

## Older and Younger African Americans' Story Schemas and Experiences of Living with HIV/AIDS

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**Abstract** This paper reports findings from a study that compared older ( $n = 21$ ,  $\geq$  age 50) and younger ( $n = 96$ ,  $\leq$  age 49) African Americans' stories ( $N = 117$ ) of living with HIV/AIDS to determine how they make sense of the experience. The purpose was to: (1) identify and describe the cultural models African Americans use to inform their stories of living with HIV/AIDS, and (2) to compare older and younger adults' HIV stories. To characterize the cultural models engaged in the telling of these HIV stories, we conducted schema analysis. Analyses documented six diverse schemas, ranging from "Stages of Grief", "12 Steps", "Wake Up Call", "Continuity of Life", to "Angry and Fearful", "Shocked and Amazed". Comparison conducted by age group showed older adults more frequently expressed their story of living with HIV as "Stages of Grief" and "Continuity of Life", whereas younger adults expressed their stories as "12 Steps" and "Wake Up Call". Findings contribute by documenting African American stories of living with HIV/AIDS, important heterogeneity in cultural schemas for experiences of living with HIV and differences by age group. These findings may help by identifying the cultural resources as well as challenges experienced with aging while living with HIV/AIDS for African Americans.

**Keywords** African Americans · Later life · Chronic illness stories · HIV/AIDS · Qualitative methods · Schema

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Improvements in antiretroviral therapy (ART) have led to the transition of HIV/AIDS from an acute fatal disease to chronic illness. As a result, people are living longer with HIV and many can expect to live into old age. In the early history of the epidemic, younger adults (aged 49 and younger) made up the bulk of HIV/AIDS cases; and it was associated with socially marginalized and stigmatized groups such as minorities and lesbian, gay, bisexual, transgender, and queer (LGBTQ) persons. However, currently older adults (aged 50 and older) comprise about half of HIV/AIDS cases in the United States and are expected to increase to 70% by 2020 (Senate Special Committee on Aging 2013) making HIV/AIDS more pervasive across the age and population spectrum and somewhat less stigmatized. Two pathways into being HIV positive in later life exist today. While the number of older adults with HIV/AIDS is increasing as many are “aging in” due to antiretroviral therapy which has increased potential length of life, others are infected and diagnosed in later life because of continuing sexual activity and improved awareness that older adults are at risk for contracting the disease which has led to routine testing in this population. The changes in the population age profile of those afflicted with the HIV/AIDS epidemic highlight the importance of understanding heterogeneity and minority differences not just in the severity of the disease but in the lifelong lived experiences of both older and younger adults who are living HIV/AIDS.

Older and younger adults share similar risk factors for HIV (Centers for Disease Control [CDC] 2017a), but differ in clinical and longer term social trajectories of living with HIV. Research comparing older and younger adults with HIV/AIDS while sparse, is now receiving greater attention (Chambers et al. 2014; High et al. 2012, Nokes et al. 2000; Sankar et al. 2011a). Findings suggest older adults experience increased mortality, later detection, faster progression to AIDS, less disclosure, more comorbid health conditions, poorer physical functioning, increased social isolation, and are more likely to live alone (Emlet 2006a, 2006b; Heckman et al. 2000; Nokes et al. 2000; Ryan et al. 2013; Wellons et al. 2002). A study on HIV related stigma found younger adults with HIV are more likely than older adults to be unemployed, never married, recipients of Medicaid, and concerned about job loss due to HIV status (Emlet 2006a). Findings have been mixed as to whether older and younger adults differ with regard to stigma (Emlet 2006a; Emlet et al. 2015) and medication adherence/medical management (Sankar et al. 2011a; Ryan et al. 2013; Wellons et al. 2002). Other research suggests older and younger adults with HIV have similar health related quality of life (Nokes et al. 2000) and social networks (Emlet 2006b).

Among those living with HIV/AIDS in the United States, the disease disproportionately burdens African Americans, who comprise 50% of HIV/AIDS cases (CDC 2017b; Haile et al. 2011). There is a preponderance of behavioral and psychological research on African Americans with HIV/AIDS that measures the psychosocial risk factors leading to the disease or its psychological impact. Findings from these studies have highlighted how African Americans living with HIV/AIDS experience increased poverty and stigma along with poorer health outcomes such as increased morbidity, mortality, and comorbidity in comparison to other ethnic groups. While we understand how African Americans as a group differ from whites and Latinos in terms of incidence/prevalence, risk factors, and clinical trajectories (CDC 2017a, 2017b; National Institute on Aging [NIA] 2016), our understanding of African American diversity in terms of subjective illness experience is less developed. In particular, we know little about African American stories of living with HIV or how the expansion of HIV into later life has shaped illness experiences but we especially lack insight into how life is meaningful and organized for this population. To address these gaps, we invited African Americans to tell their own story of living with HIV in order: 1) to identify and describe the contents and ways

of organizing life experiences and 2) to explore similarities and differences among older and younger adults drawing on a cultural life course perspective.

