

A QUALITATIVE INVESTIGATION OF PATIENTS' TRANSITIONAL STATES OF
ENGAGEMENT IN HIV-RELATED MEDICAL CARE

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ABSTRACT

This qualitative study was designed to investigate the factors related to engagement in HIV-related medical care and specifically periods that can be characterized as transitions in and out of care. Data were collected through person-level interviews followed by thematic coding and analysis. The sample consisted of 22 participants recruited from the Truman Medical Center Infectious Disease Clinic and the Kansas City Free Health Clinic. Six main themes were identified as factors related to engagement: health factors, treatment factors, personal factors, support factors, clinic factors, and resources, each of these consisting of subthemes that describe the issues more specifically. The results were analyzed in the context of how they relate to the phases of engagement on the HIV continuum of care with specific examples from the interviewees. Results were then compared to an existing framework and were found to support many previous findings and indicate the need for evaluation of funding allocation, as well as changes at the health care system and policy levels. Additional work will be done to further establish validity of the findings for development of a framework to describe the complexity of factors that need to be accounted for when developing efforts designed to support better engagement in care.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Medicine, have examined a thesis titled “A Qualitative Investigation of Patients’ Transitional States of Engagement in HIV-Related Medical Care,” presented by Stephanie Lisette Koch, candidate for the Master of Science degree, and certify that in their opinion it is worthy of acceptance.

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CHAPTER 1

INTRODUCTION

There is a consensus among providers, researchers, and public health officials that more timely linkage to and engagement in medical care is a matter of priority for individuals who are infected with human immunodeficiency virus (HIV) (Mayer, 2011). Early linkage to and engagement in primary care following an HIV positive diagnosis carry essential clinical and public health implications, including better management of the disease, minimization of viral load, maintenance of a healthy CD4 count, as well as prevention of ongoing transmission. However, many people who are living with HIV, especially those with comorbidities or mental health conditions, as well as those who are challenged with multiple barriers to medical attention, often cycle in and out of care, leading to suboptimal treatment outcomes. Factors such as residence, transportation, finances, familial support, social stigma, as well as clinic-specific factors such as the level of empathy and commitment by providers and clinic staff, have been indicated as affecting engagement in care (Christopoulos et al., 2013; Mugavero, Norton, & Saag, 2011; Raveis, Siegel, & Gorey, 1998; Tobias et al., 2007). These factors have the capacity to minimize the benefits of an otherwise highly effective treatment options.

Lack of engagement in HIV care is common in the United States and incompletely engaged individuals account for the largest proportion of HIV-infected individuals with detectable viral loads (Gardner, McLees, Steiner, del Rio, & Burman, 2011). Recent data suggest that only about 50 percent of HIV-infected individuals are retained in care after diagnosis (Hall et al., 2012). Currently, there are limited empirical data on methods for improving engagement. While some research has been conducted to

test outreach interventions, the conclusion of these research efforts has been that there is a need for further exploration (Christopoulos et al., 2013); (Liau et al., 2013); (Reed et al., 2009). Particularly, there is a great need for more qualitative studies that specifically investigate the care experience from the patient perspective in order to better understand barriers to care and how to overcome them, thereby making medical care as accessible and manageable as possible.

The objective of this research project was to investigate the factors related to engagement in medical care and the transitions in and out of care. The study focused on three specific care-related periods of time: in care, out of care, and transitioning either into or out of care. The goal of the study was to obtain understanding of the factors associated with engagement in care in order to develop a framework to be used to describe the complexity of factors that need to be accounted for when developing efforts designed to support better engagement in care. Pending the results of the study the ultimate goal of this line of research is to improve outreach interventions and support systems that could result in improved engagement in care, thereby improving management and prevention of HIV.

CHAPTER 2

REVIEW OF THE LITERATURE

The term “engagement” in care describes a spectrum of patient care, ranging from initial diagnosis to full engagement in care including viral suppression. The HIV “cascade,” is a ubiquitous model used in engagement in care research that outlines essential elements for successful treatment of HIV-infected persons (Figure 1). More specifically, it depicts timely diagnosis, linkage to care, retention in care, initiation of antiretroviral therapy, and achievement of an undetectable viral load (Gardner et al., 2011). Presently, it is estimated that of the over one million individuals in the United States who are HIV positive, approximately 82 percent have been tested and have had at least one HIV care visit, and 66 percent have been linked to HIV care. Merely 37 percent of these engage in regular HIV medical care, 33 percent receive treatment, and 25 percent attain an undetectable viral load (Centers for Disease Control and Prevention, 2011). While in past years a tremendous amount of research has been dedicated to medication adherence, the focus on effective linkage, engagement, and retention in medical care within the HIV community has been relatively limited.

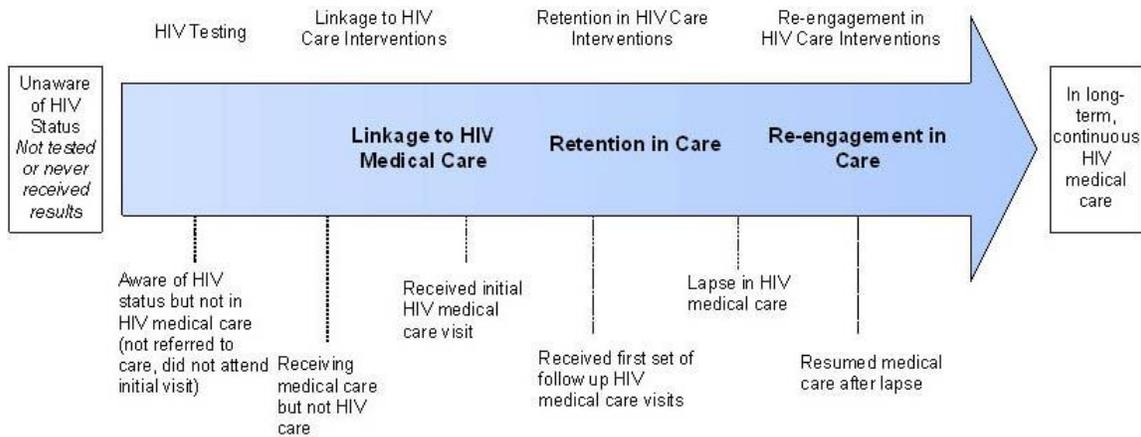


Figure 1. The continuum of engagement in HIV medical care

Source: Adapted from Health Resources and Services Administration, HIV/AIDS

Bureau. Continuum of engagement in HIV care. Cheever LW. Engaging HIV-infected patients in care: their lives depend on it. *Clin Infect Dis* 2007; 44(11):1500-02.

Thus far, researchers have directed their studies toward the specific stages portrayed on the spectrum of engagement, focusing on linkage, retention, and/or re-engagement in care, in addition to barriers to care. However, a patient’s location on the continuum of care is not static (Figure 1). The following material will review findings from studies that have investigated the various stages of the HIV care cascade and identify the deficits in engagement in care research that are in need of attention.

Initial Engagement in Care

Effective linkage to care is of utmost importance as a person’s first encounter with the healthcare system may have a profound impact on their decision and perceived ability to pursue consistent medical care. Delayed linkage to care is indicative of poor

health outcomes and has been studied previously with the hope of developing a better understanding of who is at risk for delayed entry into medical care (Centers for Disease Control and Prevention, 2003). Recent findings by Reed and colleagues suggest that delayed care entry was more likely among anonymous and first-time testers. The study results also suggested that men, persons of Hispanic ethnicity, those exposed to HIV through intravenous drug use, and those without insurance were more likely to delay care entry. The authors stated, “Methods for identifying those at highest risk of delaying care entry are increasingly needed ^(p767) and explained that in order to “further evaluate progress toward the CDC goal for timely care linkage, time to care entry should be studied from representative samples, including both those who are receiving HIV care and those who have not entered care after HIV diagnosis ^(p. 771)” (Reed et al., 2009). The study reported here had an objective of obtaining information that could contribute to establishing programs that reinforce more timely linkage to care following diagnosis.

Another provision of information regarding the first stage of the spectrum comes from Naar-King and colleagues, who conducted a study to describe newly diagnosed patients’ retention in HIV primary care and changes in barriers to care over 12 months of follow-up subsequent to enrollment in outreach interventions. They found that adequate retention in care for newly diagnosed patients was significantly associated with reductions in substance use and improvements in insurance coverage. While structural, financial, and personal barriers were identified and addressed in this study population, there remains a need to investigate barriers to care among people who are at different stages of the HIV care continuum and tend to cycle in and out of care (Naar-King et al., 2007).

Cultural and socioeconomic factors have been designated as barriers that prevent people from fully understanding HIV, its implications, and treatment options (Rumptz et al., 2007). A study by Raveis and colleagues examined factors associated with women who delayed seeking medical care following a positive HIV diagnosis through qualitative interviews. The reasons for delay included denial of HIV status, fear and anxiety, lifestyle circumstances such as being incarcerated and poor experiences with the health care system, stigma, and substance abuse (Raveis et al., 1998). The study reported here explored psychosocial factors among both women and men, and obtained information from those who initially delayed care, as well as those who did not but eventually discontinued seeking treatment.

