# "I'm Gonna Get Busy Living": Examining the Trajectories of Affect, Behavioral Health, and Psychological Resilience Among Persons Living With HIV in a Southeastern U.S. Health District

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#### Abstract

Internal psychological states and coping processes are significant determinants of resilience. The primary aim of this qualitative work is to provide further insight into how core affect influences the adaptability of persons living with HIV (PLWH) after diagnosis. In-depth interviews were conducted with a diverse group of PLWH in a health district located in the Southeastern United States. A deductive-inductive approach was taken while coding and analyzing, N = 18 participant narratives concerning the psychological and coping processes surrounding diagnosis and engagement in care. Active behavioral and cognitive coping after diagnosis was exhibited by PLWH expressing salient attributes of positive affect, whereas the salience of negative affect among PLWH was associated with avoidant coping and heightened distress. Our findings illuminate the beneficial role of positive affect and active coping on the health and well-being of PLWH. The study implications extend to the development and enhancement of programs designed to fortify psychological resilience.

#### **Keywords**

HIV, HIV treatment, qualitative, health psychology, affect

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# Introduction

The primary appraisal of an event such as HIV diagnosis as "threatening" or "relieving" or "good" or "bad" is largely influenced by affect and emotional response (Barrett, 2006; Fredrickson, 2001; Lazarus, 1991). Affect is defined as the subjective feelings or mood of individuals. It is theorized that positive affect and emotions are beneficial in times of crises because they activate and expand conflict resolution capabilities, increase access to resources, and initiate active coping processes (Folkman & Moskowitz, 2000; Fredrickson, 2001). The strategies that individuals use to cope with the stress associated with HIV diagnosis has serious implications for their livelihood and quality of life. While behavioral coping is defined by the external efforts that individuals take to manage the stressor, cognitive coping refers to psychological processes. Numerous behavioral and cognitive coping strategies have been identified but most can be categorized as either active or avoidant (Hansen et al., 2013; Roth & Cohen, 1986). Active coping includes strategies in which the individual attempts to mitigate or resolve the stressor through direct engagement and avoidant coping includes those aimed at reducing stress ignoring or denying the issue altogether (Hansen et al., 2013; Roth & Cohen, 1986). Avoidant coping is also exhibited by diverting away from the stressor and onto other issues. An individual who is actively coping in response to receiving news of an elevated viral load may seek new therapies (behavioral coping) or reduce anxiety by setting goals for reducing their viral load (cognitive coping). Alternatively, an individual who is coping through avoidance may drop out of care due of discouragement (behavioral coping) or challenge the validity of the results (cognitive coping) (Hansen et al., 2013; Roth & Cohen,

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1986). The literature suggests that among a diversity of responses to HIV diagnosis by persons living with HIV (PLWH), positive affect is positively associated with problem-resolution through active behavioral and cognitive coping (McIntosh & Rosselli, 2012), whereas negative affect is most strongly associated with increased avoidant or disengagement coping (McIntosh & Rosselli, 2012). Although evidence-based theoretical models propose mechanisms by which affect interacts with coping and health behaviors (Billings, Folkman, Acree, & Moskowitz, 2000; Moskowitz et al., 2014; Pressman & Cohen, 2005), the literature provides limited insight into how these mechanisms evolve along the HIV chronic illness trajectory. Given the alarming attrition rates along the HIV Care Continuum (Centers for Disease Control and Prevention, 2018), there is a critical need for a clearer understanding of the health and social trajectories of affect, behaviors, and resilience after HIV diagnosis.

Quantitative research has substantially contributed to the current knowledge concerning the association between affect and health (Fredrickson & Joiner, 2002; Gana et al., 2016; Park-Lee, Fredman, Hochberg, & Faulkner, 2009; Pressman & Cohen, 2005). Although an extensive review of the literature (Pressman & Cohen, 2005) concludes the evidence concerning linkages between positive affect and mortality to be inconclusive, the collective results from studies conducted on PLWH suggest positive affect to be a significant predictor of HIV mortality, in addition to constructive health management behaviors (Billings et al., 2000; Carrico & Moskowitz, 2014; Ickovics et al., 2006; Moskowitz, 2003; Moskowitz et al., 2014; Wilson et al., 2017). In prospective studies of PLWH (Ickovics et al., 2006; Moskowitz, 2003), researchers found that greater positive affect was associated with a lower risk of death from AIDS. Specifically, in research with women living with HIV (Ickovics et al., 2006), researchers found positive affect to be among psychological resources associated with lower risk of HIV mortality via increased CD4 counts and an increased likelihood of viral suppression (Wilson et al., 2017). Another prospective cohort study of men living with HIV (Carrico & Moskowitz, 2014) found that positive affect predicted increased odds of HIV care linkage at 3 months post-HIV diagnosis and increased odds of antiretroviral therapy (ART) persistence 18 months post-HIV diagnosis.