## Cultural Life Course Perspective

In contrast to the biological lifespan, the concept of the cultural life course clarifies the important intersection of the individual, culture and society in shaping how key phases, social roles, and expectations about life are understood and lived (Fry 2003). The life course is a culturally defined series of stages and transitions over the lifetime. It provides socially expectable eras, identities, and activities through time (Benedict 1938; Fortes 1949; Turner 1969; van Gennep 1960). Importantly, in contrast to chronological age, these culturally defined stages also frame the social timing (“on time” or not) for life stage transitions, and the hopes, values, and goals that give meaning to life (Neugarten and Hagestead 1976). It also suggests an interpretive framework for persons experiencing disease. Deviations from the expectable cultural life course arouse challenges to meanings and a need for explanation, and may be interpreted by others as a form of incompetence, social irresponsibility, or moral carelessness (Brandstader 1990). Importantly the life course is situated in particular socio-historical contexts which further provide particular local contexts, constraints and options into which an individual is born (Elder 1994). A life course approach provides a framework for understanding HIV within the culturally defined and whole life context. It demonstrates how developmental stage as well as historical cohort affects the experience of living with HIV and adhering to medication and using safe sex as well as a theoretical model for integrating non-HIV life events into this understanding.

To better understand the ways the culturally defined life course infuses individuals’ making sense of living with HIV we conducted ethnographic interviews. To date, public health researchers using qualitative methods have primarily focused on exploring understandings of the increased stigma among African Americans with HIV disease (e.g., (Bird and Voisin 2013; Buseh and Stevens 2007; Foster and Gaskins 2009; Haile et al. 2011)). Those qualitative studies focusing on African Americans with HIV disease have also addressed spirituality in health (Dalmida et al. 2012), prevention and care (Buseh et al. 2006; Wheeler 2005), adherence practices (Sankar et al. 2011b; DeMoss et al. 2014), coping processes (Watkins-Hayes et al. 2012), self-management/self-care (Gakumo et al. 2015; Shambley-Ebron and Boyle 2006; Warren-Jeanpiere et al. 2014), and sexuality and intimacy (Nevedal and Sankar 2015). To our knowledge, the study reported here is a first-time use of a life course perspective to compare older and younger African Americans’ stories of living with HIV/AIDS.

## Schema Framework for Understanding HIV Stories

The stories of living with HIV that participants narrated were their own self-directed accounts of their history of living with the disease. Storytelling can provide a window into the individual’s own experience of living with and thinking about HIV (Bury 1982; Crossley 1999; Singer et al. 2001). The HIV diagnosis, often a sentinel life event, requires the speaker to re-examine and refashion their understanding of themselves and of their larger social world (Bloom 1997, 2001; Bluck and Habermas 2000).

Stories can be examined to explore schemas that structure their production. Schemas are defined as

“... dynamic interpretive processes [that] mediate our understanding of the world. Schemas provide a simplified or prototypical conceptual framework integral to perceiving, organizing, interpreting, remembering, representing, making inferences about, and acting in the world” and can be considered a form of collective memory” (Garro 2000, p. 285).

Schemas can take the form of shared cultural metaphors which represent the “taken-for-granted” model of the world shared by the speaker and those in his or her social group (Holland and Quinn 1987; Strauss and Quinn 1997). These widely shared models enable people to fill in the details of stories told by culturally-same others and are utilized to make sense of events, to re-create continuity in the life course and to provide an indication of the direction forward (Luborsky 1993b; Becker 1997, 2000).

A variety of organizing metaphors may be observed across illness stories. Some stories engage explicit cultural metaphors (e.g., “the stages of life from childhood to old age,” “life is like cycle of seasons from spring to summer to winter,” “the planets cycle around the sun”) and locate the individual’s own life within, as part of, the wider natural or social order. While other stories are organized around a personal highly salient issue, life theme, or idea (ie., “it’s always a struggle”) (Luborsky 1987, 1993a, b; Garro 2000; Strauss and Quinn 1997) and depict the individual’s life as a struggle, not smoothly integrated within, the socially expected world. Unlike widely circulating shared cultural metaphors, more individual-centric themes may focus on personal incidents in order to represent a particular struggle or to emphasize life difficulties overall, and may deeply index a sense of marginality or limited fit between their own personal lifetime and the institutional, and collective worlds they inhabit (Luborsky 1990; Luborsky and Riley 1997; Strauss and Quinn 1997).

## Research Design and Methods

Stories were collected as part of an long-term ethnographic study of adherence to ART among HIV seropositive African Americans using mixed methods. The larger study and findings were reported in Sankar et al. (2011b). Conducted in Detroit, Michigan, the study recruited African American women and men, through clinics and hospitals settings as suited to a study of long term treatment to provide both objective and subjective information on adherence among a hard to recruit minority population. Inclusion criteria included self-identification as US-born African American, HIV sero positive status, duration of ART treatment (New or Long-term). The Wayne State University Institutional Review Board (IRB) approved this study. Participants were provided a 50 dollar honorarium per interview. The final sample consisted of 117 participants, from an original of 137, due to drop outs (e.g, due to death, difficulty recontacting). Following IRB regulations we deleted the data from those who dropped from the study.

Up to eight in-depth interviews were conducted over a three year period in participants’ homes or a private place on our campus. Each interview was audio-recorded, and lasted roughly two hours. Three African American and three white research assistants conducted the interviews; we found no differences in data related to interviewer ethnicity. Verbatim transcripts were prepared. We started the first interview by inviting participants to tell us their own *Life since HIV* story in order to gain an appreciation of their experiences in their own words and way of telling it before our discussion topics and also to help build rapport. The stories were elicited

using the same prompt. It invited them to, “Tell me in your own words the story of your living with HIV; start anywhere you want, end anywhere you want.” This purposively broad open-end approach was designed to enable participants to describe in their own words their experience of living with HIV/AIDS and to suggest a minimum of temporal or cognitive frames to structure the telling. For example we did not ask them to start with when they acquired HIV, or tell us the chapter structure (Luborsky 1990; see also Saavedra et al. 2009; Shweder 1991; Stuckey and Tisdell 2010). It is akin to the “grand tour” question (Spradley 2016) used in qualitative research to allow the interviewee to structure his or her way of ordering events and ascribing meaning to them. The principal investigators trained the interviewers to avoid biasing the storytelling toward socially normative answers, such as suggesting respondents talk about what is “important” or “has changed.” The interviewers were trained to listen without interruptions or probes until the participant explicitly indicated they had finished.

