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Translating the News: A Grounded Theory of Care Initiation by Individuals Living with HIV

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Abstract

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Keywords

Grounded Theory, HIV, Care Initiation, HIV Treatment, HIV Care, HIV Care Initiation

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Translating the News: A Grounded Theory of Care Initiation by Individuals Living with HIV

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The purpose of this research study was to develop a theoretical framework to explain the psychosocial process of care initiation in individuals living with HIV, and to identify the critical junctures that influence individuals living with HIV in their decision to initiate HIV care. Grounded theory method was used to identify the psychosocial process of care initiation by individuals living with HIV. Thirty individuals living with HIV (28 men, 2 women) shared their stories about initiating HIV care. Participants described a process in which they progressed through five distinct stages following diagnosis: a) receiving the news, b) interpreting the news, c) incorporating the news, d) acting on the news, and e) moving beyond the news. Each stage was moderated by influential factors including perceived susceptibility to HIV infection, symptoms, HIV information, and feedback from others. The participants were able to translate the news, from something bad into something good, as demonstrated in the constructed framework: "Translating the News: A Grounded Theory of HIV Care Initiation" A key to successful care initiation is helping individuals with HIV to realize that while the diagnosis may seem like bad news, there is also good news: HIV is not a death sentence. Keywords: Grounded Theory, HIV, Care Initiation, HIV Treatment, HIV Care, HIV Care Initiation

Throughout the last three decades, global health authorities have worked tirelessly to understand, control, prevent, and treat Human Immunodeficiency Virus (HIV). Antiretroviral therapy (ART) has the potential to increase lifespan, promote viral suppression, and decrease the likelihood of advancement to acquired immunodeficiency syndrome (CDC, 2012; DHHS, 2013a). In addition to the individual patient benefits, communities benefit from HIV treatment as it decreases the likelihood of HIV transmission (CDC, 2012; DHHS, 2013a; Louie & Markowitz, 2002; Siegfried, Uthman, & Rutherford, 2010). US data indicate that less than half of people living with HIV are achieving optimal treatment outcomes (CDC, 2014; Cheever, 2007; DHHS, 2013b; Gardner, McLees, Steiner, del Rio, & Burman, 2011). As such, there is an urgent need for scientists to investigate factors that lead individuals with HIV to initiate care following diagnosis.

The *HIV care continuum*, also known as the *HIV treatment cascade* is a framework that allows clinicians and health authorities to evaluate engagement in HIV care and treatment (DHHS, 2011; Gardner et al., 2011). The continuum is inclusive of all individuals living with HIV, ranging from those who are living with HIV but are unaware of their diagnosis to those who have achieved viral suppression, i.e. the individual's viral load has become undetectable (DHHS, 2011). Care initiation occurs at the crucial time point on the HIV care continuum when an individual living with HIV takes the action to enter HIV care (Cheever, 2007; Gardner et al., 2011). A greater understanding of factors that influence HIV care initiation will help researchers and clinicians provide optimal transition from HIV diagnosis to treatment, resulting in a greater number of individuals living with HIV who experience the benefits of HIV treatment.

Psychosocial factors are among the many variables that influence individuals newly diagnosed with HIV to pursue HIV care. Psychological response to diagnosis, stigma, and lack of social support, as well as predisposing risk factors such as mental illness and substance misuse have been linked to delayed initiation of HIV care (Burns, Imrie, Nazroo, Johnson, & Fenton, 2007; Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Marcellin et al., 2009; Pollini, Blanco, Crump, & Zúñiga, 2011; Ramirez-Avila et al., 2012; Reed et al., 2009; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009; Torian, Wiewel, Liu, Sackoff, & Frieden, 2008). Conversely, disease acceptance and tangible and informational support have been found to promote HIV care initiation (Aidala, Lee, Abramson, Messeri, & Siegler, 2007; Craw et al., 2008; Konkle-Parker, 2010; Sprague & Simon, 2014). These studies provide invaluable evidence of the impact of psychosocial factors on HIV care initiation. However, to our knowledge no studies have been reported that examine the psychosocial process of HIV care initiation used by individuals diagnosed with HIV. This study addresses this gap in knowledge by exploring the psychosocial process of HIV care initiation by a group of adults living with HIV.

Author Context

We developed a four-member research team composed of a doctoral candidate (now completed PhD in nursing; first author), a senior faculty member with expertise in the use of the grounded theory method and human social process research (second author), a doctorally trained scientist and research associate (third author), and a research project coordinator with experience in providing legal and social services to low income and disadvantaged individuals (fourth author). The doctoral candidate conducted the study to complete his doctor of philosophy degree in nursing. His interest in HIV was developed through interaction with friends, acquaintances, and patients with HIV, his experience learning about HIV and its treatment in nursing school and in the clinical environment, and through his work with a nurse scientist researching HIV/AIDS. The first author completed a year of coursework dedicated to qualitative methods and attended one on one data analysis training with his mentor (second author). All of the research team members were thoroughly oriented to the study, including the study goals, data analysis procedures, and study team member roles. The first author completed all pre-study requirements (e.g., protocol development, IRB approval), participant recruitment and data collection. The first author attended training through the Pennsylvania Mid-Atlantic AIDS Education and Training Center, which included extensive training and on-site experience with new patient intake procedures. The second author supervised and instructed the protocol development and acted as a source of guidance for the entire research team throughout the study. The third and fourth authors attended weekly data analysis meetings and multiple daylong retreats with the first and second author, and were instrumental in the analysis of study interviews, identification of theoretical constructs, and ultimately the development of the final theory. The intention of the study team was to gain insight into the psychosocial process of HIV care initiation as a foundation for further inquiry and intervention development aimed at improving the experiences of people with HIV when they initiate care. The team also wanted to identify facilitators and barriers both systematically and interpersonally that promote or impede HIV care initiation in newly diagnosed individuals.

Materials and Methods

Ethical Considerations

The protocol was approved by the university's Institutional Review Board prior to the initiation of study procedures. All study documentation was kept on a password-protected, secure research server.

Participants

The first author recruited participants in person at new intake visits within the infectious disease clinic at a Midwestern university medical center. The research team partnered with the site's New Intake Coordinator, who acted as a gatekeeper for the identification of potential participants. The New Intake Coordinator approached new patients about the study and asked if s/he would be willing to speak with an investigator. If an individual expressed interest in the study, a research team member reviewed the informed consent document with the patient, and once the document was signed, scheduled an interview. Participants were eligible to participate if they were at least 18 years of age, had received a confirmed seropositive HIV test result, had not previously initiated HIV care, and were able to speak and understand English. Participants were not eligible to participate if they were experiencing acute illness requiring inpatient hospitalization at the time of intake. Characteristics of the final study sample are summarized in Table 1.

Table 1. Sample Characteristics

Category	Type	Sample n (%)
Gender	Men	28 (93%)
	Women	2 (7%)
Age	18-24	8 (27%)
	25-34	11 (37%)
	35-44	3 (10%)
	45-54	6 (20%)
	55-64	2 (7%)
Race/Ethnicity	African American	6 (20%)
	Caucasian	20 (67%)
	Native American	1 (3%)
	Hispanic/Latino	2 (7%)
	More than one Race	1 (3%)
HIV Exposure Category	MSM	26 (87%)
	Hetero. Contact	3 (10%)
	IDU	1 (3%)
	Other	
Timeframe from Diagnosis to HIV Care Initiation	< 1 Month	6 (20%)
	1-3 Months	20 (67%)
	3-6 Months	1 (3%)
	6-12 Months	2 (7%)
	>12 Months	1 (3%)
HIV Treatment Status	Started HIV Medication	13 (43%)
	Not Started HIV Medication	17 (57%)

Design

Grounded theory (Glaser & Strauss, 1967) is a qualitative inquiry method that is ideal in the investigation of psychosocial problems, particularly problems to which individuals must adapt over a period of time. Grounded theory involves the technique of constant comparison in which study data are collected and analyzed simultaneously (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1990). Another defining feature of grounded theory is the employment of theoretical sampling, in which data collection plans evolve based on the developing theory rather than a pre-determined protocol (Draucker, Martsolf, Ross, & Rusk, 2007). Theoretical sampling was carried out in the study through modification in recruitment efforts and specificity in interview questions. All participants in the study were asked the same universal question and were able to tell their story in the same way. As the study progressed and important theoretical constructs were revealed in the data, participants with specific characteristics were sought out and specific questions were added to the interview guide in order to thoroughly explore these constructs. Finally, previously analyzed interviews were reanalyzed to ensure a rigorous review of the data was completed as the participants shared new information.