Comparatively, less is known about negative affect. Although negative affect is commonly conceptualized as a component of mental and emotional health (Vance, 2006; Woodward & Pantalone, 2012), very few studies on PLWH have isolated and examined negative affect as a separate construct, apart from associated mental health conditions (e.g., depression, anxiety). Consequently, knowledge on the acute and long-term impact of negative affect on health and behaviors of PLWH is largely ambiguous. Although some research has found negative affect to mediate relationships between social support, self-stigma, and depression in men living with HIV (Li, Mo, Wu, & Lau, 2017) and moderate the relationship between self-efficacy and unprotected sex and alcohol use and unprotected sex among PLWH (Barta, Tennen, & Kiene, 2010), findings regarding the association between affect and HIV care behaviors are understudied and unclear. For example, Carrico and Moskowitz's (2014) study of men living with HIV reported insignificant relationships between negative affect, care linkage, and ART persistence. However, recent research has contrarily found that increasing negative affect attenuates the positive relationship between positive affect and viral suppression among women living with HIV (Wilson et al., 2017).

The results of previous quantitative studies have provided a limited knowledge base regarding key biological endpoints associated with affect; nevertheless, more remains to be known about how affect (positive and negative) is associated with social, behavioral, and cognitive adaptability after diagnosis. Specifically, lived experiences delineating the health and social trajectories of affect after HIV diagnosis remain unexplored. In-depth examination of the sequence and experience of phenomena, such as psychological states and coping is a methodological strength of qualitative research (Folkman & Moskowitz, 2000). Previous qualitative research has contributed an improved understanding of the processes by which PLWH evaluate HIV diagnosis, navigate challenges and support systems, and cope with HIV illness, stigma, and other stressors (Barroso & Powell-Cope, 2000; Casale, Wild, & Kuo, 2013; Liamputtong, 2013; Moskowitz & Wrubel, 2005; Swan, 2016; Williams, Amico, & Konkle-Parker, 2011).

To date, qualitative data regarding affect and emotions have primarily resulted from studies aimed at examining other factors and processes (e.g., fear of death, guilt, anger and low self-esteem) associated with mental and behavioral adaptation (Liamputtong, 2013; Moskowitz & Wrubel, 2005; Williams et al., 2011). For example, in a 2011 study exploring the coping strategies of HIV-positive women, researchers observed how meaning-making processes were associated with positive thinking and emotional well-being (Liamputtong, 2013). That is, positive thinking can reduce stress by eliminating self-talk, which in turn, can improve positive affect. In another study of barriers and facilitators to HIV treatment, researchers found that PLWH described negative affect as a common barrier to HIV care, among other factors (Williams et al., 2011). Although these qualitative studies and others have captured themes pertaining to the role and importance of certain dimensions of affect to a variety of factors, we are not aware of any previous studies that have directly investigated affective pathways toward treatment and wellness among PLWH.

Qualitative research methodologies are key to exploring unexplained phenomena and offer the opportunity to gather the descriptive evidence needed to study the evolution of affective and adjustment processes that take place after HIV diagnosis, in addition to the ways that they might influence PLWH health and progression along the HIV care continuum (Folkman & Moskowitz, 2000). Furthermore, a semi-structured interview format enables participants to openly express emotional and affective vocabulary while allowing researchers to probe for deeper understanding of participants' subjective interpretations of the emotions, events, and behaviors concerning the research themes (Ayres, 2008). There is substantial benefit to examining positive and negative affect beyond adaptive and maladaptive coping because our interview format could, for instance, identify other issues which could help inform components of a resilience program and/ or intervention.

This present study aims to add to the existing literature by exploring the prospective interrelationships between affect, coping, and resilience among a sample of PLWH residing in a large health district. Fredrickson's (2001) broaden and build theory served as the guiding framework for the research. According to the theory, positive and negative affect define the difference between thriving or surviving. Whereas negative affect is helpful in triggering acute responses to survival threats, positive affect expands the capacity to engage in sustained active coping while also building resilience. Resilience is defined by the ability of individual to rebound during and after experiencing adversity (Tugade & Fredrickson, 2004). Resilience is particularly important for PLWH because it buffers the impact of distressful circumstances on multiple aspects of their health (Farber et al., 2000).

The specific aims of the present study were to enhance understanding of (1) how participants respond to HIV diagnosis from an affective standpoint; (2) whether or how affect corresponds with coping processes; (3) whether or how affect transitions over time, events, and circumstances; and (4) the psychosocial and behavioral pathways of affect following HIV diagnosis. By analyzing the narratives of PLWH with a diversity of HIV care experiences, we contribute to a greater insight and understanding of the psychological linkages that comprise cognitive-behavioral social pathways whereby affect influences adaptive functions and health over HIV illness careers. The implications of doing so extend to supporting the development of programs aiming to intervene on affect, coping, and build resilience among PLWH throughout HIV diagnosis and beyond.

#### Method

The data from this study come from the qualitative portion of a mixed-methods comprehensive Ryan White needs assessment for a health district located in the Southeastern United States. The purpose of the larger project was to inform the provision and coordination of HIV services within the health district through an improved understanding PLWH lived experiences with accessing HIV care (see Huff, Chumbler, Cherry, Hill, & Veguilla, 2015 for more detailed information regarding the study aims). For this particular study, we specifically focused

on the affective and emotional aspects of participants' experiences from the point of diagnosis.

