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### Permalink

<https://escholarship.org/uc/item/68w0q7wc>

### Journal

Journal of the Association of Nurses in AIDS Care, 27(6)

### ISSN

1055-3290

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### Publication Date

2016-11-01

### DOI

10.1016/j.jana.2016.05.004

Peer reviewed

## **“I Am Normal”: Claiming Normalcy in Christian-Identified HIV-Infected Adolescent and Emerging Adult Males**

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### Abstract

Acquiring HIV in adolescence and young adulthood, when development of self-identity, personal values, and life purpose are central, is challenging. The purpose of our study was to explore the spiritual needs of young people with HIV, learning strategies they used to cope with the disease. A constructivist grounded theory study was conducted. A purposive sample of 21 Christian-identified HIV-infected males was interviewed. The iterative coding phases of grounded theory, including open, axial, selective, and theoretical, were used to analyze data, and a theory of claiming normalcy with HIV was generated. We present the salient theme “I am normal,” describing young people's attempts to function the same as peers despite requiring daily treatment. Conditions associated with feelings of normalcy included disclosure status, stigma experiences, support, and health status. Participants sought meaning in the disease, ongoing social engagement, and self-belief. Reinforcing feelings of normalcy may help young people cope with HIV.  
Key words: adolescents, emerging adults, HIV, identity development

HIV is no longer considered a gay White man's disease, but rather a youth-driven disease, with 13- to 24-year-olds accounting for 22% of all new infections in the United States in 2014 (Benton and Ifeagwu, 2008, Centers for Disease Control and Prevention, 2016). HIV is the sixth leading cause of death in adolescents (Benton & Ifeagwu, 2008), and as many as 44% of adolescents and emerging adults infected with HIV are unaware of their status (CDC, 2016).

While adolescents and emerging adults account for approximately 17% of the population in the United States (U.S. Census Bureau, 2014), adolescents and emerging adults 13 to 24 years of age accounted for 22% of all new HIV infections in 2014 (CDC, 2016). Additionally, young gay and bisexual men accounted for approximately 78% of all new HIV infections in youth between 2008 and 2010, representing a 22% increase in HIV infections in this age and gender group (CDC, 2016). Adolescents and young adults (13-29 years of age) accounted for approximately 29,100 of the 58,800 cases of HIV in southern California at the end of 2014 (California Department of Public Health, Office of AIDS, 2013).

During the adolescent and emerging adult life stages, emphasis is placed on individuals understanding who they are, who they may want to become, and finding a sense of purpose. Having a diagnosis of HIV during this period can present additional challenges for the transition through adolescence and emerging adulthood. Additionally, a diagnosis of HIV may present new uncertainties for adolescents and emerging adults as many are attempting to find meaning in life and life situations. In a classic text by Hoekelman, Adam, Nelson, Weitzman, and Wilson (2001), adolescence is described as a period of identity development, usually occurring in the context of peer groups that may predispose the individual to high-risk behaviors such as substance use and unprotected sexual activity,

putting them at risk for negative health outcomes such as HIV. Cognitive development continues in emerging adulthood, and key features of this period are identity explorations in the areas of love and work; explorations in intimate relationships become more serious and work experiences become more focused on preparation for adult work roles (Arnett & Jensen, 2002).

The purpose of our study was to explore the range of factors that influence spirituality in adolescents and emerging adults with HIV. Its specific aims were to describe the range of factors that influence spirituality in adolescents and emerging adults with HIV and to describe the spiritual perspectives of HIV-infected adolescents and emerging adults.

## Background

Adolescence (ages 10 to 21 years) is usually differentiated as early adolescence (about ages 10-13 years), middle adolescence (about ages 14-17 years), and late adolescence (about ages 18-21 years; Steinberg, 2011). In an earlier conceptualization, Arnett (2000) posited a period of emerging adulthood (ages 18-25 years) as a more descriptive later phase of adolescence, accounting for continued changes in the brain that influence behavior and affect. Emerging adulthood is a stage that is empirically and theoretically distinct from adolescence and young adulthood and is distinguished by relative independence from social roles and from normative expectations:

Emerging adulthood is a time of life when many different directions remain possible, when little about the future has been decided for certain, when the scope of independent exploration of life's possibilities is greater for most people than it will be at any other period of the life course (Arnett, 2000, p. 469).