Retention

Once linked to care, the ensuing challenge on the HIV care cascade is to keep patients engaged in their care. An outreach approach was tested to explore the relationship between outreach program contacts and retention in care over a 12-month period (Cabral et al., 2007). The study was conducted among participants in a demonstration project to promote engagement and retention in HIV primary care, the outcome variable being the time from study intake to the first four-month gap in HIV primary care. The results indicated that program contacts were effective in reducing gaps in primary care among hard-to-reach patients with HIV. They found that having at least nine contacts over a three-month period was associated with an over 50 percent reduction in the rate of four month gaps in primary care; a finding that remained after controlling for baseline CD4 count. The authors specified that accompaniment to HIV primary care visits appeared to be the factor most strongly associated with retention in care for the

participants in the Outreach Initiative. Finally, the authors suggested that those who work with similar populations are encouraged to continue their efforts in promoting retention in HIV care.

Another attempt at understanding the engagement and re-engagement stages of the spectrum was a cross-sectional study that examined barriers to engagement among people who were aware of their HIV status and were not newly diagnosed (Tobias et al., 2007). This study was conducted to investigate differences between people who self-reportedly had no care for six months prior to an interview versus those who had some care in the past six months. The study results revealed that those with no care had significantly poorer mental health status, were more likely to be active drug users, and had more unmet support service needs than those with some care. The prevalence of negative health beliefs, such as the belief that there is no cure for HIV or lack of trust in the medical care system, was also higher in the no care group. Before designing interventions there are still gaps in the research that need to be addressed.

The health care system and policy factors are additional aspects that play a crucial role in engagement in HIV medical care. Mugavero and colleagues stated that “The programmatic distribution of funds between and within federal agencies supporting HIV testing, prevention, treatment, and supportive services needs to reflect the current patient profile and geographic distribution of the epidemic” (Mugavero et al., 2011). Recommendations in the article for improving engagement in care include surveillance and evaluation, information/education, resource allocation, and “Testing, Linkage to Care plus,” where the “plus” equals antiretroviral therapy service delivery. In order for this approach to work, however, it is imperative that the structural, personal, and financial

barriers to care are fully understood, broken down, and obviated for the future. The patient level data obtained in this study will hopefully contribute to the understanding of these barriers so that engagement and retention in care may be conceptualized within a framework that provides an organizing structure for understanding the factors associated with transitions into and out of medical care.

Transition

The progression of patients from not being engaged or only somewhat engaged to becoming fully engaged in care was the focus of a study that concentrated on socially marginalized HIV-positive persons (Rumptz et al., 2007) . The subjects in this study were part of the HRSA-funded multisite Outreach Initiative and were enrolled because they were not fully engaged in HIV primary care or were at risk for falling out of care. The “somewhat engaged in care” group was defined as having less than two primary care visits in the past six months, or two or more missed visits. For the analysis, the “not engaged in care” group was combined with the “somewhat engaged” group to reflect a sample that was “not fully engaged in HIV primary care.” The data were collected from face-to-face interviews and medical chart review. Of those who were not fully engaged in care at baseline, 58 percent were engaged in HIV primary care at 12-month follow-up. In the final model, discontinued drug use, decreased structural/practical barriers, decreased unmet needs, and stable belief barriers over 12 months were significantly associated with engagement in care. The authors state that “the effectiveness of these interventions indicates that additional work is warranted to reach and engage the 42% who did not become engaged.” The study reported here was designed to provide

information to fulfill the gap in knowledge through investigation of other possible factors that result in incomplete and inconsistent engagement in care.

There is a great need for a better understanding of the reasons why patients are inconsistently connected to the health care system and what they claim will be most helpful in managing their care. Perhaps the biggest gap in current research is the lack of understanding of what occurs during the transitional stages on the continuum. For instance, why newly-diagnosed HIV-positive individuals delay an HIV-related medical appointment; the causes and motivation of what eventually brings people into care; the reasons why people fall out of care; and finally, what characterizes the transitional period from being out of care for a substantial amount of time to the point of re-engagement. This study addressed what is yet to be implicitly understood in terms of the transitional states of engagement in HIV-specific medical care. The ultimate goal of this work is to identify modifiable factors that could be developed into interventions to improve engagement in care, which would be tested in future investigations. This study is distinctive in that subjects were not asked if specific factors have contributed to their care, nor were they prompted by standardized instruments. Rather, they were asked open-ended questions about what has kept them engaged or non-engaged in the past, and had the opportunity to answer freely for an agnostic approach of theory development.

CHAPTER 3 METHODS

Project Design

This project involved the collection of qualitative data via interviews with HIV positive persons in order to obtain information on factors related to the transitional states along the continuum of engagement in HIV primary care. Information was collected using semi-structured, person-level interviews, which were subsequently transcribed and thematically coded using the grounded theory approach.

Qualitative Methodology and Analysis

Qualitative research is that which produces findings not arrived at by statistical procedures or other means of quantification. It can refer to research regarding people's lives, experiences, behaviors, emotions, and feelings, as well as organizational functioning, social movements, cultural phenomena, and interactions between nations (Strauss, Corbin, 1998). One approach to qualitative research is called grounded theory, which is defined as theory that is derived from data systematically gathered and analyzed throughout the research process. Grounded theory is characterized by the lack of hypotheses or preconceived ideas. Instead, research is conducted in a specific field of study and any new concepts are those which may emerge from the collected data (Strauss, Corbin, 1998). In this case, any potential theory was generated from the information provided by the subjects. Their experiences served as the basis for the information, which was then independently coded by members of the research staff in order to identify, develop, and relate concepts for the formation of a thematic framework.

Coding refers to the process by which Dr. Gerkovich and I carefully reviewed the transcripts for themes, assigned themes to categories of engagement, and related them to form a thematic structure. Six thematic categories emerged and each of these is comprised of subthemes that more explicitly define the themes as they were described by the participants.

There are many known factors related to engagement in care, some of which are barriers and facilitators, the former being anything that hinders the accessibility of medical care, and the latter being anything that assists in the process of attaining medical care or that which makes it easier. This study was designed to allow the subjects to elucidate the barriers and facilitators in their personal experience of having HIV and managing the appropriate medical attention.

Dr. Karen Williams, a research methodologist, provided educational materials and training to study staff in conducting interviews and eliciting honest and thorough answers by application of open-ended questions, prompts and probes, and reflective listening techniques. This approach served to aid study staff in their ability to fully explore a variety of aspects that may impact engagement in care.

Dr. Williams was also responsible for conducting the formal audit trail, which is traditionally performed to ensure validity of the findings. Validity refers to the dependability and trustworthiness of the findings and their ability to be generalizable to the population as a whole.

Sample

Patients from the Truman Medical Center Infectious Diseases clinic (TMC) who are HIV positive were informed of the study by clinic staff that perform retention

tracking and contact activities. Patients who are known to either be currently out of care or have had periods of non-engagement in care were given the names and phone numbers of the project staff so they would contact them to inquire about participation. Flyers providing basic information about the study, including names and contact information of study staff, were posted in the clinic, as well as in the Kansas City Care Clinic, another major provider of medical services for HIV positive patients. An additional resource was the Kansas City Missouri Health Department HIV Surveillance Unit, which tracks individuals who have been diagnosed with HIV as well as their care history, i.e. lost to care or never in care. Eligible participants must have been at least 18 years of age, able to provide informed consent, able to speak and understand English, and have clinically documented periods of non-engagement of at least 6 months' duration. Before a study candidate could be formally enrolled, he or she was screened for eligibility (see Appendix A). Screening questions addressed detailed facts to establish HIV positive status, such as time and place of diagnosis, most recent lab values, and history of engagement in care. The study protocol was reviewed and approved by The University of Missouri-Kansas City Social Sciences Institutional Review Board.

Measures

Upon enrollment, demographic information including gender, age, ethnicity, current living situation, work status, year of HIV diagnosis, and time between diagnosis and first medical visit were collected from each participant before the interview took place. There were three versions of the interview guide (see Appendix B), each of which was adapted to be applicable to one of the three aspects of engagement being addressed (delayed seeking care, currently in care but previous periods of nonengagement, and

currently out of care). The interview guides explored factors of engagement or lack thereof, as well as the transitions that characterize the cycle of being in and out of care. Specifically, the interviews addressed the following: (1) life and health issues that have made it difficult to engage in care; (2) factors that have simplified or successfully encouraged return to care; (3) factors that make it difficult to maintain medical appointments; (4) aspects of familial and community support that have had an impact on engagement in care and overall health; (5) healthcare provider and/or clinic factors that have influenced desire and ability to engage in consistent medical care; and, (6) attitude or beliefs that have contributed toward decisions regarding healthcare engagement.

Procedures

Clinic staff and case managers were consulted in order to identify eligible patients. Patients who had been out of care and were scheduled for a “return to care” clinic appointment were approached during their clinic visit by clinic staff who briefly described the study to them. Patients who were presently engaged in care but had lapses in the past were contacted, either while they were in clinic or by phone, and given a brief project description. Those who were interested in learning more about the interview study had the option to either give permission to be contacted by project staff or call study staff directly. An appointment was set for any eligible patient who was interested in participating and study team confirmed an HIV positive diagnosis and lapses in care through clinic documentation. Flyers explaining the study complete with project staff contact information were posted at the ID clinic and the Kansas City Care Clinic and were handed out by KCMO Health Department staff who work in the field to recruit patients who are lost to care. Study participants were incentivized with a \$50 gift card

and \$5 to cover travel expenses. All recruitment procedures were designed to meet HIPPA compliance requirements.

Once TMC staff and/or the KCMO Health Department had recruited a study participant, the author obtained informed consent (see Appendix C), demographic information (see Appendix D), and conducted the interview. Interviews were recorded with a digital recorder and labeled with a study ID number that did not compromise the patients' identity. Payment was awarded and the audio files were immediately sent to the transcriptionist. Field notes were used to document emotions (i.e. crying) and to compensate when the participant was inaudible or outside noise would compromise the clarity of the recording.