Data Collection and Analysis

The first author collected data between April 2014 and December 2014. Participants met with the first author in a private room within the medical center. The researcher conducted and digitally recorded in-depth, individual interviews that lasted between 45 minutes and two hours. The same team member conducted all interviews. The researcher asked a broad open-ended question that elicited participants' experiences with the initiation of HIV care:

"I understand that you learned that you have HIV [Insert Timeframe: i.e. two months ago] and you have come here to receive healthcare for HIV. Tell me your story about how you went from learning that you have HIV to making the decision to come here to get care."

The researcher also included follow-up questions designed to obtain additional detail about significant statements made by participants. For example, when participants said they had a particularly "good" or "bad" experience with a healthcare worker during the process:

"Tell me more about your interaction with [healthcare worker]? What did they do, specifically, that made the interaction [good/bad]?"

Interview questions evolved throughout the study to explore theoretical concepts that were discovered during data analysis. In addition to interview data, the research team collected data in the form of field notes, patient education material, and information from HIV-specific websites discussed by participants.

Data Analysis

The research team analyzed the transcribed interviews under the direction of the second author. Data analysis followed constant comparison method in which the team reviewed transcripts multiple times and made comparisons within each transcript and across other transcripts to identify theoretical comparisons among data sources (Glaser & Strauss,

1967). The analysis process included three specific levels of coding: open coding, selective coding, and theoretical coding.

During open coding, the research team reviewed transcribed interviews and coded them line-by-line, forming a foundation for subsequent data analysis (Glaser & Strauss, 1967; Jones & Alony, 2011). Patterns among the open codes resulted in the tentative categorization of data, which then guided the direction of data collection and analysis efforts. As open coding revealed data categories, the research team moved on to selective coding. The categories discovered prompted the research team to seek relevant data from new interviews and previous transcripts. Table 2 contains the results of the open coding procedures as well as several case exemplars for each tentative category. A total of 16 tentative categories were developed through rigorous individual and team analysis of interview data. As the data consistently fit the tentative categories, elevation of abstraction to selective coding commenced. Table 3 outlines the procedures taken by the research team to elevate the 16 categories to the level of selective codes and ultimately to the finally to the level of theoretical concepts.

The final step in the coding process was theoretical coding, which occurred once the categories became saturated. Theoretical saturation occurred when the research team, through rigorous analysis and discussion, concluded that no further investigation into a theoretical category was necessary. Grounded theory quality control measures were also employed and recognized in the study design and analysis. Fit was exercised through the procedures used to elicit a theory from the data as opposed to running the study based on a preexisting theory. The theory was highly relevant as it involved data collection from a population that is highly affected by HIV, and care initiation remains an important issue in need of research effort. The research is also workable within the confines of the sample investigated, as participants consistently followed a similar social process of HIV care initiation. Finally, the theory is also modifiable, not only to populations of people living with HIV who are not represented in this study, but is also relevant to populations of people diagnosed with chronic diseases, particularly those disease in which there is a societal stigma attached (Charmaz, 2006; Glaser & Strauss, 1967; Jones & Alony, 2011).

Table 2. Tentative Categories Discovered Through Open Coding with Exemplars

Open Code: Exemplars
Why tested for HIV?
<i>"I'm dating somebody with HIV...you kind of expect that it could happen, especially when you're not always the safest as you could be. So I finally went and got tested"</i>
<i>"I told [my boyfriend], I am going to get tested because I think I might be, and I'm feeling like this, and I kind of feel crappy, and I don't feel right. I kind of had a feeling that I was [HIV-positive] before I even got tested"</i>
<i>"I was already giving blood [at the doctor] I decided to go ahead and get tested for HIV"</i>
What caused the problem? How did I get HIV?
<i>"I was partaking in high-risk activity let's put it like that"; "I trusted him and so I didn't use protection"</i>
<i>"[As far as] specifics of when I got it and who I got it from.... I don't really know... don't know how long I have [had] it."</i>
<i>"I really started getting more depressed and more angry at myself for not bein' accomplished...So I started enjoyin' more risky behaviors of shooting drugs, sharin' needles...prostitutes."</i>
What do/will other people think, do, or react to the HIV diagnosis?
<i>"You know what they say... it's supposed to be a gay disease ...even though I know it's not a gay disease."</i>
<i>"They think Oh I don't want to sit by that guy he's HIV-positive or I don't want to have a conversation with that guy he has HIV."</i>

<p><i>"I just had a lot of emotions running through my mind when I initially found out because I didn't know if people were going to accept me ... would my parent's accept me? My friends and family? I work in a public environment so, I thought about that too. It was just real stressful."</i></p>
<p style="text-align: center;">Receiving the Diagnosis</p> <p><i>"I was on so much pain medication [in the hospital] that I was just kind of just – I had no response....and just said, Okay. And I really didn't feel much emotion about it."</i></p> <p><i>"[My doctor said] you tested positive for HIV. And I just sat and took it in for moment I had mentally prepped myself for that for some reason I kind of thought like that's what it was going to be."</i></p> <p><i>I stood up – just in shock. And I could hear the chair that I was sitting in crash against the wall; I stood up so quickly and with so much force. And I just immediately started pacing...[the nurse] took a step back...she was afraid of me."</i></p>
<p style="text-align: center;">Symptoms/Lack of Symptoms</p> <p><i>"[What] caught my attention was the rapid weight loss... I felt like I was shedding pounds still sitting there...mentally I just knew [it was HIV]."</i></p> <p><i>"I didn't feel any [symptoms]. I wasn't going crazy or nothing like that so... it wasn't believable."</i></p> <p><i>"I would just notice a bruise in the weirdest spots. And I don't recall hitting it on anything. So it's like what's going on there? ... Those were my signals that...I need to get this checked out."</i></p>
<p style="text-align: center;">This happened to me/I didn't think this would happen to me</p> <p><i>"And then recently it was just like, Wow, I've got this. And... I feel like people looking at me weird or anything even though it's like they don't know...But I feel like they do."</i></p> <p><i>"I was shocked. And..... and... in disbelief, because how could this... how could I let this happen?"</i></p> <p><i>"After the [doctors appointments], I'm just like,... I can't believe I have to deal with all this. Like it's a little bit depressing, but I mean this is what I have to do."</i></p>
<p style="text-align: center;">Telling about HIV/Not Telling about HIV</p> <p><i>"It's definitely hard.... it took me about a week to work up the courage to tell the people that I'd been with."</i></p> <p><i>"I knew I had to tell [my partners].... It was just a matter of time of me working up the courage to tell them, because I was afraid of what their reaction was going to be."</i></p> <p><i>"I have to tell someone that I'm going to have intercourse with, but I don't have to tell anyone else, which was nice to know."</i></p>
<p style="text-align: center;">Life-Changing</p> <p><i>"There won't be a day in my life that I don't have to take a pill now or I'll be going – I'll be getting blood drawn constantly, because that's my life."</i></p> <p><i>"I'm not going to let it run my life. I can do so... I can do whatever I want but I also have to limit myself."</i></p>
<p style="text-align: center;">Life Remains Normal/ Life Has not Changed</p> <p><i>"I don't feel like I've changed or thought about changing the way I live."</i></p> <p><i>"I still feel like things are normal still and I am more worried about what to do next. It is not a life is over... It is just what plan do I make for tomorrow?"</i></p>
<p style="text-align: center;">Avoiding HIV Diagnosis</p> <p><i>"I didn't seek treatment immediately because part of me wanted to believe that it wasn't true."</i></p> <p><i>"I wanted a second test to confirm it.. I mean, I tried to search online... for false-positive...on a test... that there is a very slim chance...And I was hoping."</i></p> <p><i>"I was playing the videogame thinking like you're avoiding this [diagnosis] ...um...and I remember telling myself it's okay to avoid it today I'll deal with it tomorrow.. I will go through all the details tomorrow."</i></p>
<p style="text-align: center;">Taking Mind off of Situation</p> <p><i>"I think about it for a little while and then I change my mind to something else, or try to think about something else, or read a book, or call a friend, or something like that."</i></p> <p><i>"I think the nature of my job does not allow me to worry about anything else except what is going on right in front of</i></p>

me...I just mentally... I just put it out of my mind. And the job kind of naturally did that for me... My mind [was] busy until I had lunch...and then it kind of seeped back in."