The CDC (2016) has cited several reasons for increased rates of HIV infection in adolescents and emerging adults, including (a) inadequate sex education in school, (b) low rates of HIV testing in sexually active youth, (c) low rates of condom use in sexually active youth, (d) substance use, (e) increased prevalence of sexually transmitted infections, (f) stigma associated with HIV, and (g) feelings of isolation and lack of support in gay and bisexual youth. Mustanski, Newcomb, Du Bois, Garcia, and Grov (2011) explained that the increase in HIV during these ages may be attributed to some adolescents, emerging adults, and heterosexual men who do not classify themselves as gay participating in transactional sex (e.g., sex in exchange for food, money, clothing, or housing).

Stigma associated with HIV continues to be evident in the church as well as in mainstream society. Because of stigma, HIV-infected adolescents and emerging adults often do not get tested, which leaves many unaware of their HIV status; do not access or are lost to health care; are less adherent to medications; and often do not participate in treatment and prevention programs (Fielden, Chapman, & Cadell, 2011).

A diagnosis of HIV as a young person presents multiple challenges as, developmentally, adolescents and emerging adults face the challenges of fitting in and being accepted, making and sustaining friendships and relationships, and, very

importantly, developing a solid sense of self. The purpose of our study was to describe HIV-infected adolescent and emerging adult perceptions of spirituality and expectations of their clinicians and providers to address spiritual needs, if so desired.

## Methods

### Research Design and Setting

We used a constructivist grounded theory approach for this exploratory study (Charmaz, 2006). Rich inductively derived data, including detailed description of the participants' views, feelings, actions, and intentions were collected to better understand the spiritual needs of HIV-infected adolescents and emerging adults. Constructivist grounded theory allowed these young men to discuss personal meanings about their spiritual beliefs and how these beliefs helped them cope with their chronic illness. Theory was generated from data as they were discovered and used to explain how the young men perceived spirituality and explored their expectations of clinicians to address their spiritual needs.

### Participants

Clinic staff recruited participants during scheduled appointments or through flyers posted in clinic areas. Study eligibility included having HIV, ages 13 to 25 years, and an ability to read and speak English. Participants were recruited during a 16-month period of time.

A purposive sample of 21 Christian-identified, HIV-infected males agreed to take part in the study. Participants were gay (90%), men of color (76%), and, on average, 22 years of age (see Table 1). For the purpose of our study, Christian-identified was defined as an individual who practiced the principles of Christianity but did not belong to an organized religious faith.

### Procedures

The University of California San Francisco Institutional Review Board granted approval for the study. Written parental consents and minor participant assents were obtained for participants younger than 18 years of age. All participants 18 years of age and older gave written consent. The researcher obtained all consents at the time of the interviews. Consistent with the constructivist grounded theory approach, data were collected through ongoing interactions with participants (attendance at group meetings and outings), and thus, provided a rich, deep understanding of the participants' lives and experiences of living with HIV (Charmaz, 2006, Hallberg, 2006). Data were collected through semi-structured interviews and field notes taken during encounters with participants. The first author interviewed and audio-recorded 21 male participants in face-to-face interviews. Second interviews were conducted with three participants for clarification, verification, or elaboration of developing themes and concepts. Interviews were scheduled at a mutually agreed-upon location that provided privacy and convenience for participants. Interviews lasted not less than 15 minutes and not longer than 90 minutes. The semi-structured interview guide consisted of general (broadly worded)

open-ended, nonjudgmental questions designed specifically to explore participants' experiences of living with HIV and how their spiritual beliefs may or may not have impacted their abilities to live with HIV. There were eight primary questions, 29 secondary questions, and, as themes emerged from analysis of participants' responses, questions were added to the interview guide. All interviews were transcribed verbatim from the audio-recordings within 30 days of the interview, with the majority transcribed by the study's primary investigator and the remaining transcribed by a professional transcriptionist.

Field notes were started during each interview and completed as soon after the interview as possible. The field notes enabled the research team to compare data that may otherwise have been missed (such as participants' affect during the interview or emotional responses to questions), and provided space for notations on data that still needed to be collected.

### Data Analysis

Coding is a grounded theory process that helps the researcher define what is happening in the data while attempting to understand its meaning (Charmaz, 2006). Segments of the data were labeled with a name that described, categorized, summarized, and accounted for the data (Charmaz, 2014). We used multiple levels of coding to code the interview transcripts: open, axial, selective, and theoretical.