Interviews and thematic analysis continued until the study staff agreed that saturation had been reached (the point at which no new information seems to emerge, or even if it does, is not yielding any additional insight at that point in time) (Corbin, Strauss, 1998). A total of 22 interviews were conducted and analyzed. To reconcile the findings, study staff met to thoroughly review each transcript and confer the reasoning for assigning text to specific thematic categories and subthemes. Each theme assignment was discussed and mutually agreed upon before final analysis. It was originally estimated that as many as 45 interviews might be needed based on the expectation that individuals would be recruited based on whether they had been late initiating care, had dropped out of care and were just returning to care, or they were currently in care and had previously been out of care. In contrast to this expected differentiation among study subjects, it became clear during the interviews that many individuals fell into more than one of the distinguished categories and were able to provide insight into their experiences of

engagement or lack thereof at different points on the continuum of care. Upon coding and analysis the study team disregarded the group placement in order to analyze the data in a more holistic fashion.

CHAPTER 4

RESULTS

The sample consisted of 22 HIV positive persons, including ten women, eleven men, and one transgendered individual. Forty percent of participants identified as White and 50 percent identified as Black; 14 percent identified as Hispanic. The mean age of the participants was 45 years with a standard deviation of 11 years. The time since diagnosis ranged from 2 to 26 years, with a mean of 12 years and a standard deviation of 7 years. Twenty-two percent (n = 5) of participants have been living with HIV for over 20 years, which is valuable as they were able to provide meaningful insight into their experiences along the continuum of care. With respect to employment status, eighteen percent receive SSI or a disability check, 22 percent reported working full-time, 27 percent reported working part-time, 9 percent reported not working but currently looking for employment, and 22 percent reported not working and not currently looking for work.

Six major thematic categories emerged and were related to engagement in care, and specifically, the transitional states of engagement as are represented by movement along the continuum. Each theme describes the nature of the reasons for an individual's level of engagement and is comprised of subthemes that define the issues more specifically. The themes are as follows: *Health Factors*, which includes the subthemes health problems, health perception, health is OK, integrate HIV care into primary care, desire for positive health status, and taking care of routine medical care; *Resources*, which includes financial and insurance issues, housing, employment status, and logistical complications for acquiring services; *Support Factors*, which includes access to information and education, case managers, family and friend support, requirement to

keep services, and support programs; *Personal Factors*, which includes recognition of status, domestic issues, concern for future health, impact of stigma, and mental and emotional stability; *Treatment Factors*, which includes burden of treatment and effects and expectations of antiretroviral therapies (ARVs); and finally, *Clinic Factors*, which includes patient-provider relationship, follow-up/outreach by clinic, lack of coordination concerning meds, and scheduling. The following tables provide examples directly from the interviewees that illustrate their reasoning and circumstances as they pertain to phases of engagement, specifically, diagnosis, initial engagement, in care, disengagement, out of care, and reengagement. The entries in the tables are quotes from the interviews; any names that appear in this material have been changed from the name given during the interview to ensure privacy is maintained.

Table 1: Health Factors

Health	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
<i>Health Problem</i>	<p>"I have sinus problems and I was having problems like breathing. My nose was all stopped up. And I knew I was not feeling good and I needed to go to the doctor for that. I don't think it had anything to do with my HIV. It was just that I was so congested. And once I got there, you know..."</p>	<p>"I can't work anymore because I have so many different kind of things that's wrong with me now."</p>		<p>"I felt bad. I could tell the difference, not having my meds. I got sick a lot, with colds and stuff. I was going into [the] emergency room and then [another] emergency room and they were giving me the same diagnosis with the same prescription...and they kept on telling me, you need you to ahead and get care. You know what? I wasn't going ahead and getting care."</p>	<p>"And then usually something physical would break down that would cause me to go back to the hospital or just feel bad and I would come back into treatment."</p> <p>"I started getting, I guess you call lesions or spots on my face and stuff and someone told me that's from neglecting, not having my meds and stuff, and I had started getting sick so I came and started to get help."</p>
<i>Health is Okay</i>				<p>"Then there was a period of time where I didn't feel like I really needed to come in because I felt good and Walgreens was mailing me my meds."</p> <p>"After that happened, a day went by and oh yeah, I'll go in the next day, or I'll go in the next day and it just became one of those things where eventually I was like, it's not affecting me right now personally so I don't feel like I need to go in. I eventually just kept putting it off."</p>	

Health	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
<i>Health Perception</i>		<p>“That way I don’t become immune to the medications and I have all kinds of options if I my counts go really low and get sick again. I have all kinds of options.</p> <p>No, as long as I stay on top of my meds and stay into my care, taking care, stay on top of everything. No, I can live a normal life just like anybody else. I believe that.”</p>		<p>“And before I got care I didn’t really feel like it would cause any health problems, other than those staph bacterial infections but yeah, I didn’t really feel like it was going to cause me any problems, as long as I stayed active.”</p>	<p>“I’ve pulled myself up and said, I need to get back into treatment, I need to get well. I’m tired of being sick, I’m tired of being tired and I’m sick and tired of being sick and tired. I have a grandbaby on the way and I don’t want to be sick, I want to be able to hold her and take care of her. I have two grandchildren as it is that are great and wonderful but I want to be able to get out and play with them. I want to be able to see them graduate from high school.”</p>
<i>Integrate HIV Care into Primary Care</i>		<p>(Regarding suggestions for clinical care) “And find a way for the mental health professionals and the physical ones to come up with a plan for people who are newly diagnosed.”</p>			
<i>Routine Medical Care</i>					<p>(When asked why she returned to the clinic) “And it has to do with my mammogram’s is due, do I had to do that. It’s like yearly maintenance stuff.”</p> <p>“I haven’t had blood work done. I’ve been in the hospital twice because my diabetes. It’s just all this stuff that I need to get.”</p>

Health	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
<p><i>Desire for Positive Health Status</i></p>		<p>"It's something I would have to do. I think that kind of philosophy has to do more with my age. I'm older and if you want a good life and you want to live this much then this is what you've got to do so much buckle up and get it done." (Regarding taking HIV medication).</p>			<p>"Finally I just said I've got to go back in because I've got too much to live for, so I just decided I'd better come on back and get care. Ever since then, I've been coming, I've been doing better."</p> <p>"I want to try to stay as healthy as I can. I know the only way I'm going to be able to is to try to get back on my meds. Make sure I can do what I need to do. Kind of hope and pray that I can survive long enough where they can find a cure or something like that for it."</p>

Health factors (shown in Table 1) were associated with initial engagement, in care, out of care, and reengagement. Ten out of the 22 participants reported that health problems, such as acute illness or other chronic conditions such as diabetes, led them to reengage after being out of care for at least six months. However, even illness and multiple hospital visits do not always serve as an immediate impetus for engagement, nor do they always have the sort of lasting effect to keep individuals permanently engaged. Seven participants reported being out of care for at least six months because they felt healthy and therefore did not feel a need to see their HIV provider. Health perception played an interesting role in engagement as well. Multiple participants expressed the understanding that staying engaged and adherent to their medication regimens would allow them to live normal, healthy lives while in care. One participant explained that while out of care previously he did not feel that HIV would cause any problems other than recurring staph infections and believed that staying active would keep him healthy. Five participants described the desire for positive health status as their motivation for being in care, and eight participants said that a desire for positive health status is what brought them to reengage. Routine medical care is what brought one participant back to the HIV clinic after a year of being out of care, as she was aware of her need for an annual mammogram and blood work for diabetes mellitus.

Support factors (shown in Table 2) was the second most coded thematic category, and family and friend support was the most frequently reported subtheme. Nineteen out of 22 participants remarked that family and friend support contributed to their ability and/or desire to remain in care. Not surprisingly, loss or lack of family and friend support was associated with disengagement or being out of care, as was reported by seven participants.

Table 2: Support Factors

Support	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
<i>Case Managers</i>	“When I talked to [the case manager], all that fear was just gone. He said we got this; we’re going to take care of you. I instantly just wasn’t afraid anymore. Okay, he’s got my back, we can do this.”	(Regarding transportation) “The case workers help with that. Without that line of support, I wouldn’t be able to make it, I don’t think.”			“A case worker actually came by my house and sat down and talked to me there. Gave me bus passes to be able to make it to my next appointment, which I didn’t think they were able to do, could do, anything like that. That actually helped me. People stepping out of their work areas just to comfort me. It helped a lot.”
<i>Family and Friend Support</i>	At that moment I didn’t have a catalyst for it and [my friend] was the catalyst. He set everything in motion. Him taking care of himself and reaching out to me while doing so really just set everything into motion.	“I think if it wasn’t for my wife I wouldn’t make it. At first I looked at it like [she was] pushy. Eventually yes, it helped and right now it’s probably the best thing that I’ve ever had, support from my friends and family and [the clinic].”	“With the loss of support through friends and family, it made me decline in health. I didn’t want the support that was given to me through [the clinic]. I ended up stopping my medication myself and not telling anybody, not showing up to appointments.”	“I’m sure everybody’s different but to me, if you don’t have ... it makes things really, really difficult and it does have a snowball effect.”	“Mom was like, look boy, I’m tired of keep on going down here to get your prescriptions filled. You need to go in and get your care. She just really was concerned about my health in general. She didn’t want to see me deteriorate.”
<i>Support Programs</i>		“That in my case, as a married person that has caught HIV, not knowing which side it’s from, it’s good to know that there are people that are willing to help us. That’s been a good, good factor. I honestly didn’t know that all that resource and support was out there.”		“But if someone like you came into my life and was sitting there giving me things to think about while I was infected—and nobody ever did that. Nobody ever gave a crud. I felt like nobody cared.”	“I got into a ladies support group that was for HIV women. I never stopped trying to get information to educate myself.”
<i>Access to Educational Information</i>	“I talked to someone afterwards. They were telling me, we offer this, you can come in for counseling, you can set up for medical services here, we can do the Ryan White program.”			“But it was a total adherence class. It was a six or eight week program where all you did was go in and study your disease. And it totally opened my eyes to everything.”	