"I waivered back and forth between trying to do activities to distract myself and then other times to sit in quiet contemplation and thinking about who I was gonna tell."

How Does the Disease Define Me? Does the Disease Define Me?

"I'm not that type of person. I'm not out there whoring around, not promiscuous, none of that kind of stuff. I had one girlfriend, one girlfriend only, and she was promiscuous and she's the one that transferred it to me, and that's how I got it"

"When it comes to [HIV]..I don't feel like it was put here to bring me down or to stop me...I just feel like it was kind of like a wakeup call, because I was living a very destructive lifestyle... eventually it's going to take over my body...But just maybe.... I was put in this position to where I could get my life together."

"I'm still the same person, but I'll be taking medicine everyday."

Information About HIV (internet, in-person, friends, etc.)

"I found some stuff online... read some stuff....did call a hotline... talked to them for a little bit about it... and, um, basically what I read offline... I tried to go to government sites more than these magic cure or whatever... other sites. Basically kind of knew where I was in the disease based on having thrush."

"I just knew that I wanted to...a really good friend....I knew that he would give me good information of ... where I go from here. Um.. I went and I talked to him and he said, this is what's going to happen... you're going to go get blood work done, you're going to go get medicine, you're going to start medicine.... And...all these things are going to happen.... And then you can just go on living your life....it made me feel a lot more calm"

"[My friend] texted me, and she was like, I did some research and I just want to let you know that you'll be okay, and don't worry about it.

You'll be fine... people don't die. Just take care of yourself and I'll come over and make you healthy meals, It was nice of her. It was really nice."

Approach of Staff and Other Professionals:

"It's just their [nurses at HIV clinic] personality...just so nice and non-judgmental...easy to talk to you...talk to you in your own language, not terms that you don't understand. That's basically what I like about that."

"When I went in to see [the doctor], it was, This is what you need to be on. Here's your script. Some people have trouble sleeping so here's a sleeping pill. And that was the end of it. I didn't – it wasn't very – it was very impersonal. I felt like I was being treated like a number."

"It wasn't a cold professional relationship... it was something that was genuine."

Treatment Factors (e.g. finances, treatment process, side effects)

"I thought there is going to be tons of medical bills... I am going to be paying out the wazoo...I need to make sure that I am setting aside money so that I can afford this now."

"A lot of the medications that we have today are very much different than what they used to be back from the '90s...a lot of the stuff is toxic and it's nasty."

"I am looking forward to getting the ball rolling, get my prescriptions filled, getting into a routine. It's two pills once a day that I'll have to take."

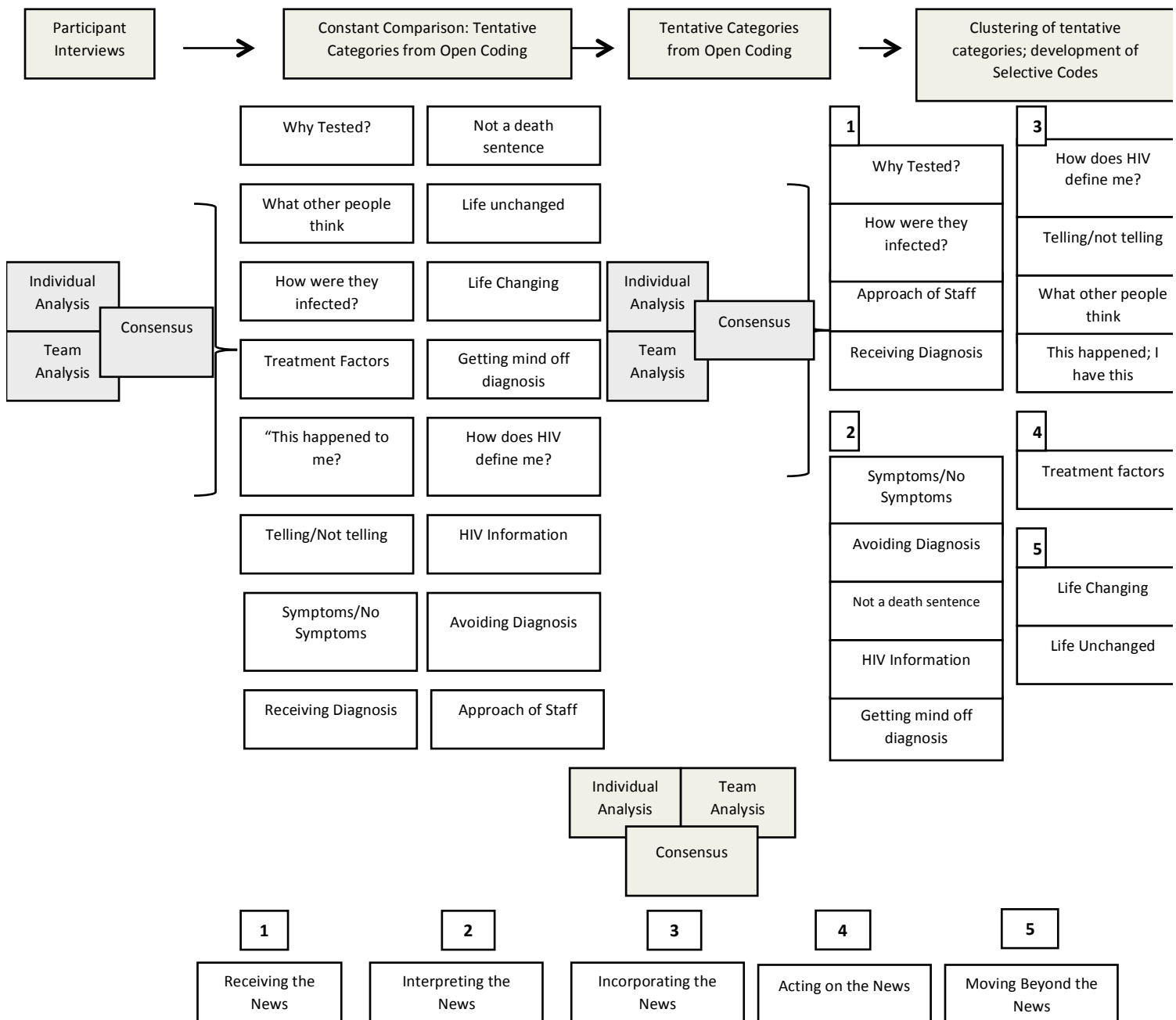
Not a Death Sentence:

"[My doctor] has been in it since 1982 or whatever, and he said, you know – he was the first one to say this isn't a death sentence, and you're not going to die. You know, he said nowadays people die of other complications, not of this."

"I talked to my friends and they were like, You know, you've got this. You're strong. This is not like a death sentence. You're fine."

"It's is not fatal.....It can be if you don't get help or treat it or get medications or anything."

Table 3: Data Coding Process



Results and Discussion

The study sample consisted of 30 participants, including 28 men and 2 women living with HIV who initiated care through the infectious disease center at a Midwestern urban teaching hospital. Table 1 provides the characteristics of the sample based on gender, race/ethnicity, age, HIV exposure category, timeframe from diagnosis to HIV care initiation, and HIV treatment status at the time of the study interview.

Participants included a) individuals diagnosed with HIV and initiating care for the first time (n=26), and b) individuals established in care who reflected on their experiences with HIV care initiation (n=4). Participants were interviewed to gain their perspective on the

phenomenon of HIV care initiation. Results from these interviews are shared within the context of the theoretical framework developed from participant responses.