During open coding, we identified concepts as they developed and examined them for similarities and differences while placing them into categories (Strauss & Corbin, 1990). We remained open to developing concepts that emerged from the data while also attending to analytic ideas that were further explored in data collection and analysis (Charmaz, 2006). The coding process generated 589 open and in vivo codes, including: "HIV is better than other diseases," "I am normal," "not as bad as thought," and "life is better." The first author coded all transcripts line by line or in small sections and completed data analysis using Atlas.ti software (Berlin, Germany) for qualitative data analysis. Biweekly meetings or telephone conferences were held to discuss codes and the emerging themes and concepts with members of the research team.

We used axial coding to put the data back together by categorizing and connecting categories to make relationships (Strauss & Corbin, 1990). Concepts that shared similarities were grouped together into categories. As an example, stigma, church views of homosexuality, personal responsibility, HIV punishment, and hypocrisy of churches were important categories that emerged from the data. As categories emerged from the data, we coded these incidents and compared them to previously coded data and with incidents that had not been previously coded. As an example, disclosing status, fear of not being accepted, stigma, and relationship challenges were categorized as "second coming out." In another example, "no physical disfigurements," "better than other diseases," "still do the same things," and "I am not dying" were categorized as "I am normal." Groups within the sample (e.g., African American, Caucasian, adolescents, and emerging adults) were compared and contrasted. The groups were compared to identify salient themes in their stories and responses to interview questions.

Selective coding involved systematically identifying relationships between the core category and other categories. After categories and their relationships were identified, we verified these relationships and filled in other categories that needed further development (Strauss & Corbin, 1990).

Theoretical coding was the fourth and final stage of the coding process. This stage of coding allowed us to move from general themes about the data to theoretical constructs (Saldaña, 2009). Theoretical codes that arose included making meaning of HIV, coming to terms with HIV, reconnecting to spirituality, living with HIV, and “I am normal.” Explanatory matrices were used to organize concepts and their relationships into a theoretical story.

Memos were written throughout the process of data collection and analysis. All memos were iterative, enabling us to build upon them as new concepts developed from the data and assisted with generating a theory.

In constructivist grounded theory, the aim is to collect and analyze data until theoretical saturation occurs, that is, no new codes, categories, or concepts occurred through constant comparison of the data (Bryant & Charmaz, 2007). With a sample size of 21 participants and a total of 24 interviews, we reached saturation with a sufficient understanding of the role of spirituality in gay Christian-identified adolescent and emerging adult HIV-infected males. The data from our sample offered both thick description and thick explanation of these adolescent and emerging adult men's perceptions of living with HIV (Holloway & Wheeler, 2010).

### Assessing Rigor

Rigor assures that the findings of a qualitative research study are trustworthy (Whittemore, Chase, & Mandle, 2001). The descriptions of our participants' spiritual experiences were reported verbatim and a broad definition of spirituality was used to prevent bias from our own spiritual beliefs. Participants' negative spiritual experiences were also reported. The first author was the interviewer and was careful to not share her spiritual beliefs with participants to decrease social desirability responses. To assure the first author's personal feelings, spiritual beliefs, experiences, and potential biases were not embedded in the analysis, other members of the research team reviewed and discussed interviews and products of analysis. The interviewing author had experience interviewing adolescents and emerging adults from her role as a family nurse practitioner and paid close attention to her role as researcher, differentiating it from that of clinical practice; she took extra precautions to not introduce personal assumptions about the age groups under consideration into the research process.

Positive and negative experiences of participants were reported, as all interviews were transcribed verbatim. As concepts developed, they were shared with participants in later interviews for verification and to assure the findings accurately reflected the perspectives of participants and not those of the interviewer. Finally, all co-authors reviewed the data to assure that the identified categories, overarching themes, and theorizing codes actually emerged from the data.

### Results

A grounded theory on reconnecting to spirituality was generated from the analysis. When 21 adolescents and emerging adult males were interviewed to understand their spiritual perspectives on living with HIV, the participants spoke of reconnecting with their spiritual faith and practices after diagnosis, as a means to cope. Participants spoke of growing up in homes where prayer, having faith, and church attendance played vital roles in assisting the family to endure difficult times and situations. Many abandoned those forms of spiritual practices during the early teen years, only to return after a diagnosis of HIV. The theory of reconnecting to spirituality and its components are fully described elsewhere (Smith, Blanchard, Kools & Butler, 2016).

Reconnecting to spirituality was enabled when these young men were able to claim normalcy in the face of HIV. With the successful navigation of this process, they were able to reconnect to the church, community, their spiritual beliefs and roots, and everyday lives. This paper focuses more deeply on the important process of claiming normalcy that was generated from the in vivo code of "I am normal." Participants used the language of "normal" to describe their conceptions of a normal self. The participants gave various descriptions of how their lives were equal to that of their uninfected peers.

