Live with the Disease Like You Used to Before You Knew You Were Infected: A Qualitative Study Among 10-Year Survivors Living with HIV in Haiti

Samuel Pierre, MD,¹ Vanessa Riviera, BS,² Circee Phara Jean,¹ Marie Jude Jean Louis,¹
Lindsey K. Reif, MPH, MS,² Patrice Severe, MD, MSc,¹ Vanessa Rouzier, MD,¹
Warren D. Johnson, MD,² Jean W. Pape, MD,^{1,2} Daniel W. Fitzgerald, MD,²
Margaret L. McNairy, MD, MSc,^{2,3} and Carla Boutin-Foster, MD⁴

Abstract

In 2003, the Haitian Study Group on Kaposi's Sarcoma and Opportunistic Infections (GHESKIO), a nonprofit organization, began administering antiretroviral therapy (ART) to its patients. This practice transformed HIV from a fatal disease to a more manageable chronic condition. However, relatively few studies focus on the experiences of survivors. This study provided a unique opportunity to interview patients who survived at least 10 years after being treated with ART at GHESKIO. The goal of the study was to elicit from patients their perspectives on what enabled them to survive with AIDS. Grounded Theory, a qualitative research method was used to guide data collection, coding, and analysis. Individual interviews were conducted, audio-taped, transcribed and analyzed in Creole, and translated into English. Data saturation was reached at 25 participants. Of which, 64% were women, the mean age was 49, range of 43–55 years, 24% were married, 44% had not completed elementary school, and 72% had no income, the remaining participants had incomes ranging from \$1000 to \$5000 annually. Qualitative analysis resulted in 681 codes, which were grouped into six categories: being spiritually grounded, having supportive interactions with providers, caring for children, setting personal goals, persevering and living life as usual, and maintaining strict medication adherence practices. The overarching theory was that having a reason to live despite one's circumstances and living life as usual enabled one to survive. Having a strong spiritual foundation coupled with supportive family and providers motivated participants to live and adhere to their ART. As the number of patients who are living longer with HIV in Haiti increases, results from this study will be important in helping tailor interventions that enhance their overall quality of life.

Keywords: HIV, antiretroviral therapy (ART), survivors, grounded theory, qualitative

Introduction

AMONG CARIBBEAN COUNTRIES, Haiti has the highest prevalence rate of HIV. Approximately 2.2% of adults are diagnosed with HIV.^{1,2} The HIV epidemic in Haiti is further complicated by abject poverty, limited educational opportunities, high unemployment rates, devastating natural disasters, and a fragile political infrastructure. However, despite these circumstances, over the past decade, the rate of new

HIV infections in Haiti fell by ~54%.³ This downward trend has been attributed to strategic efforts of the local health ministry, community-based organizations, faith-based organizations, and nongovernmental organizations. These efforts included engaging community-based organizations, training community health workers, instituting guidelines to reduce mother-to-child vertical transmission, and initiating directly observed therapy.⁴ The Haitian Study Group on Kaposi's Sarcoma and Opportunistic Infections (GHESKIO) has played

¹Haitian Study Group on Kaposi's Sarcoma and Opportunistic Infections, GHESKIO, Port-au-Prince, Haiti.

²Center for Global Health, Weill Cornell Medical College, New York, New York.

³Division of General Medicine, Department of Medicine, Weill Cornell Medical College, New York, New York.

⁴Brooklyn Health Disparities Center, SUNY Downstate Medical Center, New York, New York.

a pivotal role in decreasing the prevalence of HIV in Haiti. GHESKIO is a nonprofit organization formed in 1982 by a group of Haitian health professionals that provides HIV care with education on sexually transmitted infections, nutritional support, and economic development.⁴ A unique aspect of GHESKIO is its strong research mission supported through collaborations between Haitian physician-scientists and community partners.⁵

In 2003, GHESKIO initiated antiretroviral therapy (ART) treatment and distributed it free of charge to all patients with AIDS. The advent of ART therapy in Haiti ushered in a new era of treatment and led to an unprecedented rate of survival. The 1-year survival of 30% improved almost threefold after the initiation of ART. Ten-year survival was ~70%.⁶ These survival rates must be viewed in the context of the social and economic conditions that exist in Haiti.