The Theory: Translating the News

The core category discovered during data analysis was “HIV as News.” As participants shared their stories, they and other people mentioned within their stories often used the term “the news” to describe learning that they tested positive for HIV. The word *news* is defined as *previously unknown information, and something that has a specified influence or effect* (News, 2014). News in the context of the present study is used to describe the way that participants acquired and worked through the new and impactful information that they have HIV. News has typically been discussed in the field of communication and has been described as *information presented via a variety of media* (i.e. written documents, face-to-face communication, television, telephone, artwork etc.) *between a sender and a receiver* (Kreitner & Kinicki, 2011; Severin & Tankard, 2010). The response of a receiver of news is determined by intrinsic characteristics and perceptions of the receiver as well as extrinsic feedback, cues and events encountered by the receiver. In their stories, participants described the news of their HIV diagnosis as the catalyst that set subsequent thoughts, feelings, and actions in motion, ultimately resulting in a decision to initiate care for HIV.

Bad News and Good News

The participants described the news of their HIV diagnosis as a transformative phenomenon that evolved over time from bad news to good news. The concept of translation was used to describe the movement from bad news to good news described by participants. The term *translate* is defined as *changing from one place, state, form, or appearance to another* (Translate, 2014). The initial diagnosis was commonly interpreted as bad news, often related to the participant’s thoughts about their prognosis. One participant shared about learning his HIV status:

“I couldn’t even talk... I was like I don’t know what I’m going to do, and I don’t know how this happened. And I just thought I was going to die. I did. I thought it was a death sentence.”

Once participants were in possession of the news, they commenced into an often-rapid process of reflection and information seeking to determine how HIV would impact their current and future lives. The participants grappled with psychological, social, and pragmatic realities of having HIV. In each case, participants shared that as they reflected and gathered information, their perspective of their condition changed. Participants learned about treatment options for HIV that many did not know existed. The result was the realization that HIV was not a death sentence, and that they would be able to move forward with their lives while living with HIV. Participants often described learning this information as “good news.” One participant said that he did not know about the medications that were available for HIV and shared about the conversations with his provider and other healthcare workers in which he learned about treatment options:

“They’ve said that they’ve got new drugs that will keep you alive... and you can live almost a normal life expectancy... that’s where all the reassurance comes from.. people saying, it’s fine! We’ve got great drugs now that keep

people alive! We can get your T-cells back up...I mean it's... it's good news. When can I start? ... I was hoping to immediately start on drugs."

In the process, participants translated the news from a situation they felt was hopeless, to a situation for which they believed there was a solution. The process includes five distinct stages: Receiving the News, Interpreting the News, Incorporating the News, Acting on the News, and Moving Beyond the News (see Figure 1). The theory will be presented in the following way: each stage of the theory will be defined and illustrated using theoretical exemplars that can be found in Table 4. Following the description of each stage, four specific factors will be discussed that influenced participants during the process.

Figure 1: Translating the News

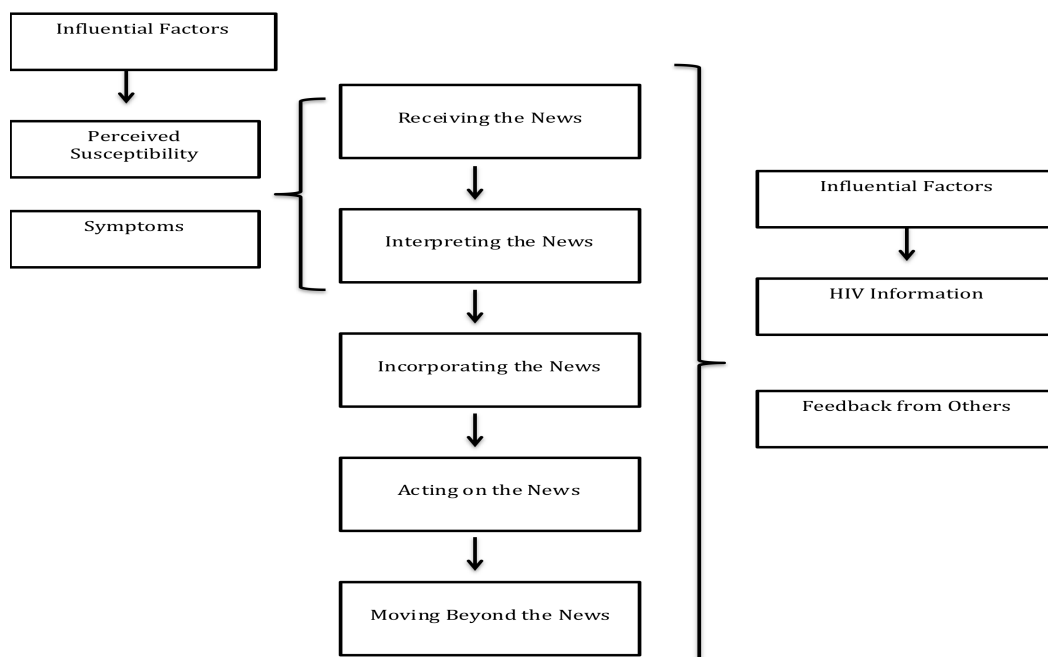


Table 4. Theoretical Exemplars

Stage	Context	Exemplar
Receiving the News	Participant describes learning about his HIV status from his physician	<i>"[The Physician] said, It's not good news and I wanted to be the one to tell you. And he told me that I was HIV positive."</i>
	Participant describes learning about his HIV status on the telephone with his provider	<i>"She called to tell me that my HIV test came back positive. I had a typical reaction that you might expect upon hearing that news. Just flushed, my heart felt like it – my stomach felt like it dropped out. I nearly dropped the phone."</i>
Interpreting the News	Participant shares his thoughts immediately after being told about his HIV diagnosis	<i>"After I heard the, You're HIV positive, it was just sort of like – I was in a state of shock and disbelief. It was hard for me to concentrate on the rest of the conversation. That's pretty much exactly how it went, as I recall."</i>
	Participant shares about the realization that treatment options were available to him	<i>"I accepted that....if I don't get treatment I'm going to die. It is a death sentence if you don't have treatment."</i>
Incorporating the News	Participant describes grappling with how his identity was shaped by HIV status	<i>"I have to say that word [HIV] over and over again, and I have to say that word pertaining to me, not</i>

		<i>pertaining to this person or that person that I know. It's now pertaining to me."</i>
	Participant describes incongruence between his diagnosis and his own preconceptions of people with HIV	<i>"I'm not that type of person. I'm not out there whoring around, not promiscuous, none of that kind of stuff."</i>
	Participant describes his thoughts on the permanency of HIV infection	<i>"Now if it's like a cold or a headache or something like that- that's not something that I typically seek treatment for. But with something like this I know that there are steps to take...knowing that it's going to be something that I have for the rest of my life is probably one of the factors that [made me realize] I need to do something about it."</i>
	Participant expresses concern about how HIV would affect his everyday life	<i>"I just knew in some way that for the rest of my life, I'm going to have to be very cautious and aware of what I do. I'm going to have to really start taking care of myself and just really watching my health."</i>
	Participant describes concerns about financing HIV treatment	<i>"It was kind of like how am I going to pay for this? I worked so hard to get through school and I still can't afford any of this. And I can't get any assistance from anybody else because I make over \$30,000.00 a year.....the drug companies denied the assistance for me because I made too much money. And at that point when I had realized that I couldn't get any assistance to help me out."</i>
	Participant describes concern about HIV status disclosure	<i>"Who do I have to tell? Like am I not going to be able to go to work? Like for my job's sake....what I have to tell my job [?] ...Is it going to affect my career in any way shape or form.... things like that."</i>
	Participant describes anxiety about taking medication every day	<i>"I have to constantly worry about that. What if I forget, what's that gonna do to me? Or, I mean, what if I forget them at home and I'm an hour away from home? What am I supposed to do?"</i>
	Participant describes his belief that his new medication regimen will not disrupt his everyday life	<i>"I feel like it is just a chronic medical issue.... Like diabetes, people use that one a lot. Like I [will] take my pill every day and I am fine as long as I am in control of it."</i>
Acting on the News	Participant describes being self-directed in the process of making contact with a care provider	<i>[The hospital] basically referred me to the [HIV treatment center]. And so I pretty much called and – well, I didn't call right away, but I called that day and set up an appointment to come in.</i>
	Participant describes feelings about case management professionals who helped him to find and make contact with a care provider	<i>"We really have some great resources and without them wouldn't be here. I think everyone plays a part. I probably would have panicked, and recluded, and not done anything. And everyone helps to get me further along. It's like droplets of water in a puddle – wouldn't be as big without each droplet."</i>
	Participant describes having a positive experience during the HIV care intake process	<i>"The appointment went really well. A lot of my questions were answered. [New Intake Nurse] was very warm and totally non-judgmental as I would expect her to be....just wanting to make sure that she got the information that she needed to give me appropriate care while also answering my questions and making sure that I left with the information that I wanted."</i>
Moving Beyond the News	Participant describes setting a goal of getting back to his normal life	<i>"I want to get care and I want to get treated. I want to live a normal life like I always have ...knowing that I'm sick but you know being healthy...work[ing]....having somebody you're in love with. Having a job...Have a life...Having HIV."</i>