#### Sampling and Recruitment

We employed a purposive sampling strategy to attract voluntary research participants who met the criteria for inclusion in the needs assessment. Recruitment criteria aimed to get participants with diverse HIV diagnosis and care experiences in Northeast Georgia. Those who were included in the study were adults between the ages of 18 and 65, who resided in the health district and had accessed HIV care in the health district. A combination of methods were used to recruit a purposeful sample of PLWH who were active within HIV care settings, as well as those who may have been hidden from such environments, yet present in the broader community, while safeguarding anonymity. Staff and personnel at the local HIV specialty care clinic and AIDS service organization (ASO) assisted with the recruitment of potential participants who were accessing care and social services at the facilities. In addition, flyers were posted at the HIV clinic and ASO offices, as well as public community venues. Flyers were also given to participants after interviews, with the goal of reaching potential participants who may have been hidden from formal clinical and organizational settings (e.g., snowball sampling). Those who met the inclusion criteria for the study were scheduled for an interview to take place in a private room located at the HIV specialty care clinic or ASO.

# Data Collection

The Institutional Review Board (IRB) at the University approved all procedures prior to data collection. Participants (N = 21) were interviewed using a semi-structured guide structured upon the purpose and aims of the needs assessment. Specifically, the guide consisted of questions designed to solicit participants' experiences surrounding their HIV diagnosis, engagement in HIV-care, and evaluation of the HIV care system. The primary questions from the in-depth interview guide are displayed in Table 1. Prior to each interview, participants engaged in an informed consent protocol, in which the interviewer read aloud a consent form detailing the study purpose, procedures, and potential benefits and harms. Each participant was provided with a copy of the consent form and given the opportunity to provide verbal consent and ask any questions about the research project. Interviews were conducted by four project team members (three women and one man), ranging between the ages of 24 and 33. Each interviewer was experienced in conducting in-depth qualitative interviews. All interviews were audio-recorded and lasted an average of 20 to 40 min. After the interview, participants completed a brief demographic survey and were provided with a US\$15 gift card. The purpose of the survey was to collect data on the sociodemographic characteristics of our sample (e.g., age, race, gender identity).

Table 1. Primary Questions From In-Depth Interview Guide.

- Can you describe the circumstances that led to you being tested and your diagnosis?
- 2. Can you tell me about your experiences using \_\_\_\_\_\_ (facility name) to access care?
- 3. What do you think were the most important factors affecting the experiences you described, both positive and negative?
- Based on your experiences, can you tell me about HIV prevention and/or education services offered in your community
- 5. Based on your experiences, what do you think are the most important informational or educational services that are (or should be provided) to your community to help people access and benefit from health care
- Describe the ideal HIV prevention program for \_\_\_\_\_ (for MSM, women of child bearing, etc.) in your community
- 7. Is there anything else regarding HIV/AIDS care you would like to share with us today?

#### Data Analysis

Analysis of the qualitative data occurred through a staged deductive-inductive approach (Fereday & Muir-Cochrane, 2006). All interviews were transcribed verbatim onto Microsoft Word documents via an independent transcription agency. During the transcription process, researchers were informed that three of the audio recordings were inaudible and could not be transcribed. Therefore, the final sample of transcript included 18 interviews, versus the original 21 interviews that were collected. The demographic characteristics of the sample are presented in Table 1. Microsoft Word documents containing the transcripts were imported into the NVivo 10 software package. NVivo 10 was used to organize transcripts according to participant ID, develop the coding schema, and analyze the data (Fereday & Muir-Cochrane, 2006).

Data analysis was concurrent with collection. The staged deductive-inductive analysis process began with the development of an initial coding template. Prior to the analysis, two trained coders met together to establish an initial coding template and a mutual understanding of code definitions, meanings, and application. The coding template was based upon the research objectives, questions in the semi-structured interview guide, and related themes identified by an initial review of the literature. After the template was developed, the coders worked simultaneously in evaluating transcripts for participants' affective verbal expressions concerning the events surrounding their experiences of HIV-AIDS diagnosis, life after HIV diagnosis, and history of involvement in HIV specialty care. Verbal expressions of affect were coded according to emotional attributes along the valence and arousal dimensions of the Affective Circumplex Model (Feldman Barrett & Russell, 1998; Posner, Russell, & Peterson, 2005), which conceptualizes positive and negative affectivity along axes ranging from

miserable to gratified, displeased to pleased, upset to serene, distressed to calm, lethargic to energized, and depressed to thrilled.

The Affective Circumplex Model is a measure that has previously been used to extract self-reports on verbal emotional experiences (Barrett, 2004). Statements, adjectives, and idioms that corresponded with attributes of distress, lethargy, depression, misery, upset, and displeasure were interpreted to represent negative affect. Conversely, statements, adjectives, and idioms communicating attributes of gratification, pleasure, serenity, calmness, energy, and thrill were interpreted to be representative of positive affect. The congruence and frequency of positively and negatively worded emotion-related language and idioms pertaining to participants' experiences with HIV diagnosis and care were further considered in the analysis of transcripts. Although reviewing and analyzing the transcripts, the coders collaborated in expanding and refining the coding schema based on the emergent themes that precipitated from the data. Themes were identified throughout the process of reviewing narratives line by line while applying codes initially found during a review of the literature. Analysts also identified themes by highlighting and discussing the meaning of redundant words and phrases that appeared in transcripts, while systematically comparing coded content. Finally, idioms (or figurative phrases) expressing affect were used to identify and classify text into code-able segments. This collaborative process resulted in the development of a secondlevel code list, consisting of overarching themes and subthemes.