The "I am normal" concept was prominent through most of the interviews, so much so that it quickly became an overarching theme in the analysis. Participants expressed this concept in the following ways: "I don't feel any different," "I am still normal," "I am like any other normal person," and "I am no different." The concept was verified in later interviews when participants were recruited via theoretical sampling. The interview guide was changed to add questions that would elicit participants' perspectives on the concept of feeling normal with a diagnosis of HIV.

As stories unfolded, they were found to be steeped in the participants' perspectives and feelings of being normal. We began to understand what normal meant to the HIV-infected adolescents and emerging adults in our study. Claiming normalcy afforded these adolescents and emerging adult males the ability to reconnect with their communities, peers, co-workers, and families without fear of being stigmatized. Additionally, claiming normalcy instilled a sense of being able to live a life equal to their uninfected peers, and thus reduce the risk of being stigmatized or ostracized. During data analysis, attention was paid to conditions, strategies, and consequences that were involved in the process of claiming normalcy. An explanatory matrix outlining the dimensions of claiming normalcy and their relationships is presented in Figure 1.

What does normal mean to young people who are living with a potentially devastating disease? Using the perspectives of our participants, we defined claiming normalcy as affirming that the individual had a state of health that afforded him the ability to function at a level that was equal to his peers in the presence of daily medications and the absence of outward physical signs of disease or disfigurement.

So who decides what is normal? Is that decision made by the individual living with the disease state or by others in the social milieu? What other qualifications or

underlying characteristics have to be considered? These questions helped to formulate a definition of what was normal for these adolescents and emerging adults and how they claimed it for themselves. Participants compared their lives with HIV to the lives of those living with diabetes and cancer. They spoke of having the same responsibilities as everyone else in society, such as work, paying bills, attending school/college, or providing a place to live for themselves, and maybe others. Normalcy and abnormality may best be defined by the individual who has the disease, as it was by the adolescents and emerging adults in our study. Our participants often spoke of not feeling or looking any different from anyone else. We will discuss the conditions, strategies, and consequences that were related to the process of claiming normalcy.

## Conditions

Several conditions were identified that could facilitate or block an individual's ability to claim normalcy. The conditions we identified were: disclosing status versus keeping private, stigmatizing versus supportive responses by others, and health status.

### Disclosing status versus keeping private

This condition was a decision each participant made about revealing or not revealing his HIV status to family and friends:

I didn't want anyone to know. I mean, I told - I told a few close friends, and then I - when I tried to tell family, the whole family found out, so that was upsetting to me. Yes. Everyone found out. Friends found out in the neighborhood [where] I grew up. Family, everyone in my family, and I mean everyone, found out. And it was uncomfortable to be around family, so I kind of moved away from - I have - I haven't seen my family in months. Participant (P) #9

Well a lot of my friends know. Um, I haven't, I just didn't say anything. I really, I really don't know why I didn't say anything. I am thinking that it doesn't matter 'cause I'm OK now and I don't want them to really stress out or anything about it. You know, worry about me. P#8

Keeping one's HIV status private or disclosing it could hinder the ability to claim normalcy and have lasting emotional consequences. The process of disclosing or not emerged as a condition of claiming normalcy. Our participants did or didn't disclose to family because they felt fine, normal.

They took it well, I guess, as well as they could take it. They're supportive of it. They don't ever bring me down on it and rarely ever mention it too much, to be honest. It's just the same thing to them. It's just something that I take pills for and go to the doctor. P#4

Um, they've, like all of my family and friends like, no big deal ... No, all of my friends like, "Have a bite of a sandwich," they'll have a bite of a sandwich that I am eating or they'll have some of my drink, you know. P#19



In addition, all of our participants received support from their providers, counselors, or social workers to assist with the challenges associated with their status, including decisions about disclosing.

### Stigmatizing versus supportive responses

Some participants disclosed their status to people they felt they could trust only to be betrayed or stigmatized by those individuals. Some participants spoke of experiences of stigmatization from the church when disclosing. As a result, some participants left the churches they had attended for many years, while others spoke of supportive responses from family and friends when disclosing.