		<i>I know medications will help you live longer... all those plans that you had you want to keep having them."</i>
	Participant describes setting a goal of attaining a better life through HIV treatment	<i>"I don't feel like [HIV] was put here to bring me down or to stop me...I just feel like it was kind of like a wakeup call, because I was living a very destructive lifestyle. It's a disease.... And I can't say that it's going to kill me, eventually it's going to take over my body.... But maybe I was put in this position to where I could get my life together, and then maybe I can help somebody else who's going through the same situation."</i>
	Participant describes medication as the route to move forward	<i>"The medication is obviously a huge factor in it not being a death sentence....I mean being on medications is one of the huge things that's preventing people from dying at an early age. So I think that knowing that has really helped me come to this point and being like, okay, I need to get on medicines, and I need medicines soon...I can't wait to be able to feel almost like normal again....I'm just ready to...be able to get up and just feel normal and feel like myself again...I mean it's pretty much like in my hands. You know? I can do whatever I want with it."</i>

Receiving the News: To *receive* is defined as *to come into possession of or to acquire* (Receive, 2014). Participants shared their stories of how they initially were given the news that they had HIV. With the exception of the five individuals who bought home HIV tests, all of the participants described receiving the news from another person. The majority of the participants received the news from physicians. Others received the news from public health workers and testing center employees. Regarding home testing, three of the five participants who received a home test chose to take the test in the presence of at least one other individual, while the remaining two shared that they took the test alone.

The majority of the participants described receiving the news in the form of face-to-face conversations with healthcare professionals who informed the participants that they had tested positive for HIV, either on a rapid test or in laboratory analyses. However, some participants did not receive the news in person. For example, one individual received the news when his test result was inadvertently released to an online medical record system prior to his follow up with his provider, and another participant received the news over the telephone. Although individuals are not officially diagnosed with HIV until they have received a confirmatory lab test, participants typically discussed receiving the news when they received their *first* positive indicator, regardless of whether the result was confirmed.

Interpreting the News: Once participants had received the news, they immediately proceeded to interpret what was happening to them. The term *interpret* is defined as *to explain the meaning of and to conceive in the light of individual belief, judgment, [and]/or circumstance* (Interpret, 2014). Participants interpreted the news through reflection about their past and present beliefs about the HIV illness and through speculation about how HIV would affect them physically, mentally, socially, sexually, and how their lives would have to change now that they have HIV. Across the study sample, each participant's interpretation was unique and grounded in his or her own personal experiences. Participants often discussed feelings of shock, sadness, disbelief and uncertainty upon finding out that they had HIV. At some point, all participants shared about coming to a realization that regardless of their initial thoughts, feelings, and beliefs about their diagnosis, that treatment was available to them and that their lives were not over.

Incorporating the News: To incorporate means *to merge, to unite one thing with something that already exists*, and *to embody* (Incorporate, 2014). As participants interpreted and found meaning in their diagnosis, they shared that they were also faced with the challenge of incorporating this new phenomenon into their lives. Incorporation of the news occurred in two primary ways: a) psychologically in the form of a new identity, and b) practically in the form of learning how to live everyday life with HIV.

Psychological Incorporation: Many participants grappled with how their identity was shaped with regard to HIV. Some participants shared that their previous beliefs about HIV and the people who have it were challenged as they incorporated the news. Participants varied in their adoption of HIV as part of their identity, with some participants sharing that they viewed HIV as a minimal component of who they are, while others believed that HIV was now a fundamental part of their identity.

Practical Incorporation: Participants shared a multitude of concerns about living with HIV, including: their general health, obtaining healthcare and its financial impact, disclosure, and the realities of having a daily medication regimen.

As participants were incorporating the news of their HIV diagnosis, concerns about what their diagnosis meant for their general health were discussed. Some participants discussed that they did not feel any differently and did not believe that HIV was going to hold them back from living their normal lives. Conversely, other participants expressed that they were plagued by uncertainty about their own health and wondered whether they would be able to continue to lead their normal lives.

Practical incorporation also included the information-seeking and actions taken by participants as they grappled with how to make HIV treatment a reality in their lives. Common among many participants were concerns about where to go for HIV care, the financial implications of HIV treatment, and concerns about HIV status disclosure. Participants discussed realizing that part of their ability to live with HIV included the reality that they had to take medicine every single day. Some participants stated that the idea of taking medication every day caused them great anxiety while others asserted that their lives would not be disrupted by having to take medicine.

Acting on the News: As participants began to incorporate the news, they commenced to take action. Participants described the different ways they navigated through the healthcare system moving from the point of diagnosis to their first entry into the healthcare arena. Some participants were entirely self-directed through the referral process, but many participants shared that employees of local public health agencies were crucial in assisting them in linking with HIV care providers.

Across the study sample, participants discussed attending their first appointment for HIV care and about the relationships they began to develop with care providers. Participants described their initial interactions with HIV care providers as profoundly influential in calming their anxieties about the HIV illness, equipping them with knowledge about HIV, and motivating them to begin HIV treatment.

Moving Beyond the News: All study interviews were conducted at a time point that followed the participants' completion of the intake process. Although not all participants had started taking medication at the time of the study interview, all participants discussed that medical treatment for HIV is providing, or will provide them with the ability to move forward in their lives. Participants discussed moving beyond the news through projections and speculations about their future life with HIV by discussing their life goals in the context of their HIV infection. Some participants described their primary goal as initiating care and starting HIV treatment so that their life could return to the way it was prior to their diagnosis.

Other participants shared that they wanted their diagnosis to be the catalyst that led to a better life than they were living previously. In each case, participants described HIV care

and treatment as the tool that would make it possible for them to accomplish their goals and to move forward with their lives. Participants offered insight into the realization that HIV care providers gave them the tools to move forward, but the choice to pursue treatment was ultimately in their hands.

Influential Factors in Translating the News

The aforementioned description provides an overview of the theoretical framework and the progression through the process of HIV care initiation. Participants' experiences at each stage in the process were uniquely influenced by four factors: their perceived susceptibility to HIV, the presence of symptoms, HIV information, and feedback from others.

Perceived Susceptibility to HIV: Perceived susceptibility is defined as the personal belief that participants had about their risk of becoming infected with HIV. Participants' stories revealed that perceived susceptibility was particularly influential in their experiences with receiving and interpreting the news.

Receiving the News: Perceived susceptibility was influential to participants receiving the news, as it often motivated HIV testing behavior. Some participants knew they were at risk. One participant described his decision to get tested was based on the fact that he had an unprotected sexual encounter with someone who was living with HIV:

"There was a situation that I thought that I probably was at risk and when I went to get tested the results were positive.... When I went to get tested it was just because I actually wanted to get tested because I needed to know."

Other participants were unaware that they were at risk for HIV, and they were tested as part of a diagnostic workup. One participant shared his experience with why he was tested for HIV:

"I was at the hospital. My [Doctor] ran a battery of tests. He had no idea that I would even be considered for an HIV candidate because, you know, I'm not that type of person."

Interpreting the News: Perceived susceptibility was also very influential in the way that the participants interpreted the news they had received. The majority of the participants described receiving the news as a shocking experience. However, the level of distress experienced by the participants differed based on their perceived susceptibility. One participant described learning that he had HIV after being called back to his provider's office following an HIV test:

"I was sad for a moment... and in a very odd way I felt like I had to fake some sadness... I don't know why... because I wasn't shocked by it.... through my life I have kind of mentally prepared myself... but in that moment I remember I felt like I had to kind of fake a little bit of sadness...but I was prepared."