The expansion and revision of the code list was concluded once analysts reached a point at which no new themes emerged from the data. Once the codebook was finalized, coders concurrently reviewed and applied the expanded code list to the transcripts. Finally, the coders organized the finalized code-list according to participant ID and analyzed the data using Matrix Coding Queries. To maintain analytic rigor and support the dependability of coding throughout the analysis, the coders arranged biweekly meetings to compare and resolve coding discrepancies through established consensus. The coding schema is exhibited in Table 2 and coding definitions and examples are presented in Table 3.

#### Results

The following sections chronologically summarize the results of the analysis according to each study aim. The results presented in the first section reference findings stemming from our initial aim of exploring affective responses after HIV diagnosis (Aim 1), whereas the second describes our results regarding how affect corresponds with coping processes (Aim 2). The last two sections present findings pertaining to our final aims concerning whether or how affect transitions over time, events, and circumstances (Aim 3) and the psychosocial and behavioral pathways of affect post-HIV-diagnosis

of In-Depth Interview Transcripts.			
Care lapse			
Care linkages			
Coping			
Coping responses to distress			
Coping responses to adversity, other			
Diagnosis narrative			
Learning and growing			
Meaning in life, finding			
Narrative linkages			
Negative affect			
Negative outcomes, specific			
Negative stress and distress			
Idioms of distress			
Non-idiomatic stress and distress			
Personal goals, achieved			
Personal, specific			
Positive affect			
Idioms of positive affect			
Non-idiomatic positive			
Positive and negative juxtaposed			
Positive outcomes, specific			
Regulating exposure to stressors			
Resilience			
Social network participation			
Social net resources			
Social network members			
Sources of distress			
Sources of positivity			
Specific adverse circumstances			
Specific positive circumstances			

Table 2. Coding Schema Developed During Qualitative Analysis

(Aim 4). The demographic characteristics of our sample are presented in Table 4.

# Aim 1: Affect Post-Diagnosis

Upon being diagnosed with HIV, participants reported a variety of emotions, ranging from positive to negative and oftentimes, mixed. Although a minority of participants specifically recalled a momentary state of distress overruled by positive affect (n = 4; one transgender woman, one cisgender man, and two cisgender women), the majority endured prolonged periods of distress and negative affect (n = 9; five men and four cisgender women); the remaining did not recall any salient positive or negative emotional reactions (n = 5; three cisgender men and two cisgender women). This confluence and sorting out of emotions is aptly demonstrated in the following participant's recollection of her diagnosis experience:

The day that they told me, in the back of my mind, I'm like, "This is a death sentence." No. I'm not fitting to die. God tell me when I'm gonna die, so I'll just see . . . I was determined from the get-go I'm gonna live with it. (Participant 1; cisgender woman)

Through analysis of in-depth interviews, we found that most of the participants (n = 14; seven cisgender women, six cisgender men, one transgender woman) had engaged in care (active behavioral coping) immediately after receiving an HIV diagnosis. The remainder of the participants (n = 4;three cisgender men, one cisgender woman) delayed care linkage (avoidant coping) for periods ranging from 2 months to 10 years. PLWH who recalled feeling optimistic, energetic, and hopeful at the time of diagnosis were more likely to have engaged in processes to facilitate coping with distress. Narratives demonstrated that when positive affect prevailed, participants were more likely to engage in both active behavioral and cognitive coping processes post-diagnosis, including linking to and adhering to treatment and engaging in information and social support seeking. One such participant recalled her response after receiving a positive HIV diagnosis from a nurse at a health department:

I was sitting there that day just watching people come in and out of this room like, "Why they crying?" When she told me, she set the tissue there, and I said, "You know what, I'm gonna get busy living. I'm not gonna get busy dying . . . " (Participant 2; cisgender woman)

We found that when positive emotions transcended negative emotions after diagnosis, as in the former example, participants not only took actions to improve their odds of living with HIV, but they were also less likely to suffer from depression and other negative mental health issues. Although positive affect after diagnosis was common among those with immediate care linkage, we did not find negative affect to be indicative of delayed care linkage. Five of the nine participants (three cisgender men and two cisgender women) who expressed negative affect engaged in active behavioral coping processes by immediately linking to care and beginning treatment, in spite of framing their HIV diagnosis from a negative standpoint. In fact, at the time of the interviews, these PLWH communicated a similar dedication to care and treatment adherence as those with positive affect. When one such participant was asked if there was anything that held her back from seeking care after diagnosis, she replied, "Oh, no. I always take care of myself. I make all my doctor's appointments. I do everything like I'm supposed to do. I ain't gonna fight it. It's no use" (Participant 3, cisgender woman). Narratives suggest that PLWH who experienced negative affect post-diagnosis were less likely to engage in active cognitive coping. A few (n = 3, two cisgender men and one cisgender woman) recalled attempting suicide despite being in treatment. We found that in most cases, these participants resorted to avoidance coping strategies such as alcohol and substance abuse as a means of alleviating depression. The following statement is from a participant who was still experiencing distress at the time of the interviews: "... I feel jaded about myself, because everybody says, 'You're HIV.' I