## Analysis

Schema analysis adapted from Bury (1982), Bernard and Ryan (2010), and Strauss and Quinn (1997) was used to characterize each story as a whole and to help appreciate ways that the telling of the story might offer insights into the organization of experience. The schema analysis guided us in identifying the cultural models participants used to make sense of their experience of living with HIV. Thus a comparative approach across many cases was used for “finding culture in talk” (Quinn 2005; Luborsky 1987, 1990, 1993a, b; Luborsky and Riley 1997) in order to facilitate insights into the intersecting of sociocultural and individual dimensions rather than deep dives into a few cases (Luttrell 2005). To prepare for sorting of whole stories and coding, we extracted the *Life since HIV* story and created a text-base of all stories. Each author independently read each story first to become familiar with the account. Then using an iterative process, the authors collaboratively compared coding. The authors read each story to identify the main schema and assign it to an initial category based on its overall structure and themes. We reviewed the emerging categorizations several times to group the schema into larger categories. The categories were developed inductively rather than reading for a priori evidence of particular schema or theme. Stories that did not readily fit into already identified categories were discussed by the entire research team until agreement was reached. Inter-rater reliability was established by having team members independently code each story. We compared coding and discussed discrepancies until reaching 100% consensus. As a result, six story schemes were identified and are described next.

## Results

### Participant Characteristics

Participants ranged in age from 21 to 79 years (Mean = 41); 18% were age 50 and older. Average time since diagnosis was 5.4 years. See Table 1 for participant characteristics.

We used age 50 and older to define the old age in this population in order to be consistent with the CDC (2017a) and existing literature on HIV and aging (Sankar et al. 2011a; Nevedal and Sankar 2015; Emlet 2006c) yet we acknowledge gerontologists typically do not consider 50 years of age to be a marker of social and behavioral conditions associated with older age. Age was dichotomized at 50 and older (older age group) and 49 and younger (younger age group).

The *Life since HIV* stories averaged about 300 words (ranging from 5 to 1575 words).

**Table 1** Sample characteristics by age group

African Americans with HIV/AIDS ( <i>N</i> = 117)	Younger ( <i>n</i> = 96), <i>n</i> ( $\mu$ or %)	Older ( <i>n</i> = 21), <i>n</i> ( $\mu$ or %)
Age range 24–82 (44)	24–49 (40)	50–82 (58)
Age group at diagnosis		
$\leq 49$		11 (52%)
$\geq 50$		10 (48%)
Gender		
Men	68 (71%)	10 (48%)
Women	28 (29%)	11 (54%)
Marital status		
Never married	66 (67%)	8 (38%)
Married	6 (6%)	0 (0%)
Domestic partner	6 (6%)	1 (5%)
Divorced/separated	13 (14%)	9 (43%)
Widowed	1 (3%)	1 (5%)
Unknown	4 (4%)	2 (9%)
Education		
Grade school	11(12%)	5 (24%)
High school/GED	57 (59%)	9 (43%)
College	22 (23%)	5 (24%)
Unknown	6 (6%)	2 (9%)
Place of birth		
Southern State	79 (82%)	12 (57%)
Northern State	12 (13%)	6 (29%)
Unknown	5 (5%)	3 (14%)
Work status		
Employed	24 (25%)	3 (14%)
Unemployed	65 (68%)	15 (72%)
Unknown	7 (7%)	3 (14%)
HIV cohort		
Pre-HAART ( $\leq 1995$ )	23 (26%)	9 (32%)
Post-HAART ( $\geq 1996$ )	66 (74%)	19 (68%)

## HIV Story Schemas

We identified six varieties of HIV story schemas. This range presents an important diversity in how African Americans told their story of living with HIV. The story schema labels are designed to remain close to the actual language and ideas as expressed by the narrators. The story schemas are labeled as: (1) “Stages of Grief,” (2) “12 Steps”, (3) “Wake Up Call,” (4) “Continuity of Life,” (5) “Angry and Fearful,” and (6) “Shocked and Amazed.” Viewing the text base of stories as a whole, most stories (87%) used schemas with popular cultural metaphors for trauma and recovery, and a smaller number (13%) of stories used schemas with personal life themes (e.g., “Angry and Fearful” and “Shocked and Amazed”). Although fewer participants used schema with personal life themes to describe their story of living with HIV, they were salient enough to warrant their own type of story, for example “Shocked and Amazed” and “Angry and Fearful” (Bernard and Ryan 2010).

The most frequent category was “Stages of Grief” (32.5%) followed by “12 Steps” (27.4%), “Wake Up Call” (16.2%) and “Continuity of Life” (11.1%). The most frequent personal theme was “Angry and Fearful” (11.1%). Regarding age groups, more older adults (age 50 and older) used the “Stages of Grief” (47.6%) and “Continuity of Life” (23.8%) schema compared to younger adults (age 49 and younger) (29.2%, 8.3% respectively). In contrast, younger adults most often used the “12 Steps” (31.3%) and “Wake Up Call” (17.7%)

schema compared to older adults (9.5%, 9.5% respectively). Notably, none of the older adults used the “Shocked and Amazed” schema. Lastly, older adults (9.5%) and younger adults (11.5%) used the “Angry and Fearful” schema roughly equally.