Reasons for low perceived susceptibility included: heterosexuality, not being an intravenous drug user, and being in a monogamous relationship. Some participants described the devastation they felt after receiving the news because they never believed that HIV infection would happen to them. One participant shared her thoughts after learning that she had HIV during a hospitalization for a back injury:

“I got really like emotional. I was like I never ever imagined that would happen to me...the first thing on my mind was oh, my God. I’m going to die. I’m going to be dead within five years.”

Generally, it was not uncommon for participants to have feelings of shock and sadness upon receiving the news. However, perceived susceptibility was found to influence both the reasons for HIV testing (and subsequent receiving of the news), and the interpretation of the news they received, particularly the level of distress the news caused the participant.

Symptoms: The presence of symptoms was a factor that primarily influenced how participants received and interpreted the news. Participants who experienced symptoms described the development and persistence of illness that eventually led them to seek medical attention, sometimes even resulting in a hospital admission. Participants who did not experience symptoms sometimes expressed confusion about their diagnosis.

Receiving the News: Participants shared that their symptoms prompted them to take an HIV test, or led to their providers’ decisions to test them for HIV. One participant described knowing he needed to get tested after persistent flu-like symptoms:

“I was tested again...probably right around three [months later]...it was just time. I’d had a feeling that something wasn’t right. That flu was really bad. I knew that that was it.”

Another participant described learning about his HIV status after being admitted to the hospital for pneumonia:

“At [the hospital] they did a battery of tests, they did two bone marrow biopsies, they went as far as that, and everything kept turning up negative-negative –negative- negative- negative...everything was negative, and I guess he finally went to the HIV test and it came up positive, because he had no reason to believe I would [have HIV], because I’m not a street drug person, I go to work and I go home and that type of stuff. And then, I don’t know what led him to believe to do an HIV test...And I was shocked when it did, and he was shocked too.”

Interpreting the News: Several participants described their difficulty with interpreting the news due to their lack of symptoms and not feeling ill. One participant shared his experience with getting tested:

“So I never thought that I would have had anything, I never showed any symptoms, I never recall feeling - I know it’s common when someone first gets infected to have that really bad cold or flu- I don’t recall ever being sick like that. So I didn’t feel like I was ill or had anything. So it was surprising to hear that too, without having any symptoms that I was – had a virus in me...I never thought that I would have HIV, not once.”

Finally, some participants experienced symptoms but described their confusion about the incongruence between the symptoms that led to their hospital admission and their HIV diagnosis. One participant in the study was admitted to the hospital with leg pain, and was tested for HIV as part of a hospital-based screening program. The participant described his

feelings of shock, and trying to reconcile his admission to the hospital for leg pain, and his discharge with HIV:

“Been in shock ever since [I tested positive]. Go in for one thing, and come out with this other. Life-changing news. At least my numbers were good, and everything else with it. It's been a rough diagnosis.”

Like perceived susceptibility, symptoms primarily influenced the beginning of the process, as participants received and interpreted the news. Symptoms prompted participants and/or their providers to test for HIV, which led to the participant receiving the news of their HIV diagnosis. It was not uncommon for positive tests to lead to confusion for participants, particularly when they did not suspect HIV as the source of their symptoms. Additionally, some participants shared about a similar confusion that resulted from a *lack* of symptoms at the time of diagnosis.

HIV Information: HIV information was influential throughout the entire process. At each stage, participants' experiences varied based on the amount of HIV-specific information they possessed or sought out. Some participants discussed already having knowledge prior to being diagnosed. Typically, prior knowledge was obtained through acquaintance with individuals living with HIV, and reflections on HIV-related information acquired via various media and social interaction. Following diagnosis, knowledge was sought out in a variety of ways, including discussions with individuals living with HIV, discussions with healthcare providers, the internet, and printed materials.

Receiving the News: Participants described HIV information as influential in receiving the news, particularly in the choice to be screened for HIV. In addition to individuals who were self-directed in their actions to be screened for HIV, and others who were screened by providers in the inpatient clinical setting, some participants were screened for HIV because they were prompted to do so by a source of HIV information. One participant described information presented in a television commercial that influenced him to get tested with HIV, and to subsequently learn that he had HIV:

“I seen' this commercial...and it was saying know your status...the first time the commercial came on, I paid attention to it but it kind of like passed by me. Then when it came on again about 25 minutes later, I'm like, I gotta go get tested...I gotta go get tested.”

Several participants discussed having feelings of disbelief when receiving the news, and seeking out information on the possibility that their HIV test was wrong. Information sources included the internet and conversations with healthcare workers. One participant described the conversation he had with a clinic nurse during a discussion about his positive HIV test result, and the internet research he did to confirm what she said:

“[The nurse] said, Your results came back that you have HIV...I said, Are you sure?... and she said, yes, you're producing antibodies on both tests...[I said] Is there any chance that the test might be wrong?...[she said] most likely not. I tried to search online...the main search that I was looking online for was a false-positive...on a test... that there is a very slim chance.”

Interpreting the News: Perhaps more than any other stage in the process, HIV information influenced the way that individuals interpreted the news of their HIV diagnosis. The majority of participants reflected on the conceptions they held prior to diagnosis about

HIV as a disease and the people who get it. Often, participants admitted to having negative opinions and limited education about HIV. One participant described his feelings toward people with HIV prior to his own diagnosis:

“When I first started hearing about HIV and finding out that some people have it and things like that, I mean I was freaked out myself. I was like, Oh, you have HIV? Like, I don’t want to hang out with you at all. Like, I don’t want to be around you. Like, I don’t want to get it.”

After receiving the news, participants shared about the HIV knowledge they had at the time of diagnosis and their efforts to obtain information about HIV to gain a greater level of understanding. Sources of information included: various forms of media, conversations with healthcare providers, interactions with acquaintances living with HIV and the internet.

The media affected the HIV-related information that the participants discussed. Participants described knowing about HIV through television show characters, film cast members, celebrities, commercials, and HIV-related initiatives aimed at increasing HIV awareness. Individuals varied in whether the information obtained from the media was positive or negative in their eyes. Some individuals discussed only knowing about HIV through high profile individuals whom they knew had HIV and died from AIDS. One participant described his fear of HIV based on what he had seen on TV:

“They [Robert Reid and Rock Hudson] were nice leading men on TV, and then in their dying years, they showed pictures of them after they had passed. I don’t know if you’ve seen the images or not or whatever, but they were just, like, frail.”

Other individuals discussed knowing about HIV from seeing high profile individuals who are healthy and living with HIV:

“[Magic Johnson] has been going good for years since he’s been diagnosed, and real healthy.”

Participants described the influence of the media as something they reflected upon after receiving the news, and often these reflections elicited strong emotional responses, particularly when the media were related to death from HIV. In many cases, individuals were not able to define specific media from which they knew about HIV. Rather, media was often discussed as a general term to describe HIV as something that one living in this day and age hears about (i.e. ‘you hear about it all the time’).

One of the most common ways in which individuals found meaning in their diagnosis after receiving the news was through efforts to find information about HIV on the internet. Participants described the specific ways they used the internet to learn more about HIV so they could understand what was happening to them. Participants described the use of smart phones and computers to visit a multitude of websites to gain insight into the news they had received. The directions participants took when using the internet was often governed by whether they were provided with internet-specific resources. For example, some participants were given specific websites that clinicians recommended they visit to get more information about HIV. Participants who used the OraQuick™ home testing kit were provided with internet resources in a booklet that comes with the product.

The majority of participants described using search engines, specifically Google, to search out information on HIV. Participants thoroughly described the searches they performed. One participant described using the internet to find out more about HIV:

“I need[ed] to look more up on the HIV. So I spent hours and hours on the computer just looking things up. And I think more importantly reading different blogs more than anything else...I started off at Google and just typed in...new HIV infection...And everything pops up.”

Across the sample, many websites were described that provided participants with information about the HIV disease process, medications that are available to treat HIV, images of individuals living with HIV, HIV-related statistics, personal stories and experiences of individuals living with HIV, and local HIV-specific groups, events, and venues. Participants described their use of the internet as crucial to obtaining information that taught them about HIV, influenced their feelings about the disease and the news they had received, and influencing the decisions they made about their next steps. In nearly all cases, individuals described their use of the internet as helpful as they interpreted the news of their HIV diagnosis.