Code	Definition	Excerpt
Positive affect	An expression of a mood or feeling that is associated with positivity (e.g., pleasure, excitement)	Interviewee: You just have to keep a positive mind-set.
Negative affect	An expression of a mood of feeling that is associated with negativity	Interviewee: I thought that my whole life was just gonna go down the drain. You just don't know, like when I found out that I was HIV positive, like it was like, "Wow."
Care linkages	The act of accessing HIV treatment	Interviewer: How long after you were tested did it take for you to seek medical care? Interviewee: Oh, it was immediately.
Care lapse	The act of disengaging or failing to access HIV treatment	Interviewee: I was always tired, didn't have no energy, and once I started taking medication and seeing the doctor like I was supposed to, I started getting better.
Coping	Cognitive and/or behavioral responses to stress or adversity	Interviewee: You've got to want the help, and you've got to be able to deal with what you're going through. I just wasn't ready to deal with it yet, so that's why was a gap as well.
Resilience	An expression of hardiness, or elasticity in the face of adversity	Interviewee: My HIV really didn't have anything on my disability My joints are deteriorating, but in my mind I'm healthy and vibrant, and can do just as well as the next person.

Table 3. Example of Relevant Codes, Definitions, and Transcript Excerpts.

 
 Table 4. Demographic Characteristics of Participants in In-Depth Interviews.

Participants	Interviews $(N = 2I)$
Age group	
20–29	I
30–39	3
40-49	7
50–59	5
>60	I
Unspecified	4
Gender	
Cisgender women	9
Cisgender men	11
Transgender women	I
Ethnic self-identity	
African American/Black	12
White, non-Hispanic	6
Native American	I
No response	2
Sexual orientation	
Straight	10
Gay	7
Bisexual	I
Other/not sure	3

could start using drugs because I figure I'm dying anyways" (Participant 4, cisgender man).

Avoidance coping was demonstrated by four participants who delayed care after diagnosis. When probed as to why they experienced a lapse between diagnosis and linkage to care, they cited being "in denial" and heavily impacted by the social stigma associated with having HIV. One participant, who waited 10 years before linking to HIV care described his reasons for delaying care as part of being "young and stupid":

I kind of was in denial till I was about 28 . . . it was a death sentence. Everybody was scared of it, and you know, I didn't want anybody to know. I was just mainly in denial. That's kind of how I dealt with things back then. (Participant 5, cisgender man)

Another who delayed linking to care for 5 months following diagnosis said that it affected him "severely":

I went into a semi-depressed state. I was 21 at the time. I started hitting bars. I just basically went down a downward spiral, but at the same time, keeping myself together. I'd never gotten my numbers done before. That's when it really hit. My T-cells at that time were in the mid-to-low 200s. I knew then it was time for me to get care. It still took me several months. I got tested in March, and I didn't get any care until August. (Participant 6, cisgender man)

# Aim 3: Affective Transition Over Time, Events, and Circumstances

As the focus of the interview shifted from emotions surrounding diagnosis to emotions after treatment, we observed that narratives included more attributes of serenity when discussing living with HIV/AIDS, more excitement when discussing the future, and more contentment with the results that they had achieved through adherence to care. Although many participants experienced emotional distress after diagnosis, we identified social support and health improvements as sources of positivity that facilitated active coping processes and positive affect. Support provided by trusted family and friends was especially helpful for those with negative affect during the initial stages of care: ... I mean, at first you go through this—or at least for me went through this emotional thing. Then, my family's been really good about everything, and that's been a huge piece of the puzzle for me, just to have that support. (Participant 2; cisgender woman)

However, all the participants who sustained negative affect were less likely to activate support network ties. The shared coping characteristics between these PLWH included non-disclosure of HIV status to others and isolation from support networks. For example, the same participant who linked to care because she didn't want to "fight it" later expressed how she currently copes with living with HIV:

I basically cut a lot of people off. I avoid being around a lot of people. I push people away. It's just like [you're] locked up, sittin' on the porch waitin' for somebody to shoot you. I guess ... I just have a phobia about it. I worry a lot about it. I just feel like I've been wronged out of my life. It's really not much to do. That's it . . . the first you think about with HIV is dyin.' There's nothin' happy about it. That's all you think about is dyin'. (Participant 3; cisgender woman)

Several participants' (n = 9; four cisgender women, four cisgender men, one transgender woman) experienced satisfactory health improvements after linkage to care and adherence to a treatment regimen. One such participant, who originally delayed care linkage, described how being diagnosed and receiving treatment improved his overall health condition. When asked how his diagnosis affected his life, he replied,

It's been the biggest blessing. I kid you [not]—I've been very sick. A year ago, this time last year was probably my worst, my absolute worst as far as just physical, as far as mental, as far as every which way shape, form. (Participant 7; cisgender man)

The progression on such health outcomes was a powerful source of inspiration and positivity for many of the participants as evidenced by the following statement from one such participant who described how her emotions evolved:

I try to be more high spirit and happy, even though I do have HIV, but see, I know that I'm not gonna die from HIV. Something else gonna kill me before I let HIV or AIDS kill me because of what my statistics say today. Now back in the day, if they'd asked me the same question, oh God, I'm fit to die looking at statistics, but medication changed me around. Prayer changed me around. The hope of people, wonderful people, people that's in the same situation that I am to help me and show me how to live with it. (Participant 8; cisgender woman)