In the following description of each schema we present representative stories for younger and older adults. Note, the illustrations are presented as spoken verbatim without editorial instructions to “correct” grammar or wording.

## Cultural Schemas

### “Stages of Grief” Schema

Popularized ideas about recovery from trauma circulate widely in public discourses and enter into conventional modes of thought (Strauss 2012) and emerge in participants’ stories of *Life since HIV* diagnosis. Elizabeth Kubler-Ross (1969) introduced the “Stages of Grief” concept into contemporary discourse through her work on how people come to terms with grief and mourning following the loss of a loved one.. Kubler-Ross’ articulation of this concept positing a sequence of experiential stages (e.g., denial, anger, bargaining, depression, acceptance) one progresses through in coming to terms with a serious loss, has become widespread in popular thought. Stories that employed this organizing schema were the most prevalent in our data. Stories using this schema opened with an initial period of HIV denial or incomprehension, followed by an era focused on moving from anger, depression, and then, to self and social acceptance. Stories included in this schema had to describe their HIV life around experiences of progressing through multiple stages of grief, although not necessary stating each of the formally defined stages. The focus was on personal experience and the consequences of HIV. Most people (32.5%) in this study used “Stages of Grief” as a cultural model for making sense of life with HIV. Ten (47.6%) older adults used this schema compared to 28 (29.2%) of younger adults. These stories made use of linguistic markers such as “since” and “then” to chart out a succession of stages in their experience. People emphasized continuing “ups and downs” in life but also described how they were working toward a greater degree of acceptance.

Mr. Brandon is 44 years old and has been living with HIV for 10 years. He grew up in a middle class family in small town Louisiana, where he describes his family as close and loving. He reported he “always” knew he was gay. After moving around the country in a succession of different jobs, he settled down with a partner and has helped with caregiving for his partner’s mother for the past ten years. Describing himself as an optimist who thinks the best is what is going to happen if you believe it, he explained how he felt when he learned he was HIV positive.

When I found out, I went through all of the stages, and cried and was depressed and called a couple of friends and cried with them.

Then I got over it; it’s like all a part of my life. It’s a matter of going on and just accepting it. (younger man, pre-ART diagnosis, naïve to medications)

Framed around the idiom of going “through all the stages” Mr. Brandon describes his experience as a sequence of stages starting with the initial loss (e.g., his healthy pre-HIV life), through encountering grief, depression, and finally “just accepting it.”

Mr. Abernathy, 62 years old, acquired HIV when he was 48 years old and has been living with HIV for 14 years. He acquired the disease in the era before the current generation of ART medications was available. He explained that he comes from a small, close family where his

mother sheltered him after his older brother died. He is well educated and has traveled extensively. He was an active leader in the gay community before his HIV diagnosis. After the HIV diagnosis, he said he became depressed. Bearing HIV, afflicted him in complex and unanticipated ways as illuminated in his story,

Being a person of faith, I didn't think that it would devastate me the way it did. But to find out that you have a terminal condition, which may cause you great pain and suffering, is not an easy thing to deal with. I was terribly, terribly depressed. And despondent.

And then finally I came to terms. Um, everybody is going to die. And just because you've been informed that this may be the reason that you die is no reason to give up living, or to accept a less, a lesser condition of life. I had to bring myself to grips with that.

Since coming to grips life is better. Still have down days. But uh...things are not hopeless. (older man, pre-ART diagnosis, long-term to medications)

Mr. Abernathy spoke about reaching a final stage of acceptance, one where, in his words, he had to "bring myself to grips with that." Gradually emerging from the depression, he began volunteering in HIV service organizations. He reflectively states that he is not rich or famous, but feels fortunate to have lived because many of his peers died of AIDS. Leaving behind a legacy is an important goal that is woven into his larger story of living with HIV and it further might be seen as a revitalization of his long-term investment in creating the kind of positive community values he pursued in advocacy roles before becoming HIV positive.

### *"12 Steps" Schema*

The second most used storytelling schema drew on the popularized discourse idiom of the "12 Step program" of substance use recovery treatment programs. Notably, stories by the younger adults (vs. older adults) predominated within this category. The recovery program model developed for alcoholism treatment by the self-help organization Alcoholics Anonymous has entered into wide circulation in popular discourses on coping with a great range of adversities (Matheson and McCollum 2008; Shinebourne and Smith 2010). The formal 12 Step model is a strategy for fully reorganizing ones' physical, mental, and spiritual life wherein one strives to admit an inability to control negative behaviors, accept a higher power for strength, review one's past errors, learn a new way of daily life, and help others with similar problems. Stories centering around the "12 Steps" schema focused on living one day at a time (e.g., taking medication, conducting self-care). In the stories using this schema, the recognition of ethical duties beyond one's own self, which are characteristic of recovery stories found in Alcoholics Anonymous or Narcotics Anonymous (Swora 2004), appeared as discussions of involvement in HIV outreach or service organizations or a stated (re)commitment to good behavior or to a higher authority (e.g. God, family) beyond the individual. Stories categorized in this schema were those framed primarily around the core 12-Step principles, but, again, every program ideal need not be enumerated. Comparatively, more younger adults (31.3%) used this type of schema than older adults (9.5%). Coding criteria for assigning the "12 Steps" schema included self-care, moral personhood, one-day-at-a-time philosophy. We did not identify differences in how this was expressed between older and younger adults.