Case managers proved to be quite efficacious in engaging individuals and providing them with the support and guidance necessary to not feel helpless, to be successful in navigating the health care system, and to be set up with services. Seven of the 22 participants expressed not only their gratitude, but also their reliance on case managers' help.

Support programs provided a curious dynamic, as two participants spoke of their high regard for specific support groups and the level of education they provided during a period in which the patient was not engaged in care. Ten participants who were in care stated that support programs, ranging from emotional support to assistance with food and other basic needs, have greatly helped them in the past and/or presently help them to remain in care. Several participants expressed the desire to join a support group but experienced difficulty in doing so. For example, one participant who was presently in care but previously out of care said he has had trouble finding a support group for straight men. Another participant who had returned after a year of being out of care and lives in a suburban area said it is difficult to find support groups outside of the urban core.

Table 3: Resources

Support	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
<i>Employment Status</i>			<p>“Then I went off treatment because I’d lost my job again at that time and that was probably about 10 years ago or more. I lost the doctors that I was going to and then I don’t remember what happened.”</p>	<p>(In response to lack of insurance through work) “The financial end of it, what I found by contacting companies, with my salary at the time. I’m unemployed now but at the time, they were able to offer something. I don’t think I encountered any of them that weren’t in some way accommodating in a kind of narrow way. I don’t know the exact cost of these medicines but they were thousands of dollars a month and 15% off that is... you might be trying and as helpful as you may be, it’s not feasible.”</p>	<p>“In the meantime I lost my job, which sounds like a horrible thing but in reality it is the only reason I’m back here. Otherwise I would still have no services.”</p>
<i>Housing</i>		<p>“Because before this six or seven year gap, I was making my appointments regularly, even being homeless. You know, I was making those.”</p>		<p>“And it wasn’t that I didn’t want to go to my appointments. I did know how important that was. But at that particular time I was trying to find some type of way to get myself back from being homeless. I would schedule an appointment then something would come up.”</p>	<p>“And what changed was I finally got stable housing. That’s what changed. I was offered a transitional living program through Restart.”</p> <p>“Like I said, the things that keep me going as far as even if they see me only once a year, is that I’m involved in the [Ryan White] program very, very little. But they have a lot to do with my housing.”</p>

Support	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
<i>Logistical Complications</i>			<p>“There's a time factor [necessary] to establish all these new services and working full time. More than full time, overtime a lot. You almost need to be unemployed and have all your days free and a secretary to find these services and complete all the paperwork and make sure that you have all the t's and the l's and those sorts of things crossed because you can certainly start over. I find the paperwork inundating, repetitive. Complete and totally repetitive and I'm not sure it needs to be like that.”</p>		

Resources (shown in Table 3) constitute the most fundamental aspects of actually having the ability to access health care. Finances and insurance, primarily, can determine whether a patient believes he or she can even seek care. One participant had no idea he was eligible for services and did not want to spend the money he had saved for college, so he disregarded his HIV status for two years. Twelve participants referenced their financial situation as the reason for being in care, and without financial stability, insurance, and/or help from case managers, they would not be in care. For one participant, losing his job meant that he was then eligible for services that enabled him to be engaged in care, which he could not afford while he worked in a job with no health benefits. When asked about the primary reason for disengaging and remaining out of care, nine participants referenced insurance and/or financial stress. One participant explained that in the past, if he had to choose between paying his electric bill and going to the doctor, paying bills took priority.

Transportation was mentioned by 16 of the 22 participants and was the primary cause of being out of care at some point in time. Several individuals suggested it was the greatest barrier of keeping clinic appointments, and without transportation it is extremely difficult to remain in care. Housing is a major structural factor that can have substantial impact on engagement in care as well. Interestingly, one participant claimed to never miss appointments despite being homeless, but did eventually fall out of care for one year due to homelessness. Stable housing is what led this participant and one other to reengage in their care. This was also motivation for one participant to return to care, as she is reliant on Ryan White for housing. This agency requires clients to keep an annual medical appointment if they wish to remain eligible for housing services; thus, it serves as an incentive to stay in care.

Table 4: Personal Factors

Support	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
<i>Recognition of HIV Status</i>		<p>“Part of that [denial] equation is also my age. Grow the hell up and deal with it.”</p> <p>“I think honestly, because I’m not afraid to die anymore. It really is not a fear of mine anymore at all.”</p>	<p>“I don’t know, I get distracted and I just want to forget [my HIV status]—I’m going to have it forever, just forget it. I got in my zone.”</p>	<p>“And that’s [acknowledging HIV status] why it took me three months to get my first care. I never did accept the fact that I was positive.”</p> <p>“I went into denial actually, for a good 8 years after that. That’s when I had the most trouble with my lab reports and getting to the doctor. That’s when I was missing regimens, screwing them up, missing doctor’s appointments, falling in and out of care because of my fear of [HIV].”</p> <p>“I think I was in the mindset of, if you don’t think about it, you don’t deal with it then it’s not real.”</p> <p>“First of all, was going through a phase of not accepting what I had, the diagnosis.”</p>	<p>“So I just started reading a little bit, just a little at a time. I didn’t want to know too much too fast. You read one thing and it brings up the question of another and you start looking at it. Before you know you start getting involved in it. I’m a reader. I think I have good cognitive ability so the more I started reading, the more the neurons were snapping into place and oh, okay, let’s do this, let me see.”</p>
<i>Domestic Issues</i>		<p>“I have my nephew now, my little sister has passed and I have him now. That’s a motivation.”</p>		<p>“Yes, and now I’m dealing with my mother who has dementia. It is definitely overwhelming. I have a lot of issue at home, other than just me being sick.”</p>	<p>“I have an 8 year old son. He’s going on 9 in October. I haven’t seen him in 7 years. I want to be able to see my son again. I want to be able to be alive and somewhat healthy so I can manage that, taking care of my son.”</p>
<i>Impact of Stigma</i>	<p>“You just walked into the building and hoped that you didn’t see anybody that you knew. And if you went in there and didn’t see anybody you knew, you were safe. If you walked in there and seen someone you knew—it was like if you don’t tell anybody I won’t.”</p>			<p>“Through my experience, I’ve come to realize how much stigma is involved...and why we don’t want to tell anybody, why we go into isolation, which then leads to not wanting to take your meds.”</p> <p>“The stigma . . . many diseases don’t kill people; it’s the stigma that does. They don’t want to take their meds, they don’t want to go to the hospital, they don’t want to believe it.”</p>	

Support	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
<i>Mental and Emotional Health</i>		"A positive attitude has a great deal to do with a whole lot of this. Because once fear comes in, it's over."	"But when you push [your appointment] a couple of weeks out, either something will come out or I'll lose interest or another reason why. Then I have right back to where I was. So it makes it hard to get in [to the clinic]."	"I had got to the point where I had started getting so frustrated and depressed that I didn't want to be bothered with people, at all... That played a big part too, to where I just didn't want to be bothered with people. I wouldn't even come outside."	"Mentally it got better as far as I was strong enough mentally, to go in [to the HIV clinic] and try this again."
<i>Substance Abuse</i>		"But currently, I do kind of use, not on a day-to-day basis but probably weekly."	"So after I had [my son] I quit coming to get care. That's when I was on drugs real bad so that's what made me stay away."	"I stopped prostituting but I never stopped using drugs. So my drug use has been one of the key factors of me not getting the medical care that I need." "I just felt like I was getting out of hand [using alcohol]. I was not doing what I was supposed to do." "I was drinking and drugging and didn't feel like going [to my HIV care appointments]."	