# Aim 4: Psychosocial and Behavioral Pathways of Affect

**Resilience.** We found that those with more positive affect exhibited a greater deal of resilience when confronted with external stressors. Their narratives had more attributes of hardiness and elasticity when describing how they have managed their physical, mental, and emotional health during adverse circumstances. Some had experienced economic shocks leading to periods of homelessness or had suffered physical side effects from medication, and/or family stressors yet, they successfully continued care. For example, one participant who had been unemployed since diagnosis expressed how he remained positive:

not employed now . . . But I can honestly say I'm probably the happiest poor person that I know as far as I don't have the issues of trying to feel obligated to taking care of others now. I feel obligated, very much so, to take care of me, which eventually, once I do find the job that I'm searching for, will give me the benefit of really staying focused on the things that I need to stay focused on. Now that I am positive to live and to just be the person that I need to be. (Participant 7; cisgender man)

Social stigma. Social stigma against PLWH was one of the most commonly cited stressors in the narratives. More than half (n = 5; three cisgender men, two cisgender women) of the participants who recalled a negative emotional response to their diagnosis also expressed difficulty with managing distress due to the stigma associated with HIV at the time of the interviews. When compared with the narratives of those who framed their diagnosis from a positive perspective, the narratives of these PLWH were saturated with expressions of misery, displeasure, and resentment. However, we observed that a positive concept and emotional outlook on living with HIV had a protective effect for PLWH in relation to HIV stigma. In fact, rather than describing depression and shame about belonging to a stigmatized group (as some participants did), a few of these PLWH described how they had confronted others when faced with slurs and derogatory statements about PLWH. The following anecdote comes from one such participant who described his approach to dealing with the stigma that he encountered within the workplace:

A young man in our break room was talking about, "Well, I should think they should tattoo all the people who have HIV or AIDS like they did to Jews in Nazi Germany." I politely got up, grabbed him, and took him in a conference room and said, "You see any tattoos?" He goes, "What?" I said, "Yeah, you need to watch what you're saying." Been my best friend. Yeah, it shocked him cuz I'm always moving, always going, always doing something [Laughter]. (Participant 9; cisgender man)

*HIV advocacy.* Finally, the desire to become a community advocate and activist was emphasized most in the narratives of PLWH who expressed positive affect at the time of diagnosis (n = 3, one cisgender man and two cisgender women). It was evident that these individuals were utilizing their experiences surrounding HIV diagnosis as a social platform to educate their family and community about HIV prevention and promote wellness to other PLWH. The following statement from a participant exemplifies their desire to be an

advocate and source of support for other PLWH who are experiencing difficulty coping with their HIV diagnosis:

The more I know, the more I can tell the world, so maybe one day I might become a peer counselor or a speaker or something—I want people to know that they're not alone. I have a family outside of my family, and we help take care of each other. (Participant 10; cisgender woman)

# Discussion

To our knowledge, no previous studies have chronicled the trajectories of affect while describing the ways that affect manifests in the behavioral and cognitive coping processes following HIV diagnosis. In this study, we explored affect from the point of HIV-diagnosis (Aim 1); through time, events, and circumstances (Aim 2); and in relation to mental and physical health outcomes (Aim 3). Overall, our findings add empirical depth to existing research demonstrating the enduring effects of psychological states on the behavior health and wellbeing of PLWHA.

# Affect Post-Diagnosis

Although the core results of the study support the findings from previous qualitative research within this area, thematic analyses revealed additional insight, as well as, a few unexpected findings. The mixed emotional response reported by the majority of our sample of PLWH at the time of diagnosis is supported by theory demonstrating the coincidence of positive and negative emotions during crises (Folkman & Moskowitz, 2000) yet contrasts with some of the findings of previous qualitative studies. Qualitative literature on HIV is saturated with narratives of PLWH describing the trauma of HIV-diagnosis (Perazzo, 2015; Psaros et al., 2015). Fear, dread, shame, and guilt are emotions often recalled by PLWH when asked to describe their feelings around this pivotal event in their lives (Perazzo, 2015; Psaros et al., 2015). Although a negative reaction to receiving this sort of news is expected and was also found among most participants in the present study, we found that other people can experience a range of emotions with varying intensity. Although most interviewees distinctly recalled framing their HIV diagnosis from a predominantly positive or negative perspective, a small fraction of our sample recalled experiencing an overlap of emotional attributes and could not distinctly identify the prominence of positivity or negativity at the time of diagnosis.

# Affect and Behavioral Coping

Although we found that active behavioral coping was exhibited by PLWH describing elevated positive affect, we also found that some of the PLWH recalling negative affect also immediately linked to care and began taking ART. This finding was unexpected given the results of other qualitative studies in which researchers identified negative affect as a

major barrier to HIV care engagement and poorer HIV treatment behaviors among PLWH with negative feelings post-HIV-diagnosis (Sprague & Simon, 2014; Williams et al., 2011). Our contradictory finding could possibly be explained by the theorized role of negative emotions in inducing survival responses during crises (Fredrickson, 2001). However, this type of survival-driven coping was not exhibited by the remaining PLWH who delayed linkage to care after diagnosis and perhaps the remaining PLWH residing in the Northeast Georgia (NE-GA) health district who never linked to care. It is possible that structural barriers to care linkage common in non-metropolitan environments such as inadequate transportation and health professional shortages could have exacerbated negative affect among PLWH (Reif, Golin, & Smith, 2005). Alternatively, those with negative affect may have perceived these barriers to be greater than those with positive affect. A closer examination of barriers to care linkage, negative affect, and the coping trajectories of PLWH could expose the differences between those who decide to link to care or delay care (Folkman & Lazarus, 1988).