Mr. Craig is 45 years old and has now lived 18 years with HIV and he was in the azidothymidine (AZT) treatment era before switching to ART as it became available. He is a



contractor for the Army Corps of Engineers. He described his family as close yet when he was 15 years old his mother and sister moved to Israel, leaving him by himself which he said required him to put into practice what his parents taught him about valuing himself and maintaining a positive outlook. He described this ethos, which was instrumental in dealing with his HIV diagnosis. He is happy with his work achievements and social life but regrets “having had too much fun” as a young adult.

Since being HIV positive, I have changed how I make decisions. I put more thought and consideration in decisions, more health conscious as far as diet and exercise.

I’m accountable for everything I’ve done. HIV was devastating; it changed me. So now I make decisions more health conscious and am more aware of my behavior. (younger man, pre-ART diagnosis, long-term to medications)

The story Mr. Craig tells is one where, despite dealing well with HIV, he must continue to be attentive to sustaining his well-being and strive to become more accountable as an ethical person, one who is “more aware of my behavior.”

Ms. Dabny is 53 years old and has been living with HIV for 14 years, and is a long-term antiretroviral patient. She has two adult daughters. At the time her daughter was 20 years old, Ms. Dabny gave birth to her son. During the interval, she “ran the streets” and was “wild”, alienating her from her family. Since her diagnosis she has reconciled with her family and “quit doing the things she used to do.” Her goal in life is to care for herself so that she is able to care for her twelve year old son. She describes her story of living with HIV as:

Oh, I quit doing a lot of things I used to do. I don’t run the streets and I’m all-I stay at home all the time now. And plus, I mostly be bothered with just my family now. No outsiders. (older woman, pre-ART diagnosis, long-term to medications)

Both the categories “Stages of Grief” and “12 Steps” of recovery engage the contemporary American cultural conceptualization of a psychology of coping with trauma, in one variety it is with “Stages of Grief” more focused on emotional states and the other “12 Steps” being more focused on daily life activities in coping with HIV. Notably, the focus on self-care is a defining feature of “12 Steps”, but was absent in the “Stages of Grief” category.

### *“Wake Up Call” Schema*

The “Wake Up Call” schema referenced a fundamentalist “calling to” along with a secularized or religious/moral code, an occasion to begin appreciating life anew or turn away from a life they adjudged as morally corrupt. It evoked evangelical religious traditions of a spiritual calling to change one’s life. In contrast to the prior categories above, stories using this schema did not talk about self-care, adherence, or daily life. The HIV diagnosis was viewed in terms of a positive transformation, one that precipitated an acceptance or attention to mortality and often a return to mainstream normative social life such as investing oneself in pursuing social ideals. Seventeen (17.7%) younger adults used the cultural model of “Wake Up Call” compared to 2 (9.5%) older adults to describe their experience of living with HIV. We did not identify a difference in how younger and older adults used this schema. This schema focused on personal growth and change.

Mr. Ebhardt is 36 years old and was diagnosed with HIV two years prior to his interview. He was divorced with a four year old son and had returned home to live with his mother. He described

himself as a very responsible person who loves learning and also fanatic about cartoons. Today he characterized himself as a very private and spiritual person which emerges in his story.

I used to be a straight up workaholic.

Since being HIV positive, it's like a wake-up call. I am alert on life, for the first time in a long time I know what a rose looks like; I've held a rose in my hand. Since being HIV positive, I learned to smell a rose and know what a rose really smells like for a change. (younger man, post-ART diagnosis, long-term to medications)

Mr. Ebhardt had not disclosed his HIV to anyone. He explained having reinvested himself in leading a positive way of life and regarded HIV as a reminder to take time to "smell the roses." Here, the "wake-up call" is indexed in learning to "smell the roses" focusing on things grounding in living the moments in each day of life.

Mr. Escher is 51 years old and has been living with HIV for 2 years. From the age of 3, he was placed in thirty different foster homes; and a juvenile home for "wayward" boys. Despite this very disrupted childhood, he strove to pick up skills from his various foster families and entered adulthood as a skilled tailor and dry cleaner. He started several businesses but stress led him to alcohol abuse and the loss of the business. He was diagnosed with HIV when hospitalized for pneumonia from which he almost died. He now devotes himself to working in HIV support organizations. Mr. Escher told his story as follows:

I am lot more relaxed and at ease. I learned to be patient, and I don't have to have everything done today within an 8 hour time-frame. I don't have to squeeze everything in one day. I can take one day at a time, and appreciate people a little bit better, and analyze people a little bit better. I'm a little bit more aware of life and little things that I took for granted, I'm now doing things that I always never had time for like going to the art museum or just going to the library, sitting down and doing some research, going down to the river park and just sitting outside. It's time to live. (older man, post-ART diagnosis, long-term to medications)

### *"Continuity of Life" Schema*

A fourth schema, labeled "Continuity of Life," denotes stories featuring assertions of a basic continuity of life and of full personhood, in the face of changing conditions, an enduring metaphor running through American culture (Nisbet 1969). In this schema stories depict a life that is little altered by an HIV diagnosis. Thirteen people (11.1%) used this type of schema, among these were more older adults (5, 23.8%) than younger adults (8, 8.3%). Here we identified important differences in how older and younger adults utilized the cultural schema of continuity. Older adults described continuity mostly as resilience and continuing on with life; whereas, younger adults described a continuous stream of life crises (e.g., many had pre-existing health problems so that the HIV diagnosis resulted in no major change in their already distressed lives).