I stopped going to the church that I used to go to 'cause they said people with sickness like that were dangerous, they cannot be around normal people and all that and I was just like, I am a normal person ... I told like, um, probably the priest and probably some other main people that I thought I could trust with that wouldn't criticize me, but it ended up being the opposite. P#21

Well, you know, "Grandma, remember when we were watching Rent and you know the part in the play where Angel dies?" And she's like, "Yeah," and I'm like, "Well, that might happen to me someday, 'cause I'm positive now, like I could get sick like that." And I started crying, and she started crying, and we were both crying, and we were just holding each other and she's like, "I don't care. I still love you." P#12

Claiming normalcy may foster a sense of not being viewed as different from others. Claiming normalcy may also decrease the likelihood of being stigmatized because of one's HIV status. "I feel that it will be abandonment there. Like I'll be judged. I think that's like one of my things like 'You ain't got nothing do you?' Or you know. I just know how, uh, they would be." P#17

... the word got out and the whole dorm where I was staying reacted very repulsive in a way like, not like, they were like more caring in a way, like talk to me more but then they were like, "OK you gonna' have your own toilet, you not going to share nothing with anybody, you're not gonna' like, like you have your own place to wash your hands." We always used to share that and they just kind of and they did feel like you can pass the disease like that, but people just have to, you know they kind of get scared about it so then I mean, I didn't want to be treated differently 'cause it kind of reminded me of the disease more. P#6

### Health status

Participants described HIV as an illness that did not present with visible signs or symptoms. They compared the diagnosis of HIV to other chronic illnesses such as cancer and diabetes. Most participants described being HIV-infected as better than having diabetes in that, "it is much easier to control HIV." Other participants described the side effects of chemotherapy and the disfigurement of certain diseases to be worse than having HIV: "... she's not normal either and she has it worse than you. She has to live plugged into her, a thing to her kidney for the rest of her life you know" P#3.

... diabetes could be worse than AIDS or having HIV cause that's just what my doctor told me. That's like the first thing they told me. Like it's not a, not a death

sentence, and diabetes is actually harder to control, to manage than, uh, HIV nowadays, so. P#8

Participants unanimously felt they were in overall great health and often forgot their HIV status until they had to take their medications. They felt “normal.”

### Strategies

Participants employed several strategies to claim normalcy, including seeking meaning in the diagnosis, believing in self, and engaging in social life. With the use of the strategies, participants were better able to feel that they were “normal” and leading a normal life.

### Seeking meaning in diagnosis

Participants defined seeking meaning as seeking personal value and meaning in their HIV status. Some participants identified drug use/abuse or sexual assault as the reason for their status. One perinatally infected participant would have many questions as he tried to make meaning of his diagnosis.

For a month I was like, “I want to die. Why does God hate me so much?” I thought I was going to be OK ... I was like, “What did I do wrong? What did I do so wrong?” And then coming time passing to where I started to understand, to be more comfortable with myself, I started realizing that I got HIV to protect myself from the war, from whatever else is going on. I am here because I saved a life. I saved two people's lives, my best friend and my husband. My husband was addicted to Crystal Meth and I changed his life. Finally, I brought him into a home you know. My parents didn't have nowhere to go so I asked them, come live with me you know and it all just worked out. P#3

I feel, I ask myself why would he give this to me. But then I say, “Well, I had a choice too and did whatever I did” and I feel, sometimes feel punished because I have and sometimes I don't. I'm a lot confused of why, 'cause I was so safe and uh you know not really knowing who did I get it from. Um, it has me question God sometimes on it as well. P#17

When participants were able to find meaning in the diagnosis of HIV and not view it as personal suffering, they were better able to accept the diagnosis and claim normalcy.

### Believing in self

Participants defined believing in self as having self-confidence in the ability to live with HIV. Although our participants' initial reactions ranged from shock to disbelief, most came to accept their HIV status as something they could live with. I know that you know that with the technology we have today, with the medicine that we have today, um, I can live a pretty healthy life. And, um, I don't have to worry about my death being imminent upon me. I feel like I can cope with the realization that HIV is not a critical, you know, it's just a chronic illness that is upon me so. P#14

In believing in themselves, the participants garnered belief that they were living a normal life, with the exception of having a chronic, life-long illness.

### Engaging in meaningful social relationships

Most participants had very active social lives. Participants defined meaningful social relationships as going out with friends and family or having friends and family over for dinner, parties, or other social gatherings.