# Affect and Cognitive Coping

Although we found that active behavioral coping was exhibited by PLWH with positive affect and some with negative affect after diagnosis, we further observed a stark contrast between the groups when the narratives focused on mental health. PLWH with positive affect were more energetic, felt more in control of their lives, and expressed mastery of living with HIV, whereas PLWH communicating negative affect expressed having a harder time managing anxiety, emotional distress, and other life stressors. The inability of PLWH to engage in active cognitive coping is a serious cause for concern as demonstrated by research showing that stress, depression, and anxiety are associated with several maladaptive outcomes, including the acceleration of HIV disease progression (Evans et al., 2002; Leserman, 2008), poorer medication adherence (Jun, Han-Zhu, Aaron, Yuhua, & Bryan, 2017), and attrition from care (Krumme et al., 2015). Although it is reassuring that PLWH expressing negative affect were active in care at the time of the interviews, they may be more vulnerable to drop out of care at some point in the future. These findings emphasize the importance of the continuity of mental health service provision for PLWH throughout the HIV care continuum.

# Affective Transition

Similar to this study, Moskowitz and Wrubel (2005) also found that many of the HIV-positive participants in their study shifted their HIV appraisal over time. The identification of relationships and health improvements as sources of positivity for transforming affect demonstrates the profound impact of social networks and health status to mitigating negative affect and promoting positive psychology. These findings are substantiated by seminal research on the impact of positive events and social

support on life stress (Cohen & Hoberman, 1983), as well as qualitative data illustrating the role of social networks in the management of illness uncertainty and the provision of support among PLWH (Flores, Leblanc, & Barroso, 2016). Study results further explicating the support types and networks which participants deemed most conducive for facilitating HIV treatment are described by the authors elsewhere (Hill, Huff, & Chumbler, 2018). The question of why some participants undergo negative-positive affective transitions post-diagnosis, while others do not remains. It is possible that those who sustain negative affect are not activating social network support and/or are burdened by health issues. In their longitudinal qualitative study of illness appraisals, Moskowitz and Wrubel (2005) found personal HIV-related health issues (e.g., T cells) and illness among friends to be the most frequently cited life stressors among HIVpositive caregivers. Thus, an emphasis on patient referral to support and counseling therapies may be especially important for patients who are lacking an effective HIV treatment regimen or recently received news of a health decline. It is also possible that avoidant cognitive coping behaviors reinforce negative affect through a positive feedback mechanism, whereby negative affects lead to avoidant coping which exacerbates negative affect. To advance the development of interventions for promoting positive psychology, it is important to understand the factors that differentiate people who are able to break this cycle and those who do not. Also, individual needs may vary in terms of the factors which enable affective transition. Although support and health status may be source of positivity for some, others may be inspired by other sources of positivity. Individually tailored affective-cognitive therapies may be the solution to disrupting the cycle between negative affect and avoidant cognitive coping. Moreover, creative recruitment or referral approaches may be necessary to getting those within that cycle engaged with these therapies.

# Psychosocial Pathways of Affect

In this study, PLWH with narratives of positive affect appeared to be more resilient against life stressors. Those expressing positive affect not only seemed less depressed than their counterparts but were actively invested in multiple aspects of their physical, mental, and social wellbeing. In 2017, Furlotte and Schwartz performed a qualitative study of resilience among older PLWH and found several themes that are consistent with our findings concerning positive psychology, perseverance, and generativity. Specifically, the concept of generativity, defined as an individual's desire to mentor the next generation (McAdams & de St. Aubin, 1992), was emphasized most by PLWH expressing positive affect in this study and by 40% of the participants in Emlet, Tozay, and Raveis's (2011) study. The importance of social support from peers (Derlega, Winstead, Oldfield, & Barbee, 2003) coupled with certain PLWH's aspirations to become mentors, may present an opportunity for novel programs that equip PLWH opinion leaders with the skills to promote awareness and positive behavior change on the community level.

#### Limitations

The dynamic relationship between affect and coping presents a methodological challenge for explicating the succession of cognitive and behavioral processes that may unfold after a distressful encounter, such as HIV diagnosis (Folkman & Lazarus, 1988). Although we were able to identify patterns of cognition and behavior among our sample participants, it is possible that the positivity participants were experiencing at the time of the interviews may have influenced their retrospective evaluation of affect at the time of diagnosis and linkage to care. The amount of time transpired between diagnosis and the time of the interview may also present bias among those who had been diagnosed for a longer time. Therefore, it may have been more difficult for long-time survivors to recall salient positive or negative in comparison the newly diagnosed participants. We also imperatively acknowledge the limitations of making practical generalizations of the personenvironment interactions documented within our findings.