Ms. Fletch is 54 years old and had been living with HIV for 1 year at the time of the interview. She came from a family with four brothers and two sisters; with only one of her brothers surviving. Her father was a Cherokee and her mother, African-American. Ms. Fletch ran away from home at age nineteen to marry a man twenty-one years her senior. She wanted to escape the strict control of her father and brothers. She finally left her husband due to ongoing conflict with his mother with whom they lived. Her next partner was HIV positive but

did not disclose it. Since diagnosis, she has lived a well ordered life, taking medicines on schedule and hopes to grow old gracefully. She described her story of HIV as:

The only things that's changed is taking that medicine.

Since then I haven't had a sex partner in two years, but if I did, I would make sure he knew I was HIV and I would make sure he wear protection.

Otherwise nothing really changed in my life. I'm still the same me. (older woman, post-ART diagnosis, long-term to medications)

Ms. Grant is 45 years old and has been living with HIV for 1 year. She described having a wonderful childhood and was one of six siblings. Yet, she slipped into drug use in early adulthood. The mother of five children, she was infected by her partner who did not disclose his infection. She was diagnosed when she was hospitalized for Pneumocystis Pneumonia (PCP) while pregnant with her fifth child. The court threatened to remove her parental rights if she did not stop using substances. She choose to retain her children and managed to stop using substances. She repaired her relationships with her family and has been sober ever since. Ms. Grant told this story of living with HIV:

The only thing that has really changed is sometimes it might have just been in my head that just by me knowing I was HIV [positive], now the colds; I would get colds much easier.

But as far as things being different, I wasn't dealing with anybody else but the one guy anyway, before I even found out.

And it's still been the same way. We might be fighting and he might say something like, "that's why you got HIV." That's something I know that I don't need to hear, because to me that's a, that's a mental abuse thing. (younger woman, post-ART diagnosis, long-term to medications)

Now she is well supported by her family and focuses on being a good mother.

### *"Angry and Fearful" Schema*

"Angry and Fearful" was personal theme schema, characterized by a focus on blame of others, rejection of the diagnosis, or blame of self. Also, stories in this schema spoke about the future as an unknown. Here participants used phrases emphasizing anxiety, distress, devastation, suicidal thoughts, dying, difficultly accepting HIV, shame, HIV stigma, fear of disclosure, losses (such as in confidence or sexuality), lack of a future, or an undifferentiated focus on death. These narratives did not feature a sequential dimension (for example, the "Stages of Grief" category); rather they focused on a core concern. Roughly the same proportion of younger (11.5%) and older (9.5%) people used this type of schema. Analyses did not identify a difference by age group within this schema.

Mr. Houghton is 42 years old and has been living with HIV for less than 1 year. He described his family as large and loving and his childhood as idyllic, except for being abused by a relative at age three. He was the exception among his siblings, all of whom he saw as quite successful in life. He wanted to be a boxer but gave it up as he matured. After high school he drifted into drugs and sex. He has three young children and his goal at the time of the interview was to be a good father to them, but told us that due to AIDS he was too sick to work and financially support his family. No one among his family or friends

knew his diagnosis, not the children, their mothers, nor his family. Mr. Houghton told this story of HIV:

Its been devastating, very hard for me to accept.

Its been blame, me blaming other people, me blaming myself, me blaming God. It is very, very hard to deal with. One thing I know-I did it to myself. (younger man, post-ART diagnosis, naïve to medications)

Mr. Ingram was 54 years old and had been living with HIV for 6 years. Born in Detroit in the 1950's into a strong loving family, he was a rambunctious high-strung teen. After ranting about Black Power to a policeman, he was jailed and later wrongly accused and convicted of armed robbery. At age 17 he was sent to prison, to "punish" him. Angry at the injustice, he started using drugs in prison and was sexually abused there. He said acquiring the HIV infection was the ultimate affront in an unfair life. He is very bitter, and described his HIV story as:

It's just been messed up, man. I don't feel confident, man, with women. Nothing, I just don't feel confident, man, about nothing. Somebody messed you up with something like that? Make you ill like that. You ain't gonna get no woman-no baby. You can't have a good relationship 'cause you got to tell her. I wouldn't want nobody to go through this. (older man, post-ART diagnosis, naïve to medications)

### *"Shocked and Amazed" Schema*

The stories in the "Shocked and Amazed" schema category were distinctively individual-centered and were told only by younger women (2, 2.1%). No older adults used this schema. Both younger women emphasized how they did not suspect an HIV diagnosis because they believed themselves to be in monogamous relationships and at a life stage where they were no longer at risk.

Ms. Jessup is 47 years old and has been living with HIV for 1 year. She has five brothers and three sisters. She was infected by her husband, an intravenous drug user. She described herself as having led a "bad life" as a gambler. When she was hospitalized for PCP and almost died, she made a deal with God that she would stop gambling if he saved her life. He did and she quit gambling. She started living "right", paying attention to her health and believed that an HIV diagnosis saved her from her family's history of kidney failure by making her pay attention to her health before it was too late. Ms. Jessup's story of living with HIV was narrated briefly as follows:

I was amazed when I found I had it because I was always the little church girl. I had only a relationship with my husband so I knew that that's where it came from and I didn't know you could catch it from-because he didn't have a problem with a bunch of women. It was drugs. (younger woman, post-ART diagnosis, long-term to medications)

## **Discussion**

We examined the personal stories African Americans told when invited to narrate their own story of living with their HIV disease. Findings offer several key contributions. By describing African Americans' own stories of living with HIV, the study helps fill a well-documented dearth of literature depicting the voices and experiences of African Americans. Further, it

reveals important heterogeneity in the experiences and storytelling of living with HIV, which provides a counter perspective to the tendency to overgeneralize about African Americans. In addition to describing six varieties of story schemas, it systematically explored age dimensions, which adds to scant literature on qualitative comparisons of older and younger persons with HIV.