We're kind of wild crazy party people, yeah. Mmm. I like alcohol. I like to party. I like to have fun. I like to go out. I'm a normal human being. I like to do what normal people like to do, I guess. P#9

Um, I think I'll probably get into more dating when I am in my 30s too. I want to start doing that when I am a little more stable with money. Right now I am more worried about myself than anything else. Like I focus on my career and how I am doing, my pumpkin carving party tonight, {chuckle} you know. P#19

These young adolescents' and emerging adults' social lives were reflective of the typical social lives of most of their peers who were HIV-infected or not. Participating in these activities gave them a sense of normalcy, and disclosure of status was neither a requirement nor an exclusion criterion for participation.

### Consequences

Our participants discussed the consequences to claiming normalcy; not all consequences were positive and the outcomes were on a continuum. The outcomes or consequences were dependent on how participants moved through the process of claiming normalcy. Participants spoke of times since the HIV diagnosis of (a) feeling poor self-esteem and other times of feeling a positive sense of self-worth; (b) being engaged versus being disengaged in work, school, church, and social life; and (c) having poor versus better health outcomes related to HIV.

### Positive sense of self-worth and value

Participants described feeling good about themselves and believing that HIV did not define nor mean the end of life, with a positive sense of self-worth and value. Our participants believed the diagnosis often served as a catalyst that created change from high-risk behaviors or moved them forward to pursue personal goals.

Um, now it's a day, I know that it's not the worst thing in the world 'cause they have, you have to eat a, live, try to live a healthy lifestyle to help you get better - Um, it's just something I have to keep taking my meds to get better so, I guess it's a part of me - And every day of my life I go, like I tell myself like, "This is not the end, this can't stop me cause I am still living. I am not dead yet so I won't let this be the reason why I do die." P#16

Participants found it was possible to live with HIV. Living with HIV did not diminish hope for a long life for our participants.

Engaged in workforce, school, church, and social life

Participants characterized being engaged as being actively involved in the church, enrolled in school, socially interactive with peers and classmates, and/or gainfully employed. Being able to engage in work, and to attend school, church, and social activities afforded participants the normalcies of everyday that their peers enjoyed without having to disclose their status.

Um, I also am looking to finish my college degree, a bachelor's degree in mathematics, and hopefully that will occur sometime soon - But I also work so I have, um, working in the afternoon, um, if I don't have any appointments I work - And, um, it's just, um, I went out with them at my church to eat some dinner and we had a great time and it's very supportful, very, uh, it's not exactly spiritual, it's just friends getting together and enjoying time together and knowing that you all care about God and God cares about you and all that good stuff so. P#14

When participants were able to participate in the normalcies of everyday life, the process of claiming normalcy was achievable.

Better health outcomes related to diagnosis

Participants described their lives as better in multiple ways since the diagnosis. They identified some of the improvements in their lives as health insurance, dental care, and housing. The participants defined better health outcomes related to the diagnosis, such as having undetectable viral loads, healthier diets, exercise programs, and fewer depressive symptoms related to HIV.

I don't see myself different from a person who doesn't have HIV just because, you know, well, in a way we are different just because, well, we have the HIV, but a person with HIV what they - I've noticed, they tend to have a better lifestyle, as in, they eat healthier. They go to the gym. They take care of themselves, you know. They're being healthy. They're doing healthy things, you know, being spiritual, gym, eating healthy. There's all these things that they, they do, so that their body could, you know, have more strength to fight off this disease, you know. P#11

In addition to medication management, treatment regimens, and the uncertainties of HIV, disease management often requires lifestyle modifications, including daily physical activity (Bosworth, 2006). Our participants viewed their lives as normal and equal to that of their uninfected peers.

Poor self-esteem

Participants questioned their self-worth and value at the initial diagnosis, and some participants continued to struggle with low self-esteem. Feelings of shame and guilt about how the participant was infected became central in several interviews.

It affected me pretty, I already thought low of myself. But, um, it affected me pretty bad. I, um, it made me actually, when I first found out I used to tell myself, like I am nasty like, just eew! Like, I just tell myself negative, very negative things. P#20

I was always that, "Oh he has this, he has that," you know, slow disability, pat him on the back and tell him it's OK, you know. That kind of attitude. And with my HIV, I feel like I am gross, you know, like people are grossed out. P#3

Other participants used the word "contaminated" to describe how they viewed themselves after becoming HIV infected. The feeling of being "contaminated" devalued their worth as productive citizens.