Support	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
<i>Concern for Future Health</i>	<p>"I just watched a friend of mine die [from HIV] and I didn't want to die, so I went and talked to [my doctors]."</p>	<p>"The fear is always there that it can turn for the worse."</p> <p>"But then when you get here, the overwhelming part of hearing your status sometimes can be overwhelming to a person to where they scare themselves from coming back again because they're afraid it's going to get worse the next time. They psych themselves up for more horribleness than what really could be."</p>		<p>"I work in a gay bar and I listen to all these stories of people about when [HIV] first came out, the friends they lost, the stories they had to tell and knowing that this has become part of my history. It is part of my history. I am gay. I should be concerned, not just for myself but for those people around me. The friends that they lost, all the efforts they put to take care of their friends during that time."</p> <p>"The biggest thing I can say that is a factor, is the fear of you don't want to walk in that office and be told, okay, you're getting ready to get really, really sick here in a couple of months. Or, we can put you on these meds but it probably won't do any good. That fear, I think would probably be one of the biggest driving forces of people not [wanting to seek care]."</p>	<p>"Yeah, [my brother] is five years older than me and [his MI] scared me. I can't go on like this; I need to start taking care of me."</p>
<i>Using Previous Success to Motivate Health</i>					<p>"You build on your success. In the beginning I didn't have a lot of success so it was slow; it was like a rolling ball down a hill. So the more success I have, the more years, the more things I'm conquering, the bolder and stronger I've become to know, hey, I do have that strength and energy. I do have resources, I can do this, I've done it before, I'll do it again. So that makes it easier as far as reaching that goal and knowing how to make the appointment and knowing how important it is."</p>

Support	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
<p><i>Feeling Overwhelmed and Vulnerable</i></p>			<p>"[After my diagnosis] I freaked out and quit my job of 21 years that very night."</p>	<p>"I didn't seek any type of medical treatment or anything for a while because I took a while to process [my HIV status]. My first problem was how was I going to deal with my family."</p> <p>(In response to learning about his HIV diagnosis)"This is a lot of stuff, I don't know. I'm that smart. So then I just went home and isolated some more."</p> <p>"Trying to figure out how to tell my family [my HIV status]. I didn't know how far the information was going to go at the time. I didn't know what they were going to do with the information. I was real leery and just one of those people who were in the back of the room, having questions but didn't know what to do or how to go about it."</p>	

Personal factors related to engagement in care are shown in Table 4. Recognition of one's status was found to have both positive and negative impact on engagement and was also a theme that occurred related to a person's reaction to being told of their diagnosis. Seven participants admitted that denial of their HIV diagnosis kept them out of care for extensive periods of time. One participant explained that he became disengaged because he wanted to forget he is HIV positive. In contrast, acceptance of HIV status led three participants to reengage and stay in care.

When participants were asked directly what had kept them out of care presently or in the past, six women stated family or domestic responsibilities either took precedence over doctor's appointments or distracted them enough to remain out of care. Another common sentiment expressed by women participants was the desire to ensure their family was taken care of in case they were to experience poor health outcomes. However, two male participants stated that their reasons for reengaging and being in care were to be alive, well, and engaged in the lives of a nephew and son, respectively. In addition to domestic issues, the impact of stigma was reason enough to keep six people out of care.

Compared to women, men seemed to lack motivation for engagement and had a greater degree of difficulty articulating their reasons for being out of care and/or returning to care. While ten participants, including both genders, expressed being afflicted with mental and emotional instability, male participants seemed more severely affected by loss of loved ones, which they expressed contributed to their deficiencies in engagement.

Three participants reported substance abuse as a reason for disengagement. One participant acknowledged that after her son was born she started using again and that was what led her to be out of care. A husband and wife who were interviewed independently

both admitted to using drugs while out of care attributed their absence from care to the fact that they did not want the drugs to show up in a urine analysis, so they postponed appointments until they thought their systems were drug-free.

Table 5: Treatment Factors

Support	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
<i>Burden of Treatment and Diagnosis</i>	<p>“Probably that they had some medicine that I can take that I didn’t have to take a whole bunch of pills. When they showed me that, you know I couldn’t see taking some of them . . . Six pills in the morning, six at 12:00 and six before you go to bed...”</p>	<p>“Taking medication] is stressful, it’s a pain, it’s every day and I think that’s why, rather than take the medicine because of HIV, I get overwhelmed and sometimes you just wish . . . I remember when I didn’t have HIV. Right now my regiment, I take one pill because they combined them so that’s better than what I used to take before. I used to take a lot of pills, about 12, 14 pills.</p> <p>“...one time, I had to take 6 [pills] but it was twice a day. Six or 7 twice a day so a lot of pills. Sometimes you want to forget about taking pills but some days you can’t.”</p>	<p>“[I] kept making excuses. Frustrated. Didn’t want to go because I kept having other appointments and it seemed like [I] was up here every other day and I just got tired and didn’t want to come no more.”</p>	<p>“Just the fact that you’ve got to take a lot of medicine...makes it a little stressful.”</p>	
<i>Effects and Expectations of ARVs</i>	<p>“Then by ‘92 it seemed like things had changed [in HIV treatment]. There were some new meds and all that and that’s when I got into treatment.”</p>	<p>“The newer medicine is better because you don’t have to take it as often, it seems like it works a lot faster, a lot better. The old medicine was hard on you because it was hard on your liver and your kidneys and stuff like that.”</p> <p>Definitely, definitely. Because you feel the difference when you’re not taking them for a couple of weeks or even a month or so. Then when you get back on them, you do feel the difference, you know it’s really tiresome to your body when you’re not on your meds and you don’t take it. Then it’s tiresome when you are on your meds. But you’re more functional when you take your medication. Excuse me, I would say I’m more functional when I’m taking my medications than when I wasn’t.</p>	<p>“I aimed it at exactly two weeks and I ditched the pills. I ditched the program.”</p> <p>“Before the side effects were bad. Now that you mentioned it that was one of the things that kind of kept me out because side effects were really severe.”</p>	<p>“I kind of heard there was the AZT and I also knew there were a lot of issues with that. When I first got diagnose I figured, I’m not going to think about it because I have no recourse.”</p> <p>“Today they’re awesome. Today’s cocktail, I take three pills one time a day. No side effects. Awesome. In fact, they are so awesome that’s why it took me a year to get here. Because I take my pills, I feel great.”</p>	

Burden of treatment refers to the workload of health care as well as its impact on patient functioning and well-being (Eton et al., 2012). This burden is often associated with the effort and ensuing stress that many patients experience when attempting to remain fully engaged in care, especially those with chronic conditions that require frequent appointments, labs, and daily medication. Treatment factors are shown in Table 5. Five participants explained that the burden of treatment is what kept them out of care for some time, and seven participants who were fully engaged reported a sense of burden that accompanies the responsibilities of patients who attempt to adhere to the health care regimen expected of HIV positive patients.

Effects and expectations of antiretroviral medications (ARVs) play a considerable role in the lives of HIV patients. While to some people taking medicine every day is relatively easy and worth the positive effects, to others it is burdensome and a reminder of their HIV status. Three participants admitted avoiding HIV care for several years upon diagnosis because of the reports they had heard regarding the side effects of AZT, the only available drug at the time; they reported being excited to engage when alternative drugs came on the market. Many patients, however, still experience a myriad of negative side effects with ARVs, which three participants reported as reasons for being out of care. In contrast, one participant stated that he was out of care for one year because his ARVs worked so well that he did not feel the need to make appointments.

Table 6: Clinic Factors

Support	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
<i>Clinic Factors</i>	<p>"[Clinic staff asked] is it okay if we give your number to one of our people here and they can contact you and keep in touch with you, see how you're doing? I was like yes, absolutely."</p> <p>"Everybody was real nice. Everybody was pretty persistent, which was great."</p>	<p>[...it's very positive, warm individuals, people that show they care, not just because that's their job title. They're doing it out of the kindness of their heart, so yes, [the clinic is] a very wonderful place to be and get the support from."</p> <p>"[There is a need for] more doctors, or even if they had a private office or whatever. And another thing that gets me too, you have a doctor . . . I know this is a study hospital, sometimes when the doctor comes and sees you, you want to talk to the doctor. You have four people come in before the doctor. The doctor will be in, in 10 minutes. I told four different people the same thing so when the doctor comes in, they should have already wrote that down and informed him when they come back in..."</p>	<p>"A simple thing as they don't call you back can run me away. I feel like why am I chasing down somebody to get an appointment?"</p> <p>"Any kind of change [in the clinic] can throw me off though; it can even be a front desk girl."</p> <p>"Then when I did keep the appointment, I went over there it just took so long a couple of times and I just left."</p>	<p>"I would call [to make an appointment] and say, I really need to get in. I haven't seen my doctor in a year, I really need to get an appointment, but all you get is voice messages and nobody calls me back. By the time I get a call, they're nasty with me because the last call wasn't too friendly."</p>	<p>"This time I went back to the clinic, there was even more support than what I had before. It actually worked. I had a support group so strong to the point that now I don't want to miss nothing. I'm staying on top of things."</p>
<i>Patient-Provider Relationship</i>	<p>"All the nurses, all the staff was real nice. They went over and talked me through everything. If I was concerned about anything, did I have any fears, was I confused about anything? And then telling me that they'll get on the phone, make sure I've got my meds when I need my meds..."</p>	<p>"I had [my doctor] ever since. I prefer not to change. He's been there for me."</p> <p>"...when I do come I love my doctor. He's really great. He takes time with you, he explains to you, to where you can understand. I love my doctor..."</p> <p>"But the people here in this clinic have been so wonderful, so helpful, so demanding on me to do right for myself that it's overwhelming, it really is. I didn't care about the things I care about until now."</p> <p>If I didn't have the relationship I do with [my provider], I would probably not be in care at all.</p>	<p>"[She] went to a private practice so I had to seek somebody else. That will throw you out of care because you had connected with somebody and now they can't see you. You feel like it's personal but it's really not, but you feel that way because I feel like I was connected to her."</p>	<p>"I thought I had a good rapport with [my doctor] but I never heard from him. At that point, it was at [the hospital], [the hospital], the Infectious Disease Department. So, I thought well, they're not concerned. I'm feeling fine. Oh, well, if I heard from them, I probably would have done something. Whatever they urged me to do, probably."</p> <p>"It's bad enough taking the meds and knowing all this, but to talk to your doctor and sometimes feeling that you maybe let them down</p>	<p>"And they told me, you've got to go back to see a doctor. I had no problem with that. And I was glad I was able to see the same doctor, come back to the same clinic."</p>