Notably, confounding of age, cohort, and period effects was minimized in reporting results of analyses. For example, analyses explored the period in medical history when HIV was diagnosed (ART medications, before, after) which differentially affected survival prognosis as well as the complexity and difficulty of adhering to antiretroviral drugs; and, age at diagnosis compared to duration of living with HIV to ensure living longer with HIV was not confounded with old age.

Analyses identified an important heterogeneity in stories and experiences. Six diverse types of schemas emerged. The majority of the stories were told using organizing schemas that drew upon contemporary cultural metaphors for making sense of personal adversity, which situated the speaker in a socially shared frame. In the first four types, we identified differing schemas embodying storied experiences of living with HIV (“Stages of Grief”, “12 Steps”, “Wake Up Call”, and “Continuity of Life”). These schemas illuminate diversity in the ways African Americans described and made sense of adversity and integrated HIV into their lives in the process of refashioning life after a stigmatizing diagnosis (Becker and Newsom 2005). In the remaining two schema categories (“Angry and Fearful” and “Shocked and Amazed”) the stories were individualistic and focused on personal anger, fear, and enduring distress without expressions of a sense of resolution or a larger organizing life script.

Importantly, the diversity of schema identified here contributes to breaking down the homogeneous ethnic category utilized in HIV research in which African Americans are typically discussed as an undifferentiated population, as are Latinos (George et al. 2014; Heckman et al. 2000; Jackson and Sellers 2009). Research suggests the importance of understanding diversity and variation among African Americans with HIV/AIDS (George et al. 2014) as well as among older African Americans in general (Jackson and Sellers 2009). Qualitative studies to date that have focused on African Americans with HIV/AIDS have examined specific sub-groups such as women (Buseh et al. 2006; Dalmida et al. 2012; DeMoss et al. 2014; Shambley-Ebron and Boyle 2006; Warren-Jeanpiere et al. 2014; Watkins-Hayes et al. 2012), men (Buseh and Stevens 2007; Wheeler 2005), men who have sex with men (Bird and Voisin 2013; Haile et al. 2011), and older adults (Nevedal and Sankar 2015; Foster and Gaskins 2009; Gakumo et al. 2015; Haile et al. 2011; Warren-Jeanpiere et al. 2014). These studies have helped create a more nuanced picture of the experience of living with HIV for African Americans. To our knowledge, this study is the first to employ a systematic in-group comparison of African Americans with HIV/AIDS. Our study expands previous literature because we explore the variation in the meaning of HIV/AIDS between older and younger African Americans and contribute to a deeper appreciation of the diverse experiences of this epidemic for a disproportionality affected population.

Research on aging requires attention to cohort and history period settings not just chronological age. How might the settings enter into experiences of aging and HIV and shape the stories? We explored how the specific historical cohorts defined by the medical treatments available, for prognosis, and social meanings at the time of the speakers’ HIV/AIDS diagnosis (relative to ART drugs introduction) might pattern the story schema as opposed to speakers’ age today. Persons diagnosed in the pre-ART cohort (the medication became available in 1996; the first antiretroviral, protease inhibitors, was approved in 1987) encountered HIV as an almost certain death sentence; or, somewhat later after protease inhibitors were introduced,

those diagnosed then were faced with extreme adherence challenges with some people taking more than 37 pills a day often with severe side effects. The post-ART cohort (after 1996) included people who were diagnosed up to two years (1998–2000) before the start of the study and during a time when HIV had become a treatable, but not curable, chronic illness and the large number of daily medications was greatly reduced. We reasoned that the trauma experienced by those diagnosed early when there was no treatment for HIV or very burdensome medication regimens with extreme side-effects might inform the stories they told about coming to terms with their disease. Yet, no differences were identified relative to how participants of the pre-ART and post-ART cohorts told their stories.

Historical birth cohort was a relevant factor differentiating between the young adults and the old adults studied here. Following Elder's (1994) work, we found the socio-political historical contexts of the two birth cohorts helped explain differences between older and younger adults. Elder revealed how the particular historical era into which one is born (e.g. Children of the Depression, the Sixties generation) defines powerfully shared values, experiences, opportunities and the challenges shared by an entire cohort apart from other enduring social differentials regarding socio-economic status, ethnicity, or gender. For the African Americans discussed here, the historic cohort is associated with the types of schema engaged (i.e., older and younger age groups) but not the shared disease history in terms of the HIV-specific cohort groups (i.e., the era when the individual was diagnosed with HIV). Thus we explored the possibility that schemas may, in part, reflect such historical cohort specific interpretive and value resources for life reorganization in the face of living with chronic HIV. Yet we acknowledge that this study was not designed to capture the extensive lifetime contextual data needed for definitive conclusions beyond describing the variety, distribution, and possible sources of schemas used.

Another cohort pattern emerged. For example, stories using the "12 Steps" recovery schema highlighted historic cohort differences because 31.3% of younger adults used this schema in comparison to 9.5% of older adults. Historical cohort social settings may offer insight into this pattern. The younger people in this study were born into a culture era when the "12 Steps" metaphor featuring responsibility for self-care, moral personhood, demonstrated in the case of HIV through responsible sex, and the live-one-day-at-a-time philosophy were prevalent. "12 Steps" philosophy has extended far beyond its initial home in alcoholism treatment to substance use treatment in general and to all forms of addiction. "12 Steps" has also gone beyond the realm of substance use and is a popular metaphor referencing serious engagement in changing the self. This pervasive metaphor is typical of the popular culture where younger adults were raised.