Well, just that I feel a bit contaminated in a way and I shouldn't feel that way but there is just a lot of things that HIV, uh, can hold you back from - The military was something that I was thinking about, can't do that now. So it, like there's a lot of things I'm like, "Fuck, it's holding me back." So it's like I am a contaminated being and have, like you know, there's nothing I can do for my country anymore, you know. P#18

Feelings of low self-esteem have the potential to hinder the ability to cope with the HIV diagnosis and inhibit the ability to claim normalcy as well.

Disengaged from church and social life

Our participants defined being disengaged as removing the self from a place or setting where he felt he was not accepted or was stigmatized because of sexual orientation or the assumption of HIV status. Participants spoke of stigma or feeling unwanted:

And I haven't been to church in a while - long time because every time I go to the church, the person's personal test - the preacher, whoever is testifying at that time, will change the testimony from the personal testimony or to whatever they're speaking about to the Sodom and Gomorrah thing. P#13

I try to be as happy as possibly, um, I'm a very, um, you know, lonely guy and, uh, you know right now I try to do as much to give back, um, to feel like I am part of something, you know. I want to be part of someone else's life even if it's for a little period, even if it's for a minute, I'll do it, you know. P#15

Although some participants chose to disengage from church, they continued to participate in spiritual practices such as praying, reading spiritual materials, and listening to spiritual music. They considered these practices to be a part of having a normal life.

Poor health outcomes related to diagnosis

Medication resistance, depression, or increased fatigue, often associated with HIV, were some of the potential poor health outcomes related to HIV. Most participants in our study stated that they were adherent to their medications and had very few episodes of depression. Some, however, were nonadherent to medications and described experiences as follows:

Everyone, literally, fucking everyone, keeps telling me that I need to be on a pill and I know that I probably should, but I don't want to and that's my decision and I feel that everyone should respect my decision, because it's my body and I don't have to

do anything I don't want to do. If I want to just let this virus take hold and run its course, that's my decision, and I'm allowed to do that. You know, that's not necessarily what I'm gonna' do, but you know, I'm - I just - I'm doing my own thing right now and it's a bit unconventional and everyone disagrees with it, but I don't know. P#12

Because it, my life right now, it's kind of hard to remember [to take medications] and it's unhealthy for you to take them once here and once there. 'Cause when I first got my medicine, I was doing it, I was taking it fine, but then a lot of stuff was stopped, stuff was happening and I kind of forgot and my body was aching and, it actually, 'cause I already got some resistance. My body could gain more resistance by me taking meds like one here, one there. P#20

Several participants described the concept of a life relegated to the unpleasant task of a daily medication regimen to be anything but normal. This could certainly hinder an ability to claim the normalcies that have been identified as strategies to cope with the HIV diagnosis.

Challenges adolescents may face in taking antiretroviral therapy include forgetting, the associated fear of disclosure, and not fully understanding the need for medications. Just as adolescents often take risks without fully weighing the consequences of sexual behaviors, these risks may also spill over into health-related activities.

Believing in and claiming normalcy may afford people the opportunity to live with HIV while enduring the stigma, shame, and guilt often associated with the disease. Participants in our study were able to cope with the diagnosis and live with HIV by claiming normalcy. Although some encountered isolated incidents of stigma, overall, they lived a life relatively free of stigma.

## Discussion

The overarching "I am normal" theme and the related process of claiming normalcy were evidenced across interviews in our constructivist grounded theory study to understand spirituality in HIV-infected adolescents and emerging adults. Claiming normalcy, and thus, being normal, connected these adolescents and emerging adults to their families, friends, and communities, and gave them a sense of value in everyday life. Feeling normal provided a feeling of hope and empowered them to live with HIV. Participants were able to interact with peers in places of work and school as well as the community providing the social connection that is so important during this developmental stage (Steinberg, 2011). The invisible scars of HIV (e.g., depression associated with HIV, pain of rejection) enabled our participants to harmonize with peers without revealing their HIV status.

Some participants, however, did not find their lives to be normal with HIV. They worried that HIV would limit the ability to choose certain career options or to travel to certain locations, and also felt that HIV would reduce life to daily medications and lifelong monitoring. In other words, having a chronic illness with limitations and restrictions would not lead to life as normal.

The findings in our study were similar to findings in a study of 78 adolescents with cancer. Hendricks-Ferguson (2008) used a cross-sectional descriptive design to study hope and spiritual well-being in adolescents with cancer and found that the adolescents reported the cancer diagnosis and treatment to restrict their lifestyles. Cotton et al. (2009) studied religious coping in 48 adolescents with sickle cell disease (SCD) and 42 parents of adolescents with SCD and found that more than 30% of the adolescents questioned why SCD had happened and God's love for them. This may be interpreted as a form of questioning normalcy, especially during a time of heightened social relationships with peers and social development.