Support	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
		<p>No, because coming to [the clinic] with [my doctor], I'm comfortable with him. When you come in he makes you comfortable. He makes sure that you're okay physically, mentally, everything.</p> <p>You feel like you know them then. You can say "my doctor" instead of "the doctor."</p>		<p>because you're not doing as well and you have to confess to them. Have you been taking all your meds? And you have to lie to them or hear the reply of, whatever it's going to be. Most people at least me, you get kind of a rapport with your doctor; you feel they're saving your life and all that. So you don't want to let them down."</p>	
<i>Follow-up/ Outreach by Clinic</i>	<p>"The only reason I went in in the first place is because I got numerous letters in my mailbox and the phone calls. They were all filling up my mailbox, voicemail. Okay, go in; get this taken care of so I don't have to put with this anymore."</p>	<p>"[The clinic staff] don't do a follow up. I think maybe more than one phone call."</p> <p>"More contact notifications might keep people more engaged in their care."</p> <p>"[The clinic] thing should be how is it that I can get you to come? Would you like this and that? Would you want a call? Can I call you in a week or two and we'll just work on up until we make sure that you're here at your appointment. Do you need transportation?"</p>	<p>"On my own, I felt like I was given a death sentence [when diagnosed with HIV]—and I really didn't care. But if they had took me, I probably would have. But because they let me go, I didn't care."</p>	<p>"No phone calls, no emails, it was one of those things where I felt like you go and get tested and they say they'll do this but there was no follow up."</p>	<p>"Plus [the clinic] called me one time to remind me I had to make an appointment. Even though I didn't answer, I heard the voicemail."</p> <p>"[The clinic staff] called twice. It's helpful even when they called. It's more helpful when they call you twice."</p>
<i>Lack of Coordination Concerning Meds</i>		<p>"The doctor should have a chart like this and they should be able to say, by you having this insurance, let's see what medication will be covered and let's see how this medicine don't work, if this one don't work, we'll try another one that's listed on there. If that don't work, then we can write a specialty request, stating that you need this kind of medication and we're going to waive this where you can get this."</p>	<p>"One reason was my medication, my Medicaid Standard and your insurance, you may have the medications or whatever and probably be doing good for a certain length of time and then always you need a second authorization."</p> <p>"Now you're on a medicine, you're missing two or three days, you're waiting on authorization to come back and you find out your Medicaid</p>		

Support	Initial Engagement	In Care	Disengagement	Out of Care	Re-engagement
			<p>won't pay for it. You have to track your doctor down for him to rewrite something for you that's similar or cheaper. And you have these different programs, sometimes you don't qualify because you have an income and they're saying you have to pay so much money. Nobody has \$1200 for one certain medication. Nobody has \$600 for that so what do you do? What's the point of me still be coming and I can't afford it and every time you ask for help you get frustrated and the resources that you send that you got, they're not really there."</p>		
<i>Scheduling</i>		<p>"In the past, what made it difficult would have been scheduling and working and taking off from work. When I first started on the stuff, I had to have at least monthly appointments for blood draws. Sometimes it was a week before the appointment. So it was all a matter of scheduling, getting back and forth, and the time off from work and explaining all that. That was kind of difficult."</p> <p>"I'm on disability now, so I have the time to schedule appointments."</p> <p>"You have to go see your doctor. In this case, you've got three good doctors here. They're booked up. Now [my doctor] is booked up until November. It's August. How is that possible? Nobody else can write his scripts for him. He does it on his own. So you have to come in and see him."</p>	<p>"But when you push [an appointment] a couple of weeks out, either something will come out or I'll lose interest or another reason why. Then I have right back to where I was. So it makes it hard to get in there."</p>	<p>"[My employer] didn't let nobody take time off. I had to miss some appointments."</p> <p>"[The scheduling is] the main problem, and getting off of work. Yes. The main thing with her would have been the hours of the clinic."</p> <p>"I had started another department at my job so it was kind of hard to take off and then I think [my doctor's] schedule, he started going, I'm not sure, he was working at another clinic too so it was always full."</p>	<p>"I think it was more of a commitment issue of just keeping that schedule, for me."</p> <p>[My work] had a dinner that gave me extra hours so I finagled it with [my boss] that I'm going to work 12 hours this day and I'm going to be late tomorrow. So I literally called and arranged that to that specific day."</p>

Clinic factors are displayed in Table 6. A patient's experience in the clinic seems to have the ability to make or break his or her decision to stay in care. Experiencing positive interactions with the staff and providers and being able to schedule appointments were important themes identified for initial engagement, reengagement, and staying in care. The patient-provider relationship was the most coded subtheme across all themes. Eighteen out of the 22 participants reported that a good relationship with their provider was the utmost important clinic factor and suggested that having to switch providers would be a considerable deterrent. However, two participants admitted that being out of care resulted in them wanting to avoid their doctor for fear that the provider would be disappointed with their failure to stay in treatment and take care of themselves. This information suggests that trust and rapport with one's provider and clinic staff is a vital part of engagement in care.

Disengagement and falling out of care was ascribed to lack of outreach and follow-up by the clinic for five participants. One participant expressed the feeling that if the clinic did not appear to be concerned about his absence, then everything must have been fine. Six participants told of their reengagement and ability to remain in care because of outreach by the clinic and multiple follow-up calls.

One patient reported frustration due to the lack of coordination concerning her medications, claiming that ARVs had been prescribed to her in the past that were not covered by her insurance. She held that providers should be aware of what is covered by select insurance companies to avoid confusion and headache for the pharmacy and the patient. For this patient, this lack of coordination added to the burden of staying in care.

Finally, scheduling was defined as a barrier to engagement by 13 participants, two of whom disengaged due to the inability to schedule an appointment at a time that would allow

them to keep their work schedule. Those who work conveyed experiencing exceptional difficulty in making appointments, either due to a lack of paid time off or fear of revealing their HIV status. One participant explained that when he has had to wait several weeks to see a doctor, he has either lost interest or experienced emotional stability issues that hindered him from keeping the appointment. Another patient reported several instances when she had to sit in the waiting room for over an hour and ended up leaving before seeing her provider. There was a consensus that clinics need to accommodate patients with jobs, transportation concerns, and those who need to be able to see their provider in a timelier manner.

CHAPTER 5

DISCUSSION

From the information provided by the 22 interviewees the study team was able to investigate the engagement in care experience from the patient perspective in order to identify themes that constitute the interplay of factors that impact patients' ability and/or decision to be engaged in care. In order to understand the implications of these findings it is helpful to place them in the context of existing information. Figure 2 shows a social-ecological framework that has been proposed to conceptualize the interactions of individual, relationship, community, health care system, and policy factors that influence the processes of engagement in care (Mugavero et al., 2011).

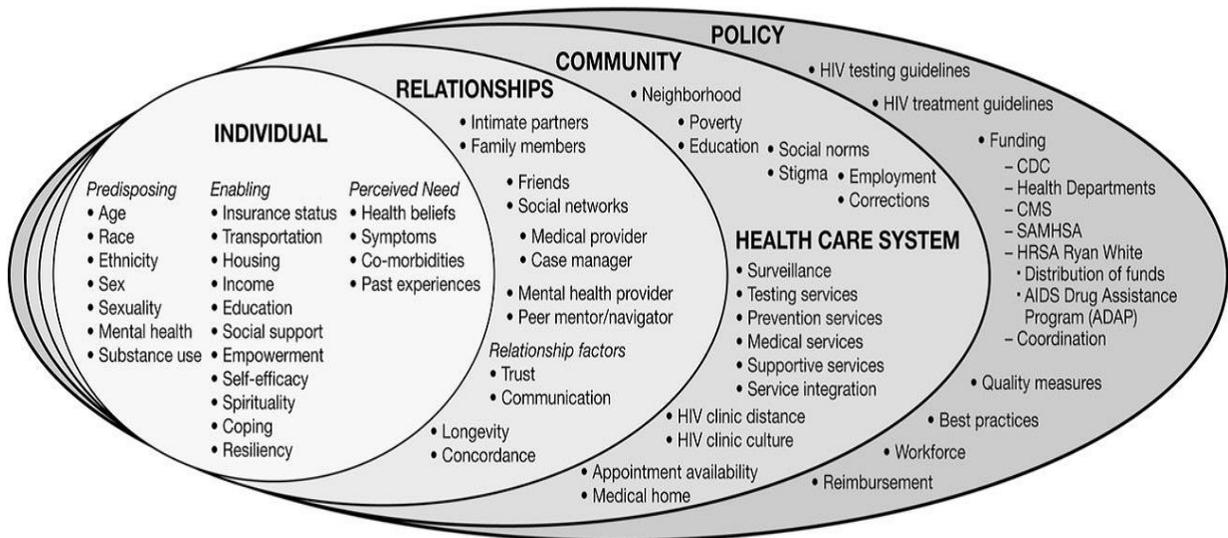


Figure 2. A social-ecological perspective, which provides the framework for this article's arguments, serves as a road map outlining the complex interplay of individual, relationship, community, health care system, and policy factors that influence the processes of engagement in care. CDC, Centers for Disease Control and Prevention; CMS, Center for Medicare and Medicaid Services; HIV, human immunodeficiency virus; HRSA, Health

Resources and Services Administration; SAMHSA, Substance Abuse and Mental Health Services Administration (Mugavero et al., 2011).