Survival in the middle of political unrest, economic turmoil, and one of the most devastating earthquakes in the western hemisphere underscores the resilience of the people of Haiti.⁷⁻⁹ In many countries, including Haiti, HIV, once an inevitably fatal disease, has now become a chronic and more manageable condition.^{10,11} The conceptual basis for this study was the observation that despite these dramatic social and political events in Haiti, people have lived with AIDS for over a decade in the middle of dire circumstances.

This study uses qualitative methods to elicit patients' perspectives on what enabled them to survive. In this study, survival was viewed as a process and not just an outcome. The experience of living with AIDS is complex and cannot be easily captured or enumerated with quantitative methods alone. A qualitative research approach is best suited for this study because it allows patients to describe their experiences in their own words. Qualitative methods have been used extensively in AIDS research to provide insight into patients' experiences.¹²

Phenomenology and Grounded Theory are two approaches that are often used in qualitative research. Both Grounded Theory and phenomenology have in common the goal of understanding lived experiences. Phenomenology tends to be descriptive and answers the question: "What was the experience of living with AIDS like?" The Ground Theory technique takes this a step further and asks "How did they survive?" Phenomenology provides a composite description and Grounded Theory provides an explanatory theory.^{13,14} Therefore, Grounded Theory methodology was used as the qualitative approach in this study.

Grounded Theory methodology is an iterative process in which data analysis is done concurrently with data collection. When applying a Grounded Theory methodology, there is no a priori hypothesis, rather a theory is developed from participants' responses.^{14,15}

Methods

Sample and recruitment

This qualitative study is nested within a larger study looking at cumulative survival at 10 years after the initiation of ART at GHESKIO. The methods to ascertain survival have been described elsewhere.⁶ Of the 910 patients at GHESKIO who initiated ART from March 1, 2003, through April 30, 2004, at 10 years, 53% were alive and retained in care at GHESKIO clinic, 27% were deceased, 12% were lost to follow-up, and 8% had transferred to another clinic.⁶ This

qualitative study was conducted among patients who were recruited from this cohort and are alive and still receiving care at GHESKIO. Interviews began in December 2014, 10 years after the first initiation of treatment.

Participants were recruited from the GHESKIO clinics; they were approached by the clinic's nurses and told about the study. Given the stigma that is associated with HIV in Haiti, careful steps were taken to ensure that all participants understood the rationale for the study and understood the reason for their participation. Participants were asked to complete a questionnaire detailing information about the study as a means of assuring that they understood the objectives of the study and their role in the study. There was a detailed discussion on the goals and outcomes of the study and on how this information would be used.

Participants were recruited from GHESKIO by a nurse who scheduled routine follow-ups. During their routine visits, patients who had been receiving ART at GHESKIO for at least 10 years were told about the qualitative study. Thirty patients were approached, 27 expressed an interest in hearing about the study and were referred to the study's principal investigator. Among patients who were referred, 26 signed informed consent, one declined because she wanted to consult her husband before consenting, and another signed the consent, but did not return for the interview. Participants received 100 Haitian gourdes (1.5 US \$) for cab fare.

Data collection

The interviews were conducted in Haiti at GHESKIO during an 8-month period from December 2014 to August 2014. Interviews were conducted individually using a semi-structured format. Each interview was audio-taped, then transcribed verbatim. Questions focused on understanding how participants survived in the middle of challenges over the 10 years since starting ART. There were four questions: (1) In general, how are things going for you? (2) Tell me what life has been like for you during the past 10 years; (3) What has it been like for you living with AIDS and what has been your experience on ART, what has made it harder or easier to take your ART? (4) What is your greatest hope (aspiration) for the next 10 years? The first question was to set the stage for the discussion and used as an introductory question. Subsequent questions focused specifically on life with HIV and experiences on ART. The interviews were all conducted in Creole by a Haitian investigator who received formal training in qualitative research.

After the first five interviews were conducted, analysis was done and new questions were added. For example, several participants in the study described the importance of religion and having children. Therefore, as subsequent participants were interviewed, additional probing questions were asked to gain further insight into specific dimensions of religion and having children. Participants were asked about coping strategies that they used to overcome challenges and accomplishments that they made during the 10 years. No new questions were added after the 20th interview. However, interviews continued in an effort to recruit more men.^{16,17} No questions were eliminated. The study was approved by both the GHESKIO and the Weill Cornell Medical College Institutional Review Boards. All study participants provided written informed consent.