Historical cohort contrasts may also be discerned within "Stages of Grief" stories. More older (47.6%) than younger people (29.2%) use this schema. Kubler-Ross' (1969) theory of stages of grief predates "12 Steps" or "Wake Up Call" in terms of popular cultural uptake and thus would have been familiar to older adults. But "Stages of Grief" also has an implicitly moral component associated with organized religion. In this way it is similar to the moral personhood idea associated with "12 Steps". In "Stages of Grief" we see people struggling with adversity and seeking acceptance of their lot in life. In "12 Steps" and "Wake Up Call" we similarly see people expressing individual moral self and seeking to triumph over adversity by their activities and behavior. Perhaps the implicit spirituality of stages explains why one-third of younger people as well as one-half of older people utilized this schema. In a similar vein, the "Wake Up Call" schema, which was more prevalent among younger adults, may have roots in the "New Age" philosophy of "be here now" which gained wider circulation in popular thought as part of the cultural setting in which the younger adults grew and matured.

Findings on the “Continuity of Life” and “Angry and Fearful” schemas both support and contrast with Emler et al.’s (2015) quantitative cross-sectional survey examining age differences in stigma experiences among people with HIV/AIDS in Canada. Emler et al. (2015) found older adults reported lower stigma than younger adults. We found older adults used “Continuity of Life” more often to describe their story of living with HIV, which emphasizes a more resilient rather than stigmatized response to HIV. However, “Angry and Fearful”, is a schema that indicates distress and stigma, and was used approximately as often by older adults as by younger adults. This finding highlights the value of qualitative approaches and contrasts with the Emler et al.’s (2015) suggestion that younger adults report more stigma compared to older adults. Of consideration, our sample included US-born African Americans while Emler et al. (2015) studied Canadians.

Finally, 24% of older adults used the “Continuity of Life” story schema compared to 8% of younger adults. “Continuity of Life” schema was marked by clear statements that the guiding pattern of their life has remained the same, that being HIV positive has made little difference in the life lived. However, what was continuous differed between those older and younger than 50 years old. Older people referenced a life filled with hardships and their own resilience in the face of these hardships. Older African Americans’ resilient response to living with HIV supports previous research on African Americans living with chronic illness by Becker and Newsom (2005). In contrast, younger people with this schema had stories filled with crises and health problems so that HIV was just added to their list of life’s challenges. These stories did not emphasize resilience, a well-documented theme found in the narratives of older African Americans recounting adversity (Becker and Newsom 2005).

Admittedly, a variety of analytic limitations as well as the nature of this data set limit making more definitive conclusions about why some people have one schema as opposed to another, or how schema influenced or were influenced by the illness experience. But perhaps we can say that the schema that were available to people for making sense of adversity and for refashioning their lives were influenced by the historic cultural setting in which they were raised and, further, that these ways of making sense appear to endure into later life. As the HIV epidemic continues to age, it will become increasingly important to understand how the historical cohort of the individual influences this experience and, in turn, how having HIV influences the later life story telling about experience of living with HIV.

Church, faith, spirituality, or religion were not a major schema among the HIV stories based on our analyses. This is somewhat surprising given their widely reported significance in research among African Americans in managing health and coping with illness (e.g., Harper et al. 2013; Levin et al. 2005; Schulz et al. 2008; Taylor and Chatters 2010). Considering this, we reexamined the stories for any mentions of church or spirituality. Only 12 stories included any such mention, but again, it was not the primary guiding pattern for the story. Four expressed disappointment with the church’s negative stigmatizing and homophobic attitudes, and eight stated a personal relationship with God and faith as a resource for living with HIV. The schema “Wake Up Call” had some mentions of faith or spirituality. None of the HIV stories were centrally organized on religion, faith, spirituality or church.

### **Strengths and Limitations**

Study limitations need to be acknowledged. Two key contributions of this study are to first, provide large scale descriptive information on African Americans’ own ways of telling the story of living with HIV/AIDS, a group which has not received adequate attention in HIV

research to date, and second, to systematically compare older adults and younger adults. The large scale qualitative study illuminated important diversity in African Americans' experiences of living with HIV, which strongly undermines the tendency to overgeneralize about African Americans as if they are a homogenous group. Limitations of this study include that the study participants, in order to gain IRB approval and address concerns about disclosure of seropositive status, were recruited through two large urban hospitals so there are some geographical limitations. However, given that the two hospital systems differed greatly in terms of the populations served (inner city and greater metropolitan area residents), and the inclusion of participants from across this large metropolitan area, findings may be comparable to minorities in other larger urban regions. Given the rapid increase of older adults with HIV, future studies should work to include larger samples of older adults. The findings provide systematic information on the culturally shared schemas that pattern the telling of stories and experiences of life after HIV by African Americans; generalizability to other populations and regions may be limited due to the qualitative nature of the data.

## Implications

We note that even though, or perhaps because, HIV is a highly stigmatized disease, African Americans drew on deeply rooted cultural schema and ideals to make sense of their HIV experience. These data show the dilemmas distinctive to an HIV diagnosis such as the challenge of successfully reorganizing and continuing on with life after a highly stigmatizing diagnosis.

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