Next, the limitations associated with the dependability of consensus ratings are to be noted. Although the use of multiple coders during our analysis may have assisted with reducing research biases, consensus approaches to resolving coding discrepancies can possibly be influenced by interpersonal differences in power and influence due to the positioning of the coders (e.g., principal investigator vs. research assistant), and differences in knowledge on the subject matter, which may influence the negotiation of finalized coding decisions (Campbell, Quincy, Osserman, & Pedersen, 2012; Ulin, Robinson, & Tolley, 2015). In the future, intercoder dependability may be improved by unitizing coding segments, or calculating quantitative measures describing the proportion and percentage agreement between coders (Campbell et al., 2012) and using this information to adapt and inform coding decisions. Each interviewer was experienced in in-depth qualitative interviews. However, we could not totally rule out the fact that an interviewer's age and gender could influence a participant's responses. Therefore, future research should consider the age and gender of the interviewer vis-à-vis the participant's responses.

Finally, affect and coping have been described as "freefloating" phenomena that vary largely across the context of the individual, environment, and circumstance (Barrett, 2006; Folkman & Lazarus, 1988). There are a variety of other known and unknown factors inextricably associated with psychological states and coping responses. In 2005, Posner et al., highlighted the complexity of studying affect by proposing that certain individuals may have different "proclivities" for affective processing that is more positive than negative and vice versa. Therefore, our interpretation of results could be biased by different individual and group variations in processing and communicating affect according to demographic and psychosocial traits, ranging from personality to age, gender, race, or culture. For example, some research suggests that men and women express emotions differently; women express broader and more intense emotions

after interactions, whereas men express limited and less intense emotions after an interaction (Barrett, Robin, Pietromonaco, & Eyssell, 1998). Longitudinal research has also found lower negative affect with increasing age and higher positive affect at a younger age among the general population (Charles, Reynolds, & Gatz, 2001), whereas another study found sexual orientation to have an exacerbating effect on negative affect among lesbian, gay, and bisexual people living with HIV (Cramer, Burks, Plöderl, & Durgampudi, 2017). Variation in how different cultures experience and express affect is also an important consideration (Schimmack, Oishi, & Diener, 2002). Especially given research showing how cultural beliefs, attitudes, and stigma surrounding HIV diagnosis and treatment shape psychology, such as found in one qualitative study where pervasive cultural HIV stigma was found to be a source of negative emotions, unemployment, and social isolation after diagnosis (Setlhare, Wright, & Couper, 2014). The cultural context of HIV may also evolve over time due to the stigma and the nature of the illness. For example, people who were diagnosed at the beginning of the epidemic may have been predisposed to higher postdiagnosis negative affect due to the acute nature of the illness and highly stigmatized social climate. Whereas, those who were diagnosed in more recent years may have a more positive outlook given the chronic nature HIV and reduced community-level stigma.

Altogether, the unique characteristics and qualities that distinguish individuals and groups may predispose their affective position and trajectory. Although conducting a comprehensive and thorough analysis of affective differences between people is outside of the scope of the present study, further investigation into the sociocultural context of emotion across the life course is necessary to determine whether the experience of emotion significantly impacts affective-behavioral trajectories post HIV-diagnosis. Quantitative analysis that performs a careful breakdown of affect, coping, and behavioral health outcomes by subgroups may also reveal traits of vulnerability among different groups of PLWH. In addition, investigation of potential mediators that heighten the salience of positive emotions and minimize negative emotions of PLWH within various stages of the HIV care is necessary for informing the development of novel strategies for cultivating positive affect and active coping (Fredrickson, 2000). Despite these common limitations with qualitative data management and analysis, the findings from the present study were novel and will help guide program planners and policy makers to devise policies and programs to provide timely and accessible care for PLWH.

#### Implications for Nursing

From diagnosis to viral suppression, nurses play a pivotal role in the treatment throughout all stages of the HIV care continuum. Particularly, mental health nurses who counsel patients can implement strategies for promoting positive

psychology, whereas HIV nurses can be central to connecting newly diagnosed, depressed, or recently re-engaged patients with mental health resources, such as, affectivecognitive-behavioral interventions. Learning the characteristics that distinguish one's propensity to frame HIV diagnosis from a negative versus positive perspective or the inclination to engage in active versus avoidant coping will enable service providers to better predict responses to diagnosis and intervene during incipient stages care linkage and treatment. Also, it is important to note that HIV/AIDS is a global challenge situated in diverse environments which present unique challenges to coping with HIV diagnosis and accessing treatment. Therefore, it is imperative that researchers and nurses aiming to intervene on positive or negative psychology are aware of factors which may influence affective responses to HIV diagnosis and adapt their approaches to the unique sociocultural context of their community.

#### Conclusion

Our thematic analysis of PLWH narratives surrounding distress, affect, and coping in a health district located in the Southeastern United States supplements the current knowledge within this area by documenting and analyzing the events that may occur after diagnosis within lived narratives of a diverse sample of PLWH. Utilizing such methods enabled us to identify possible psychosocial and behavioral mechanisms of adaptability as well as opportunities for further scientific exploration. Our findings are consistent with theory and research regarding the detrimental implications of negative psychology and the cumulative benefits of positive psychology on the wellbeing of PLWH. The qualitative data obtained from this study further support previously established theoretical models and further evidence suggesting that positive affect may play a significant role in supporting shifts in mortality and biomarkers of health among PLWH (Moskowitz et al., 2014; Pressman & Cohen, 2005). Our results add to the literature by identifying how affect facilitates improved health by buffering distress and facilitating social and behavioral modifications leading to sustained adaptability of PLWH residing in the Southeastern United States.

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