Data analysis

The steps used in data analysis included developing codes, categories, and overarching themes.¹⁵ Codes are descriptive labels or tags that represent key ideas that are being conveyed in individual responses. Codes can be actual responses or select words from the transcripts. Each code was reviewed for similarities and frequency of occurrence. Similar and reoccurring codes were then grouped into larger categories. Categories were then analyzed to identify recurring and dominant themes, similarities, and patterns. This analytic process continued until no new findings emerged. In qualitative research, this is called the point of theoretical saturation.^{15,18} Detailed notes were taken, categories were compared and contrasted, a method known as constant comparative analysis. The review of these notes or memos led to the construction of an overarching theory that explained from the participants' perspectives how they were able to survive after 10 years of starting ART treatment.

This study was a cross-language study done in Creole and translated to English. An important consideration for this study was ensuring that interpretation of the qualitative data did not differ from its true connotation in the original language. In an effort to maintain the true essence of survival as was being described in Creole, additional steps were taken to ensure that participants' responses retained their authenticity and true meaning.^{19,20}

Codes and categories were developed in Creole and were then translated to English. A bilingual team of investigators reviewed the final codes and categories in both Creole and English and jointly developed common themes in English. The analysis used a collaborative approach to translation during which two Bilingual investigators sat side by side and discussed the themes. Rather than a word-for-word back translation of themes, the investigators discussed their underlying meaning.²¹ The techniques used represent more of a collaborative iterative approach to translation.²² Alternative meanings of each theme were discussed until a consensus was derived. The final results were reviewed by a panel of volunteers, investigators, and clinicians at GHESKIO. The final codes and categories are presented in English for the purpose of this article. There were 12 people on the research team, which comprised both Americans and Haitians, of which 8 were physicians, the rest were graduate students and staff at GHESKIO. All Haitian investigators were bilingual. Four of the investigators (two Americans and two Haitian investigators) read all of the transcripts and coded responses. The final set of codes and categories were given to the remaining members of the team for their review. If they disagreed with the way a response was coded or on a particular category, alternative codes or categories were discussed until a consensus was reached.

Results

Data saturation was reached at 25 participants. As shown in Table 1, 64% were women, 24% were married, and 44% had not completed elementary school. The majority of participants (72%) did not have a source of income for the past year; the remaining participants reported incomes ranging from \$1000 to \$5000 annual income. The mean age was 49 (43–55 years). These demographics closely approximate statistics reported in other studies on the HIV population in

TABLE 1. CHARACTERISTICS OF PARTICIPANTS (N=25)

Characteristic	n	%
Gender		
Female	16	64
Marital status		
Single	6	24
Married	6	24
Domestic partners	7	28
Separated	3	12
Widowed	3	12
Age group at art initiation		
13–24	4	16
25–50	11	44
>50	10	40
Education level		
None	11	44
Primary/secondary	12	48
College	2	8
Income		
None	18	72
\$1001–5000 US	7	28

Haiti.²³ Interviews lasted about 45–60 min. At the time of the interview, the duration of antiretroviral treatment ranged from 10 to 12 years; 16% of participants started ART between the ages of 13 and 24. Interviews resulted in 681 different responses that were coded; similar codes were grouped into the following six categories: being spiritually grounded, having supportive interactions with providers, caring for children, setting personal goals, persevering and living life as usual, and maintaining strict medication adherence practices.

Being spiritually grounded

The following quotes illustrate the strong religious culture of Haiti. Responses depict the role of God and faith in their lives. Many participants alluded to God several times in their responses. God was described as a major reason for their survival. Many participants stated that their interactions with their church gave them a sense of purpose. Despite being ill, remaining active in church events was an important aspect of survival. The following statements are examples of the importance of being spiritually grounded.

“As of today the most important thing in my life is first of all God. I am living for God’s sake.”

“I am an active church member. I am a missionary lady. I am a member of my church singing group. I take part in all church activities.”

Despite living with HIV for 10 years, some participants had not disclosed their status to family members. Having God to confide in was essential for some participants who felt that they were unable to disclose their status to anyone else. Participants felt that God was the only one in whom they could confide. They described stress from not being able to share their status with others. The following are examples:

“My problem is that I was stressed because I could not find a person who could understand me to share this with. And I realized that if I tell someone about my status that person will share it with others.”

“My only support comes from God because I did not want to tell anyone about that (about my disease).”