As presently understood, insurance, transportation, housing, income, and support, as seen in the “Individual” section of the framework, were highly referenced in the interviews as the basic needs that must be met in order to initially engage and retain patients in care. Health beliefs, symptoms, co-morbidities, and past experiences were all identified as subthemes that emerged during the interviews as well, which helps to solidify the current understanding that these person-level needs and experiences are of utmost importance to address during and continuously after diagnosis. The “Relationships” section of the social-ecological framework is also supported by the interview data; participants described family and friend support, as well as relationships with case managers and providers, as invaluable in their ability to be engaged. As this framework proposes and as was reported by participants, trust and communication with one’s provider are also necessary for treatment success. Stigma, employment, poverty, and education issues, as outlined in the “Community” section of the framework, were all represented in the interviews as part of the patient experience in being HIV positive. Stigma often caused emotional distress as loved ones who may not fully understand the virus would become distant or make insensitive remarks involving fear of contracting the disease. The impact of stigma seemed to reinforce feelings of shame that had a compounding effect leading to disengagement.

It is crucial to note that misunderstanding of HIV is not just prevalent among those without the virus. Based on commentary from the informants, another theme emerged that indicated a compromised level of health literacy specific to HIV and reproductive health.

Several participants made statements that clearly illustrated their lack of understanding regarding various aspects of HIV. The following are quotes from participants that illustrate the inadequacy of HIV education:

Then I have three teenage boys, two of them that are very sexually active. So, before this was going to happen, I needed to have enough education to say look, you don't want this to happen. I didn't even care about babies at that point. I don't care about babies with my kids. They could have a tribe as long as they're safe in doing it
(HIV positive eight years).

And from a medical standpoint, it seems like an almost contained disease. But from a human basic level, it's heartbreaking. You have to mourn things. Like I have to mourn the fact that I won't be able to naturally have children
(HIV positive two years).

And that's what I tell the grandkids. I love you, I just don't want my body hurting you. Because I'm not for sure how much contact that can do. That's still kind of vague, but I'm learning. But I would rather not take no chance. I would rather just don't come around me at all if you see me with cuts. And I'll tell you when I've got a cut and I don't want to be bothered. Because the kids don't understand. And I'm not for sure on a child how I can give them, if that can even happen. I do and I am aware that if we kiss and saliva gets in their stomach, that the amino acids will kill off the virus
(HIV positive 22 years).

This information not only provides evidence for lack of health literacy, but also demonstrates there is room for improvement on behalf of providers and clinic staff to make education a priority. Improving patients' understanding could be critically important if poor engagement is related to misunderstandings of their disease and treatment. While clinics are usually full of pamphlets and reading material, it is important to keep in mind that many HIV positive patients do not have high levels of basic literacy to begin with or the educational background necessary to teach themselves viral mechanisms or modes of transmission. Patient-provider relationship and clinic factors played a substantial role in engagement in care, and an intervention to assess the incorporation of a personalized educational program could potentially improve engagement and health outcomes, including decreased viral load and minimization of transmission risk.

The health care system is an integral part of the thematic framework in terms of the logistics (i.e. clinic location, culture, and appointment availability) of engagement in care. The interviews yielded substantial data in each of these categories to justify designating clinic factors as a main theme of engagement. Clinic distance was problematic not only for people without transportation, but also for those living in suburban areas where HIV specialists are few or completely absent. Clinic culture, including patient-provider relationship and clinic factors, such as camaraderie with clinic staff and the resources made available to patients, play an essential role in making patients feel comfortable, welcome, and supported. However, despite good clinic culture, scheduling seemed to be difficult for many patients with the exception of those who no longer work and now have much more time for appointments. Improving access to appointment times may require substantial system support and funding. One participant explained that even a small clinic change like a

different secretary at the front desk could throw her off and serve as the basis for disengagement. Unfortunately, this is a person-level issue that may not be feasible to address in terms of system or policy change, but it is noteworthy as evidence of the unexpected factors that can influence engagement.

There is a fundamental need for improved synergies between funding and service agencies that provide care and resources for the HIV positive population. This assertion was supported through the interview study, as despite what seems to be generous funding through the Ryan White HIV/AIDS Program, there are still limits to the availability and accessibility to these services. The presence or absence of resources, while perhaps the most obvious of challenges in acquiring health care, presents an interesting dichotomy among its subthemes financial issues and employment status. HIV medications are rarely covered one hundred percent, and the average annual cost of antiretroviral therapy is estimated to be \$19,912 (CDC, 2013). Therefore, even with private insurance coverage, participants explained that paying for HIV medical care and treatment isn't always feasible. One participant disclosed that he felt well enough to work while on his HIV medications, but his insurance changed and he could no longer afford the approximate \$1,000 per month medication cost on his salary. However, his income was still too high to qualify for services through Ryan White or other federal subsidies. After losing his job due to a decline in health, he became eligible for Ryan White, and now all of his HIV-related expenses are paid. The issue is that several participants express the desire to be employed, tax-paying citizens, yet are denied any sort of financial assistance if they have any kind of private insurance or are within a certain income bracket. In the 11 county catchment area surrounding Kansas City, a patient's income must be at or below 300 percent of the poverty level to apply for Ryan White services (Missouri

Department of Health and Senior Services). This creates an opportunity for a reevaluation of policy surrounding eligibility for services, which could be economically favorable for all parties involved over a long period of time if it keeps patients engaged in care so they can avoid costly health crises. Another aspect of this involves the case managers and their responsibility to aid patients in navigating the health care system as well as available resources. Based on the numerous misconceptions regarding HIV care, treatment, services, and resources, a great need remains for increased case management. Two references were made regarding the logistical complications surrounding the application process for health services that could perhaps be obviated in the future with the collaboration of the patient, providers, hospital administration, case managers and health care representatives.

There are several limitations to this study. First, this convenience sample is not necessarily representative of all HIV positive individuals who have delayed linkage to care, been out of care, or are currently out of care with history of being engaged. However, a major strength of this study is the inclusion of participants who were able to describe their various transitional states of engagement along the continuum of care. Second, with this convenience sample there is lack of information on what keeps people out of care who have never engaged or do not come into the clinic. The Kansas City, Missouri Health Department staff that handed out flyers in the field while working to link HIV positive individuals to care did not generate any interest in participation.

Future work will involve presenting the theoretical framework to clinic staff including providers, nurses, case managers, and peers to acquire their feedback and suggestions regarding the framework. An additional check of the validity of the theoretical framework will be obtained by conducting focus groups with patients. From the finalized

model interventions may be designed and tested to determine whether addressing the common barriers to care and causes for disengagement will increase retention in care and improve health outcomes.

APPENDIX A

SCREENING DOCUMENT

Screening Document

Study ID:

How did you find out about the study?

What is your age?

Where were you tested for HIV?

What is the date of your HIV diagnosis?

How long did you wait after being diagnosed with HIV to see a health care provider for your HIV?

Are you currently receiving treatment?

Do you know your current viral load and/or lab values?

Has there been any point in time in the past five years when you were not getting treatment for a period of at least six months?

If so, how long were you not getting treatment or check-ups?

APPENDIX B

INTERVIEWS

Interviews

Factors Related to Engagement in Medical Care

IRB #13-490

Interview – Patients waiting >6 months to initiate care

Intro – The clinic is working with a national group to try to get an idea of how well clinics are doing keeping their patients coming in for regular medical care. This is something we are very interested in doing well. We think you have a point of view that would be very valuable for us to learn from. We think we have a lot we could learn from patients about why there are sometimes long breaks in time between visits to the clinic. We are interested in finding out the kinds of things that can get in the way of people coming in for appointments, and what kinds of things can make it easier for people to come regularly. As we learn more, we hope we can make changes in the clinic that will make it easier for all our patients to keep coming in on a regular basis. Your thoughts and suggestions will help us a lot.

1. When and where were you diagnosed as being HIV+?
- 2a. What were your thoughts about your diagnosis in the week after your diagnosis?
 - 2b. What about a month after your diagnosis?
 - 2c. When you were diagnosed, what did you know about HIV?
- 3a. When you found out about your diagnosis were you linked up with any services to help you access medical care?
 - 3b. If yes, what were they?
4. When was your first HIV-related medical appointment?
5. Can you talk a little about why you waited that long to see a doctor?
6. What made you decide to come to the doctor when you did?
7. How do you think your health was during the period of time after your diagnosis before you accessed medical care?
 - 5a. Are there things in your life that may make it hard for you to make or keep appointments at the clinic?
 - 5b. If yes, what are they?

- 6a. Who else in your life knows about your HIV status?
- 6b. Have they been supportive of you seeking care?
- 6c. How has that been shown?
7. On a scale of 0-10, with zero meaning “I know nothing about HIV/AIDS” and 10 meaning “I know everything about HIV/AIDS”, how would you rate your knowledge about HIV/AIDS?
8. How do you think being on HIV medications would affect you?
9. If being on HIV medications would keep others from getting infected, how would you feel about being on HIV medications?
- 10a. Do you feel that HIV infection will cause you any health problems over the next year?
- 10b. If yes, what do you think might be a problem?
11. What changes in the clinic would make it easier for you to come in for appointments?
12. What changes in the clinic would make it harder for you to come in for appointments?
13. Is there anything else you can think of that would help you take care of yourself?
14. Is there anything else you would like to tell me?

Factors Related to Engagement in Medical Care
IRB #13-490

Interview – Patients currently in care, previously out of care

Intro – The clinic is working with a national group to try to get an idea of how well clinics are doing keeping their patients coming in for regular medical care. This is something we are very interested in doing well. We think you have a point of view that would be very valuable for us to learn from. We think we could learn a lot from patients about why there are sometimes long breaks in time between visits to the clinic. We are interested in finding out the kinds of things that can get in the way of people coming in for appointments, and what kinds of things can make it easier for people to come regularly. As we learn more, we hope we can make changes in the clinic that will make it easier for all our patients to keep coming in on a regular basis. Your thoughts and suggestions will really help us.

