnosis was less than 2 years. Many of our participants were men who have sex with men, reflecting the demographics of the HIV epidemic in San Francisco. Women and heterosexual men appeared to have more difficulty with the development of an HIV-positive identity and seemed less likely to have strategies for managing stigma, but our numbers are too small to draw definitive conclusions. Finally, this study was conducted at a single clinical site, which limits its generalizability. Despite these limitations, we feel this study allowed us to develop important insights about patient experiences with the HIV care continuum and propose the following areas for intervention development.

Potential areas for intervention development

Based on this formative qualitative data, we see three key areas for intervention development and testing in the HIV clinical care setting (Table 2). One is formalizing the idea of a "timeline" for individuals newly diagnosed with HIV and having linkage staff and clinical providers incorporate this idea into every visit. This timeline would include setting expectations around the trajectory of the HIV illness and care experience, reassurance that improvement in psychological as well as physical health is possible, and developing a common language for encouraging and monitoring this progress. The timeline would also focus explicitly on the role and frequency of primary care appointments and other kinds of clinic visits. Clinic-based messaging about the importance of keeping appointments has been shown to improve retention rates.[35] A second area of intervention development is continuing to define, refine, and study successful elements of the linkage to care process, including clinic orientations that maximize patient familiarity and comfort, thoughtful matching of patients and providers, and support around navigating administrative aspects of care (e.g., appointment reminders, check-in calls, and follow-up calls after a missed visit). Determing how best to train peer mentors/navigators is an area of ongoing research.[36] A third area of potential intervention is to develop systematic clinic-level resources for disclosure, including strategies to confront stigma and rejection, and for connecting patients to social activities where they can find emotional and psychological support, even if these group activities are not HIV-related. By providing a space where an HIV-positive social identity is not stigmatized, the clinic can help patients learn to build a support network. In developing interventions such as these, the engagement in care field can help move the continuum from a solely biomedical paradigm to one that acknowledges the importance of psychosocial steps in care.

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