An important aspect of their relationship with God was an expectation of a cure. Participants described praying to God for a cure or even a miracle. The following are three illustrative quotes:

“I hope that God will make the cure available, as the treatment is now available to improve our health.”

“The same way he let the disease enter my body; if he wants he can make it disappear.”

“I always pray to God. I never stop doing that. I tell God that I’m waiting for a miracle from him.”

Having supportive interaction with providers

These responses highlighted the strong bond between patients and their providers. The role of providers may be particularly important if the patient has no one else to confide in about their status. Providers were an important source of emotional and tangible support for patients who are often bereft of the most basic necessities. Providers enabled survival by giving moral support or providing access to food and shelter. This support was demonstrated by all members of the healthcare team, doctors, as well as nurses and staff. Providers were highly revered and appreciated. It is important to note that these relationships come from many years of the GHESKIO staff working and partnering with the community at large. The following three responses depict the importance of the provider–patient interactions:

“Since I started to come here, everybody here has become my friend. I come here because everyone in the staff is my friend, because of my familiarity with my doctors, my familiarity with my nurses.”

“My friend, I can tell you if doctors did not exist, the country itself would disappear. I can say that the doctors come right after God.” “Well, thanks to my doctor. My doctor gives me moral support.”

“The hospital provides me with food when they can, sometimes they spend 6 months feeding me; after 6 months, they take (help) someone else; after a year they take (help) me again.

Caring for children

Approximately 60% of the participants were women of child-bearing age at the time of diagnosis. Therefore, the role of children was a dominant category. Having children and supporting their children were perceived by some participants as factors that enabled them to survive. Children gave participants a sense of purpose. Participants wanted to rear their children and viewed the well-being and education of their children as a source of motivation. Participants had a desire to see their children grow up. Participants described hopes and aspirations of success for their children. There was an emphasis on staying alive to ensure that their children received proper education. The following are examples:

“In order to grow (raise) my 2 kids, I am obliged to do something for my living.”

“Well (my kids), that’s a great accomplishment for me, because I didn’t expect that. Because when you are working to

pay school tuition for your child and the child really understands what you’re doing for him, he understands the importance of education and completed high school, that is a great accomplishment for his parents (us)”

“A dream that I want to become a reality is to see my kids’ future play in front of me just as I have programmed (just as I planned) it in my mind.”

“The thing that I’m proud of is the fact of my daughter goes to university now. I prayed to God for that. I want her to be married before my death. I want God to keep me alive for that.”

“I just wanted to live, because I didn’t want to die letting go of my children. Who would take care of them? I don’t know. They wouldn’t be educated.”

Setting personal goals

Setting personal goals and persevering were strong attributes that characterized the respondents in this study. The participants did not allow their circumstances to define them or to limit them. Despite being diagnosed with HIV, many participants set long-term goals for themselves. Participants described a desire to stay healthy and have the ability to support themselves and their family. The following quotes are examples of the goals and aspirations that were voiced by participants:

“If for some reason I cannot do the laundry then I try to sell a few things out of my store. I respect my dignity as long as I find something to do I will always try my hardest.”

“For me, I want to complete my secondary studies, find a scholarship and to go study medicine, and become a pediatrician.”

“In my case, I will keep on taking the medicine, I do not want to fail in my studies, and I have to focus on them so that I can reach my goals.”

“I had the plan to have a drugstore so I want to go and attend a Pharmacology class and then do all the other stuff I have to do.”

Persevering and living life as usual

Participants’ responses provided insight into coping strategies that may have been adopted as a means of survival. Despite challenges that many faced, there was also a positive outlook and appraisal of their circumstances. Participants described ways in which they managed stress by joking or considering the burdens of others. Illustrative responses include the following:

“The most important thing is living with the disease like you used to live before you knew you were infected. Even if people are criticizing you, act as if nothing happened.”

“Sometimes I give them jokes. I resigned on myself by giving jokes. That is how I confront life, in order to prevent stress from getting me down.”

“I was born with the disease and I know that everybody has their cross to (bare) lift in life. And I sometimes say if I was not infected and I could be handicapped or blind or have cancer. If I had to choose (between these conditions) I would prefer being infected by the virus, because I can lift this cross but the other ones would be too heavy for me.”

Maintaining strict medication adherence practices

Having a positive attitude toward medication adherence was described as an essential aspect of living with HIV. Participants described strategies that they used to take their

medications under less than optimal circumstances. For some participants, it meant having to take their medications clandestinely because they had not disclosed their status to close relatives. Participants devised strategies that facilitated adherence such as developing a routine or viewing medication taking as a daily act such as brushing one's teeth. These following responses reinforced the importance of medication adherence in their survival.