The findings from our study supported the notion that acceptance and not being perceived as different were important in the lives of adolescents and emerging adults (Steinberg, 2011). The findings also highlighted the importance of peer relationships for adolescents and emerging adults (Steinberg, 2011). Our participants talked about interactions with family members, classmates, and people in general without the fear of being stigmatized, but rather feeling like a part of the group or like they belonged, "like everyone else."

### Clinical Implications

Acknowledging and reinforcing normalcy in adolescents and emerging adults with HIV may help them cope with an HIV diagnosis and promote better overall health outcomes. Stressing the impact of claiming normalcy, as it allows HIV-infected adolescents and emerging adults to function at levels equal to their uninfected peers, may increase adherence to care and medication regimens and decrease depressive symptomatology associated with HIV. Claiming normalcy instilled a sense of being able to live with HIV for our participants.

Acceptance and relationships are priorities for adolescents and emerging adults. Having a safe place where adolescents and emerging adults can express concerns about acceptance, peer pressure, and living with HIV is also important. Clinicians should take opportunities on every visit to address these issues and make referrals to ensure that the potentially unaddressed social needs of their patients are being met. Our participants were able to live with HIV in the presence of feeling normal and claiming normalcy. Future research should investigate the psychological impact of HIV on adolescents and emerging adults during this heightened time of physical and psychosocial development. More specifically, research on the impact that feeling normal, despite HIV infection, has on health outcomes is needed with the findings translated into clinical practice in a way that is age appropriate and relevant to optimize social development during adolescence and emerging adulthood.

### Limitations

Our study had several limitations. Despite concerted efforts to recruit females and younger adolescents, none agreed to participate. In total, 11 young people (younger adolescents and females) declined to participate. With only male participants in the age range of 17 to 25 years, theorizing was limited to young men. The findings from our study do not represent the perspectives of living a normal life with HIV from younger adolescents or females as a result of our inability to recruit from these two

groups. Additionally, we were able to recruit only one heterosexual participant and, therefore, the findings were not representative of heterosexual male experiences. Creative recruitment strategies to capture the perspectives of younger and female patients are needed in future studies to better understand our findings.

## Conclusions

Although the study had limitations, the research design was implemented with systematic procedures to maximize rigor. We highlighted the impact of our participants' perceptions that their disease state had had on the ability to cope with HIV. We found evidence that claiming normalcy impacted HIV-infected adolescent and emerging adult male abilities to remain socially connected in their communities. And, to our knowledge, ours was the first study to describe the impact of the concept "I am Normal" and the process of claiming normalcy from the perspectives of HIV-infected adolescents and emerging adults in the western region of the United States.

## Key Considerations

- HIV-infected adolescents and emerging adults may have better health outcomes when encouraged to live a normal life.
- Acknowledging and reinforcing normalcy may assist HIV-infected adolescents and emerging adults to cope with the diagnosis.
- Encouraging adolescents and emerging adults to claim normalcy may increase medication adherence.

## Disclosures

The authors report no real or perceived vested interests that relate to this article that could be constructed as a conflict of interest.

## Acknowledgments

The first author would like to thank the participants and the staff at both clinics who participated in this research. She would also like to thank Bruce Smith for editing the manuscript and JoAnn Walls for professional transcriptionist services. This research was supported by the Sigma Theta Tau International Dr. Sandra Wise Founder's Scholarship, the University of California San Francisco Alumni Century Club Fund, and the University of California San Francisco Graduate Research Award.

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**Table 1.** Sample (N=21)

Age Range	Mean	SD	Median	
			23	
17-25 Years	22.19	2.32	N	%
Race/ethnicity				
Hispanic			7	33
African American			6	28.5
Caucasian			5	23.8
Biracial			3	14.3
Sexual orientation:				
Homosexual			20	95
Heterosexual			1	5
History of abuse: sexual, physical, substance				
Sexual			6	28.6
Physical			2	9.5
Substance			11	52.4
Religious affiliation				
			Youth (%)	Current (%)
Catholic			43	29
Baptist			29	14
Lutheran			4.7	0
Nondenominational			14	14
Religious/spiritual experience				
Church experience			100	57
Spiritual			0	43

Note. Church experience means having attended church at some time or point in life.

**Figure 1.** “I Am Normal” matrix.