1. We are glad you are coming in for regular medical care. Thinking about the last 5 years, what is the longest period of time that you have gone between medical appointments?

2. Can you talk a little about why you went that long?

3. How was your health during this break?

4. What brought you back to the clinic?

5a. Are there things currently in your life that make it hard for you to make or keep appointments at the clinic?

5b. If yes, what are they?

5c. If no, what has changed in your life that has made it easier for you to get to the clinic when you need to?

6a. Who else in your life knows about your HIV status?

6b. Have they been supportive of you seeking care?

6c. How has that been shown?

7a. Have you been on HIV medications before?

7b. If yes, are you on them now?

7c. If you aren't on them now, how long has it been since you were on them?

8. How do you think being on HIV medications would/does affect you?

9. If being on HIV medications would keep others from getting infected, how would you feel about being on HIV medications?

10a. Do you feel that HIV infection will cause you any health problems over the next year?

10b. If yes, what do you think might be a problem?

11. What changes in the clinic would make it easier for you to come in for appointments?

12. What changes in the clinic would make it harder for you to come in for appointments?

13. Is there anything else you can think of that would help you take care of yourself?

14. Is there anything else you would like to tell me?

Factors Related to Engagement in Medical Care
IRB #13-490

Interview – Patients returning to care after absence

Intro – The clinic is working with a national group to try to get an idea of how well clinics

are doing keeping their patients coming in for regular medical care. This is something we are very interested in doing well. We think you have a point of view that would be very valuable for us to learn from. We think we have a lot we could learn from patients about why there are sometimes long breaks in time between visits to the clinic. We are interested in finding out the kinds of things that can get in the way of people coming in for appointments, and what kinds of things can make it easier for people to come regularly. As we learn more, we hope we can make changes in the clinic that will make it easier for all our patients to keep coming in on a regular basis. Your thoughts and suggestions will help us a lot.

1. It's been a while since you were last in the clinic. How have you been doing?

2. Can you talk a little about why it's been that long?

3. How do you think your health has been during this break?

4. What brought you back to the clinic at this time?

5a. Are there things in your life that make it hard for you to make or keep appointments at the clinic?

5b. If yes, what are they?

6a. Who else in your life knows about your HIV status?

6b. Have they been supportive of you seeking care?

6c. How has that been shown?

7a. Have you been on HIV medications before?

7b. If yes, are you on them now?

7c. If you aren't on them now, how long has it been since you were on them?

8. How do you think being on HIV medications would/does affect you?

9. If being on HIV medications would keep others from getting infected, how would you feel about being on HIV medications?

10a. Do you feel that HIV infection will cause you any health problems over the next year?

10b. If yes, what do you think might be a problem?

11. What changes in the clinic would make it easier for you to come in for appointments?

12. What changes in the clinic would make it harder for you to come in for appointments?

13. Is there anything else you can think of that would help you take care of yourself?

14. Is there anything else you would like to tell me?

APPENDIX C

CONSENT FORM

Consent to participate in a Research Study *Factors Related to Engagement in Medical Care*

Request to Participate

You are being asked to take part in a research study. This study is being conducted by University of Missouri-Kansas City.

Investigator: Dr. Mary M Gerkovich is conducting the study. While the study will be run by her, other qualified persons who work with her may act on her behalf.

The study team is asking you to take part in this research study because you have an HIV positive diagnosis. Research studies only include people who choose to take part. This document is called a consent form. It explains what to expect: the risks, discomforts, and benefits, if any, if you consent to be in the study. Please read this consent form carefully and take your time making your decision. The researcher or study staff will go over this consent form with you. Ask him/her to explain anything that you do not understand. Think about it and if you would like to talk it over with your family and friends before you decide you may do that.

Purpose

For this study we are looking for HIV positive persons to talk to about their experience in getting medical care for their HIV treatment or why they have not gone to get medical care. From this information, we hope to develop ideas of what could make it easier for people to get medical care.

Procedures

If you decide to participate in the study, you will be asked to complete a brief survey to record your age, gender, race, living situation, and date of HIV diagnosis.

The study will only be one visit for this interview. The interview will last about one hour.

The interview will be audio-recorded so that we can listen to it again and so that the interview questions and answers can be written down. The audio-recordings and the papers with your answers on them will not include your name. You will be given a study number to protect your privacy and no one else will know your name.

Once we have finished with all of the interviews we would be happy to share with you what we have found if you are interested.

This study is completely voluntary. You will always have the right to decide not to participate in the study. You also have the right to decide not to answer certain questions. If you decide not to participate after the interview has started, the information you provide will be erased if you request that we do so. If you are willing for us to use the information you provide up to that point, we will treat your recording as we do those from people who complete the entire interview.

The audio recording of your session will be transcribed so it can be reviewed by the study team. After we have finished reviewing and summarizing information from the recording, it will be destroyed.

Risks and Inconveniences

Although there are no known risks for participating in this study, it is possible that you could be upset by the survey or interview questions. You may refuse to complete the survey or refuse to answer any questions, and/or discontinue your participation at any time. Should you experience any emotional upset triggered by the interview questions, and are interested in counseling assistance, a counselor from Truman Medical Center Behavioral Health will be contacted to talk with you. **To contact Truman Medical Center Behavioral Health call 816-404-1000 and ask the operator to page the therapist on call.**

Benefits

There may be no direct benefit to you in this study. However, it is possible that you may gain a better understanding of the importance of seeing a doctor for your HIV care. It is our hope that a better understanding of how HIV patients feel about medical care will allow us to help those who wish to have access to treatment and support.

Fees and Expenses

There are no costs or fees for participating in this study.

Compensation

After the interview has taken place you will be given a gift card worth \$50.00. You will also receive \$5 to cover your transportation cost.

Alternatives to Study Participation

The alternative to participation in this study is to not participate in this study.

Confidentiality

All of the information that you give us about yourself will remain private. We will not share your information with anyone. The information we receive from you will be labeled with a study number only.

Contacts for Questions about the Study or In Case of Injury

The University of Missouri-Kansas City appreciates the participation of people who help carry out its function of developing knowledge through research. You should contact the Office of UMKC’s Social Sciences Institutional Review Board at 816-235-5927 if you have any questions, concerns or complaints about your rights as a research subject. You may also call the researcher, Dr. Gerkovich, at 816-235-1322, if you have any questions about this study or if any problems come up.

Voluntary Participation

Taking part in this research study is voluntary. If you choose to be in the study, you are free to stop participating at any time and for any reason.

You have read this Consent Form or it has been read to you. You have been told why this research is being done and what will happen if you take part in the study, including the risks and benefits. You have had the chance to ask questions, and you may ask questions at any time in the future by calling Dr. Gerkovich, at 816-235-1322. By signing this consent form, you volunteer and consent to take part in this research study. Study staff will give you a copy of this consent form.

Volunteer Subject

Printed name
Date

Signature

Person Obtaining Consent

Printed name
Date

Signature

APPENDIX D

DEMOGRAPHIC DATA SHEET

ID # _____

Thank you for assisting us in our project to help patients stay engaged in their medical care. Your participation is greatly appreciated and will provide us with helpful information. Please complete the following questionnaire about yourself.

1. Which best describes you?
 - a. Male
 - b. Female
 - c. Transgender
 - d. _____
2. How old are you? _____ years
3. How do you identify your ethnic background? (Select all that apply)
 - a. White
 - b. Black
 - c. Hispanic
 - d. Asian/Pacific Islander
 - e. Native American/Alaska Native
 - f. Other _____
4. How would you describe your current living situation?
 - a. Homeless, staying on the street or in vacant houses
 - b. Homeless, staying in a shelter
 - c. Transitional/Temporary housing program
 - d. An apartment or house that you rent/own
 - e. In my parent's/friend's/relative's home
 - f. In a nursing home/group home
 - g. In jail/prison
 - h. Other _____
5. Which of the following describes your current work situation? (Select all that apply)
 - a. Disabled, receiving SSI or Disability check
 - b. Working full time (At least 36 hours per week)
 - c. Working part time (Less than 36 hours per week)
 - d. Not working, but looking for work
 - e. Not working, but NOT currently looking for work
 - f. Student
6. What year were you diagnosed as being HIV+? _____
7. How long after your diagnosis, did you have your first HIV related medical appointment?
 - a. Within one month
 - b. 1-6 months
 - c. 6-12 months
 - d. 1-2 years
 - e. Over 2 years
 - f. Have not had my first HIV related medical appointment

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VITA

Stephanie Lisette Koch was born on July 23, 1987 in Overland Park, Kansas. After spending her childhood in North Carolina and Kentucky, she moved with her family back to Leawood, Kansas and attended high school at Notre Dame de Sion College Preparatory School. Despite a love for performing arts she chose the practical route and pursued a Bachelor of Arts in Spanish at the University of Kansas where she graduated in 2009 with plans for further education and a career in the medical field. After working as a research assistant and later as a Spanish medical interpreter and scribe, academia was calling her name. She graduated with her Master of Science in Bioinformatics in December 2013, and will continue to pursue her dream of becoming a clinician by way of a Master of Medical Science degree as a student in the inaugural Physician Assistant program at the UMKC School of Medicine. Her future goals include using bioinformatics systems and patient portals to address health literacy concerns and improve patient engagement in care.