"I take my medicine as if I was taking vitamins. I may hide the bottle to avoid people from reading what is written on the bottle. But I don't mind, I just buy water and take my pills, I don't care."

"Even when my relatives do not know about my status, they know that I always attend to my appointments. I always take my medication. I told them that it is gastric ulcer medication."

"I know I cannot spend one day without brushing my teeth so I have to do the same when it comes to taking the medicine, it is a must for me like brushing my teeth." Another response was: "So for me, it is like every day I wake up I have to eat, it is the same for the medication."

"When I do not take the medicine, I feel upset, nervous, stressed, I feel I have one day missing in my life."

Discussion

The devastating impact that HIV and AIDS have had on life expectancy and mortality in Haiti is well known. However, less is known about the factors that are associated with long-term survival. Six categories that described participants' perception of factors that they think enabled them to survive and their account of their experiences of survival in this study were identified: being spiritually grounded, having supportive interactions with providers, caring for children, setting personal goals, persevering and living life as usual, and maintaining strict medication adherence practices. Based on the responses in this study, one way of explaining these findings is that having a reason to live despite one's circumstance and living life as usual enabled survival. Having a strong spiritual foundation coupled with supportive family and providers motivated participants to live and adhere to their ART.

The reliance on social support, having a positive outlook, caring for family, and setting goals are coping strategies that have been described in other studies. In a study comparing the coping strategies of women with HIV that was well managed and HIV that was not well managed, Brody and colleagues found that those with well-managed HIV were more likely to describe active coping styles such as engaging social supports, setting realistic goals, and engaging in self-care.²⁴ Positive appraisal of the illness was also described as a coping mechanism that was associated with physical and psychological well-being.²⁵ Similarly, self-care and moving toward a healthier state were common mechanisms described by Mosack et al.²⁵ Religion and spirituality are important aspects of culture in Haiti.^{26,27} The role of having a supportive provider and healthcare team and the importance of religious support, as well as medication adherence, have all been previously cited.²⁸

Barroso described five dimensions of surviving AIDS that included normalizing, focusing on living, taking care of oneself, being in relationships with others, and triumphing.²⁹ Participants in our study also reported similar activities such

as making self-care a routine, focusing on their goals, and triumphing or coping through faith. Being in close and trusting relationship with supportive family members was also cited.

A unique aspect of this study was that it was a cross-language qualitative study. Creole, one of the most common languages spoken in Haiti, has many dialects and syntaxes that may confer different meanings when translated. One concern raised by the GHESKIO staff and researchers was that during the process of translation, the underlying meaning may get lost with subsequent translations. A series of steps were taken to address this concern. Therefore, this study provides a framework for qualitative studies that are conducted in different languages.

There are some limitations in this study. It was done at one site. However, it is important to note that GHESKIO was one of the first sites to provide free ART, and thus long-term survivors are not currently identified at other sites at the present time. This was a self-selected population; however, the demographic approximates that of the population of people with HIV in Haiti.²³ Another limitation is the preponderance of women in this study, which may reflect the feminization of HIV in Haiti.^{30,31} While the sample size was 25, this is a pattern that is consistent with prior qualitative studies.³² There was also a lack of a control group, which limits the ability to determine whether similar themes would emerge in a non-HIV population. The themes that emerged were based on patients' perceptions of factors that enabled their survival. Whether or not these actually enabled survival cannot be determined in this study. Given the sensitive nature of the questions that were being asked, participant identifiers were removed. Therefore, participant responses could not be linked to their clinical data.

Despite these limitations, our findings also have implications for clinical care and HIV program development. In this study, there was a heavy reliance on God and the role of God in their lives. Therefore, clinical practices that integrate access to spiritual resources may enhance coping for some patients. Religious perspectives also inform health beliefs and attitudes and should be considered in health promotion programs.³³

An important area for future work is to use these findings to inform interventions that will increase the likelihood of survival and enhance the quality of life of people living with HIV and AIDS in resource-poor countries such as Haiti. The study points to many resources that can be leveraged such as relationships with family and building strong ties to faith-based organizations. Educating healthcare staff on their role in promoting trust is also important.