As participants were interpreting the news, some of the most influential sources of HIV information were other individuals living with HIV who shared their personal experiences with the participants. Individuals living with HIV were particularly influential in helping participants to realize that their HIV diagnosis was not a death sentence. One participant shared that he immediately sought support from a friend with HIV after receiving the news:

“I just knew that I wanted to go and talk to him because he um...he’s...he’s a really good friend and I knew that he would give me good information like...where I go from here. I went and I talked to him and he said, this is what’s going to happen...you’re going to go get blood work done, you’re going to go get medicine, you’re going to start medicine....And...all these things are going to happen....And then you can just go on living your life.”

Incorporating the News: HIV information also influenced the way that participants incorporated the news, both psychologically and practically after being diagnosed. Many participants described how other people living with HIV helped to give them insight into living life with HIV. One participant described realizing the reality of living with HIV after an interaction with a friend who was living with HIV:

“The day before he approached me I didn’t expect to be [monitoring my health]. And then just suddenly it happens. This is – that’s my reality now...there won’t be a day in my life that I don’t have to take a pill now or I’ll be going – I’ll be getting blood drawn constantly, because that’s my life. I’ll be on vitamins for the rest of my life.”

Participants also shared about the use of HIV information to help prepare them for the practical realities of living with HIV on a daily basis. One participant described doing research about changes he would need to make in everyday situations:

“I have a knowledge is power mentality. I wasn’t afraid of learning about...what it meant for me and how it was going to change my lifestyle. I

even worried about telling my dental hygienist and just visualizing her having to put a face mask on that she didn't used to wear before and coming to terms with feeling like my semen and my blood were toxic to my partner."

Acting on the News: After participants made the decision to pursue care, they described using HIV information when acting on the news. Participants described using conversations with healthcare professionals, internet resources, and interactions with individuals living with HIV to learn what steps to take to practically incorporate HIV care and treatment into their lives. Participants sought out information about local HIV care facilities and the providers that work there. Acquaintances living with HIV were able to provide insight into how the process of getting started in care would work. Participants were also able to learn about local HIV resources using the internet. One participant described visiting the website of a local HIV treatment center which influenced his decision to approach them for care:

"I don't remember exactly what it said... but it gave me the feeling that they knew what they were doing. They have been around and they have very experienced and qualified people that can help me. Because I didn't want to go to some guy who for all intents and purposes, has a private practice."

Multiple participants described using materials they received while being tested for HIV and web-based resources to become more educated about HIV and its treatment prior to approaching their HIV care providers for the first time. One participant described reading HIV literature from his primary care provider and from the internet prior to his first appointment with an HIV provider:

"I was thirsty for knowledge I needed to control the situation...I needed to take in as much knowledge as possible so that I'm educated about the subject...I know what to expect when my appointment happens...I don't know what questions I should ask...I want to know what route to take next...I need to be able to look at a doctor and say are you going to be adequate for my needs?"

Another participant discussed using web-based resources to investigate medical treatment options prior to his appointment with his HIV provider:

"I was very concerned about the side effects. I already have pretty high cholesterol and I knew some increased cholesterol. I have a history with depression and anxiety and night terrors. Those class of drugs that increase – have the potential to increase anxiety and depression and vivid dreams, I was very concerned about. I went into my first appointment with those – with that knowledge and those questions to ask."

In addition to HIV information obtained prior to care initiation, nearly all participants described the information they received during their new-intake consultation as profoundly helpful and influential in their decision to pursue HIV treatment. One participant shared about the profound impact that the new intake visit had on him:

"I get back there with [New Intake Nurse], and it was the tip of the iceberg for the phrase knowledge is power because when it comes to HIV, it's absolutely

what it is because I feel so much more ready to deal with this because I know more.”

Moving Beyond the News: Participants described how the information they had received, particularly from their initial appointments with HIV providers was going to influence their future paths. Participants often described feeling very hopeful for their futures after meeting with HIV care providers, and described their care and treatment efforts as the necessary tool to help them achieve their goals. One participant described a takeaway message from the information provided at his intake visit:

“I think that I will be okay...today’s medicine is improved so much...the way [New Intake Nurse] explained it to me, you can also take a pill a day and it will take your T cells up and try to make your viral load very low...stuff like that to make you feel you’re going to live a healthy life...everything is going to be okay as long as I get treated.”

Feedback from Others

Another factor found to be influential throughout the entire process was feedback from others. Feedback from others included personal interactions, conversations with other people, and even their perceptions about others’ beliefs. At each stage in the process, participants described their interactions with people in their lives, including healthcare providers, family members, friends, and even people they did not know.

Receiving the News: Feedback from others was very influential to how individuals with HIV experienced receiving the news. Participants often discussed their feelings about the way they were told about their HIV diagnosis. Some participants described an optimal experience in which they were provided both informational and emotional support, while others believed that they did not receive adequate support. One participant described his appreciation for the way a public health worker delivered the news:

“It was a wonderful experience because she was just totally compassionate and totally understanding with the situation that was gonna occur. When she was gonna report the findings to me, she done it in a way that I didn’t feel no harm is gonna come to me.”

Other participants described feeling as though their provider did not offer them adequate support. One participant described his interactions with his provider the day that he was diagnosed:

“There was no information given about where to go, what to do. Do you need counseling? Do you need help? There was no assessment taken of anything about me. You’re HIV positive. Here’s a doctor that you might want to call to make an appointment. Have a nice day. Simple as that.”

Some individuals did not receive the news in a clinical environment, but instead, chose to take the test at home. Several individuals shared that they wanted to have someone else with them when they took the test at home. Such people included siblings, partners, and friends. One participant described learning about his HIV status with friends while taking a home test:

“He said that mine was positive. And then like I said, I just started crying. And they both held me, and as I’m bawling my eyes out and getting snot and tears everywhere, all over their shirts and just whatever. They just – they were there for me when I was having a low point. And we were close before, but we’ve been closer since.”

Interpreting the News: Participants also described the effect that feedback from others had as they interpreted the news. Often, individuals speculated on what other people were going to think about them now that they had HIV. One participant described his concerns about the opinions of others while at a social gathering with loved ones who did not know he had HIV:

“I am HIV-positive. None of these people know I’m HIV-positive... but I’m HIV-positive. And I thought what is [friend’s] family going to think when I tell them... They are like my second family even more than my first family. I mean, they are so close to me. What are they going to think? When am I going to tell them? Will I ever tell them?”

Other participants shared their fears about having HIV based on what they believe society generally thinks about people with HIV. As one participant stated:

“A whole bunch of things go through your head...but it’s always fear of judgment...some people attribute it to being a gay disease. Some people attribute it to just being flat out nasty...not having protected sex...I felt fear of judgment...[when] you [are] dealing with a complete stranger, you have nothing to fear. But when you’re dealing with somebody that know your status, you don’t know their opinion or their beliefs on HIV.”

Another participant shared:

“I thought people were just going to reject me just because of the diagnosis and not actually get to understand me as a person...more like a presumption like, oh you’re HIV positive...you’re...you’re a slut, you’re like...you’re dangerous...you don’t take care of yourself. Things like that.”

Participants also shared about the impact that positive feedback from others had on their ability to interpret the news. One participant discussed his healthcare provider talking to him about HIV stigma:

“What I was most afraid of in that moment was the stigma part of it because I was thinking about that... And she was very quick to reply with the only stigma that it has is the stigma that you give it. So it doesn’t matter what other people are thinking... You need to be empowered.”

Several participants described interactions with friends and family after receiving the news that helped them as they interpreted what their diagnosis meant in their lives. One participant described that he felt guilty about getting HIV, and his sister helped him to get perspective:

“[She said] Don’t walk around moping and mad and feeling like it’s your fault... it can happen to anybody...A weight was lifted off my shoulder when she told me that... because...somebody was already in my corner...I was already...I was already took under somebody’s wing...somebody actually cares about me.”

Incorporating the News: Feedback from others was also very influential in the incorporating stage of the process. Participants shared that healthcare workers, friends, family members, and acquaintances living with HIV helped them to realize that HIV was not a death sentence and gave them insight into their reality of living with HIV. One participant shared that his sibling encouraged him to realize that his HIV status did not change him as a person, but rather added a component to his life:

“[She said] don’t let you having this virus affect your life. She said, the only thing that’s going to be different about you having this is you’re going to be taking medicine.”

Participants also described the impact of receiving feedback from individuals living with HIV, in particular, observing their ability to lead normal lives. Often, it was the feedback from these individuals that truly defined that HIV was not a death sentence for participants. One participant shared about observing his friends with HIV leading healthy lives.

“I’m amazed at how many people that I know that are HIV positive...that has turned into a really good thing for me...they’re like living a functional healthy lifestyle, and that has become very helpful.”

Acting on the News: Feedback from others was often crucial to participants as they took action to initiate their care. One of the greatest challenges for many of the participants was taking their first steps into HIV-specific healthcare. Often, participants were fearful about having to discuss their HIV status for the first time since being diagnosed. One participant described his anxiety about calling the HIV treatment center for the first time:

“I felt nervous because I made the phone call and I got a secretary...A general person...And I remember I was going to have to say the words ‘I was diagnosed HIV-positive can you connect me to someone who can help me?’ ...it made me feel bad that this person is going to know that I’m HIV-positive and they are going to judge me now.”

Similarly, multiple participants experienced anxiety upon entering the HIV treatment center for the first time. As one participant shared:

“I’m thinking, Is this doctor going to like me? Am I going to like this doctor? Is the nurse going to look at me this kind of ways? You understand? Is other people in the lobby looking at me wondering why I’m [here]?”

Some participants described being championed by people in their lives as they prepared to go into care. One participant shared about his mom helping him overcome his fear of talking to HIV healthcare workers for the first time about his HIV status:

“My mom is like my cheerleader. We were on the way there and she's like I can't tell. I cannot fathom walking up to a stranger and telling them this. She says, no you're gonna walk up and you're gonna tell them, and we're gonna start this. This all starts today.”

Participants discussed interactions with healthcare workers that helped them in the care initiation process. Such individuals included public health workers, clinicians, and office workers. One participant shared about the nurses and office workers at the HIV treatment center and the impact they had during the care initiation process:

“She talked to me like I was a normal person...she asked me what I do...why I was there...She just made me feel at ease...She made conversation with me...it wasn't about you're here for the first time as an HIV-positive person...It was...let's have a conversation and that's what made me feel really good.”

Moving Beyond the News: Participants shared that feedback from others was instrumental in helping them to move beyond the news. In addition to their own thoughts and feelings about their life goals, participants shared that friends, family members, clinicians, and acquaintances provided them with encouragement and helped them to feel hopeful as they moved forward. One participant shared the encouraging words he received from his friends:

“[My friends] have been telling me...Get on medicine. Just go to the doctor...get help... do that as quickly as you possibly can, and you'll be fine. You can do whatever you want to do.”

Finally, another participant shared advice given to him by his family regarding his future life with HIV:

“Be strong... you've still got a full life ahead of you...do what you need to do to get what you want...having HIV does not stop you... does not stop the show. All it does is make you look at life more carefully.”

The data in the study revealed the process of translating the news. Following diagnosis, participants progressed through a series of stages from the time they were diagnosed with HIV to the time that they initiated HIV care. These stages included: receiving the news, interpreting the news, incorporating the news, acting on the news, and moving beyond the news. As they progressed through the process, participants' experiences were influenced by their perceived susceptibility to HIV, the presence of symptoms, HIV information, and feedback from others.

The findings in this study are in line with the findings of current research on psychosocial factors that influence the initiation of care by individuals living with HIV. The results of the present study suggest that the psychosocial process is defined by the movement from negative beliefs (bad news) to hopeful, positive beliefs (good news). Perret and Biley (2013) yielded similar results in the *Negotiating Uncertainty Theory*, in which eight participants described their transition into life with HIV. Similar to the present study, the investigators uncovered a process in which individuals move from hopelessness to optimism following HIV diagnosis (Perrett & Biley, 2013). Participants' stories about incorporation complements findings by Mallinson et al.'s (Mallinson et al., 2005) *Maintaining Normalcy Theory*. Participants in the study (n=27) demonstrated that successful engagement in HIV

care is influenced by contending with obstacles and assimilating HIV care and treatment into their everyday lives (Mallinson et al., 2005). Similarly, incorporation allowed participants to begin the process of moving forward after being diagnosed with HIV.

As evidenced at each stage of the theory, participants' experiences about initiating care were often shaped by feedback from people in their lives, including family, friends, significant others, and healthcare workers. This finding is closely aligned with current literature that suggests the presence of social support increases the likelihood that individuals will successfully engage in HIV care with minimal distress (Burns et al., 2007; Craw et al., 2008; L. I. Gardner et al., 2007; Hightow-Weidman et al., 2011). When describing the experience of receiving the news, some participants described the experience as negative when they did not feel the provider was supportive or understanding about the diagnosis. This finding is also well-supported in current literature on provider-patient dynamics that suggests that negative interactions with healthcare workers has the potential for clients to lose trust in providers and can deter the care initiation process (Barfod, Hecht, Rubow, & Gerstoft, 2006; Kinsler et al., 2007; Mallinson, Rajabian, & Coleman, 2007; Nordqvist et al., 2006; Sprague & Simon, 2014). Finally, participants expressed the importance of their first HIV care visit to their ability to obtain HIV knowledge and to move beyond the news. This finding is similar to findings by McCoy et al.'s (2009) investigation in which individuals diagnosed with HIV cited their first HIV care visit as critical to their coping process following HIV diagnosis.

Our study contributes to the current state of the science in several ways. First, while investigations to identify specific psychosocial factors that influence HIV care initiation have been conducted, no study to date has explored the specific psychosocial process of HIV care initiation. Second, while the impact of patient-provider dynamics on medication adherence has been investigated, this study contributes insight into the impact of patient-provider dynamics during diagnosis, referral, and intake. Finally, the present study establishes that a crucial component of the HIV care initiation process is each participant receiving not only the news of their HIV infection at diagnosis, but also the importance of in-depth discussion about HIV infection not being a death sentence. This is a critical juncture that often prompted participants to begin searching for HIV-specific healthcare.

This study has several limitations. Although the majority of participants were interviewed within two months of their diagnosis, the retrospective design allows for error in recall of events and details shared by participants. The majority of the study sample was Caucasian men who have sex with men. Although the study team did not identify significant differences based on gender or race/ethnicity, the study is limited by underrepresentation of women and racial/ethnic minorities. The team only interviewed individuals who had initiated care, and was not able to capture the experiences of individuals who have not made healthcare contact following diagnosis. Finally, the findings of the study are not generalizable to the general population, but rather, are transferrable to similar samples.

The results of this study provide a framework for clinicians who are working with newly-diagnosed HIV patients. Participants often felt emotionally distressed upon receiving the news, but reported feeling much better about their situation when they learned that a) HIV was not a death sentence, and b) there are many options for treatment despite any preconceptions. As such, clinicians should be diligent in providing both emotional and informational support to people newly diagnosed with HIV. Finally, participants in the study consistently sought out information using various media in order to learn more about HIV. Clinicians should provide newly diagnosed individuals with reliable, literacy-appropriate resources, and encourage patients to become actively involved in the initiation of their care and treatment.

Participants consistently cited acquaintances living with HIV as an invaluable source of support. Future research should examine the impact of developing and implementing HIV

support interventions leveraging participation from individuals living with HIV. Partnership between clinicians and individuals living with HIV will help to provide optimal informational, emotional, and social support following HIV diagnosis. Since so many of the participants discussed using the internet as a source of information following diagnosis, future research should determine the impact of web-based interventions that are aimed at promoting transition into HIV care for individuals newly diagnosed with HIV. The results of the study provide evidence that micro-system level interventions should be developed to transition individuals diagnosed in the primary care setting into HIV care. Finally, community-based investigations should be conducted to gain insight from the experiences of individuals who have tested positive for HIV but have not initiated HIV care.

Conclusion

HIV treatment presents both individual and community-level health benefits. Gaining a greater level of understanding of the process of HIV care initiation will result in a greater number of individuals being linked with care, and by extension, provide a strong contribution to stopping the spread of HIV.

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