Another important avenue for future work is to use these findings to develop programs that mitigate HIV-related stigma. In this study, some participants felt that they could not disclose their status to friends and family. Some described secretly seeking help or taking their medications in hiding. Reducing stigma has important implications for stemming the spread of HIV and for promoting treatment-seeking behavior. Studies among people living with HIV have found that more than half of the participants experienced stigma and discrimination following disclosure of their HIV status. Greater efforts toward reducing stigma are needed.³⁴

This study provided participants with an opportunity to share their survival stories or experiences and perceptions on living with AIDS for at least 10 years. The sharing of stories

can provide patients who are often stigmatized or marginalized with a sense of power.³⁵ One participant said that he has never been asked about how he survives and welcomed this opportunity to talk about the past 10 years. He said, “During those ten years that I am taking medication here, I have never found someone calling and asking me: how do you deal with the medication? But today it is privilege for me to do so.” Another unique aspect of this study, is that it paints a portrait of Haiti that is not defined by death or hopelessness, but one marked by survival. Until there is a cure, programs that enable people to live full lives in the middle of their circumstances are needed. As the number of patients who are living longer with HIV in Haiti increases, results from this study will be important in helping to tailor interventions that enhance their overall quality of life.

Acknowledgments

The authors are indebted to all of the participants at GHESKIO who made this study possible by sharing their personal survival stories. They would also like to thank the staff at GHESKIO for their support.

Author Disclosure Statement

No competing financial interests exist.

Funding Support

Funding for this study was provided by the Center for Global Health, Weill Cornell Medicine: R25 TW009337; Brooklyn Health Disparities Center: P20 MD006748; and Center for Excellence in Health Disparities Research and Community Engagement: P60 MD003421-02.

References

1. Malow R, Rosenberg R, Lichtenstein B, Dévieux JG. The impact of disaster on HIV in Haiti and priority areas related to the Haitian crisis. *J Assoc Nurses AIDS Care* 2010;21:283.
2. Gilbert MTP, Rambaut A, Wlasiuk G, Spira TJ, Pitchenik AE, Worobey M. The emergence of HIV/AIDS in the Americas and beyond. *Proc Natl Acad Sci U S A* 2007;104:18566–18570.
3. UNAIDS. Global Report 2012. Geneva: UNAIDS, 2012.
4. Koenig S, Ivers L, Pace S, et al. Successes and challenges of HIV treatment programs in Haiti: Aftermath of the earthquake. *HIV Ther* 2010;4:145–160.
5. Koenig S, Leandre F, Fitzgerald D, et al. Public health aspects of HIV/AIDS in Haiti: epidemiology, prevention and care. In: *Public Health Aspects of HIV/AIDS in Low and Middle Income Countries*. B Celentano, ed. New York: Springer-Verlag, 2008:671–695.
6. Pierre S, Jannat-Khah D, Fitzgerald DW, Pape J, McNairy ML. 10-year survival of patients with aids receiving antiretroviral therapy in Haiti. *N Engl J Med* 2016;374:397–398.
7. Verner D. Social Resilience and State Fragility in Haiti: Breaking the Conflict-Poverty Trap. Geneva: World Bank, 2006.
8. Severe L, Fitzgerald DW, Deschamps MM, et al. “I am proud of myself, just the way I am” (Mwen fye de tet mwen, jan mwen ye ya): A qualitative study among young Haitian women seeking care for sexually transmitted infections (STIs) in Haiti. *AIDS Educ Prev* 2014;26:158–169.
9. Fawcett J. Organisational and cultural factors that promote coping: With reference to Haiti and Christchurch. *NZ J Psychol* 2011;40:64.
10. Russell S, Seeley J, Ezati E, Wamai N, Were W, Bunnell R. Coming back from the dead: Living with HIV as a chronic condition in rural Africa. *Health Policy Plan* 2007;22:344–347.
11. Russell S, Seeley J. The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy. *Soc Sci Med* 2010;70:375–382.
12. Power R. The application of qualitative research methods to the study of sexually transmitted infections. *Sex Transm Infect* 2002;78:87–89.
13. Thorne S. Data analysis in qualitative research. *Evid Based Nurs* 2000;3:68–70.
14. Merriam SB. *Qualitative Research: A Guide to Design and Implementation*. San Francisco, CA: John Wiley & Sons, 2009.
15. Eaves YD. A synthesis technique for grounded theory data analysis. *J Adv Nurs* 2001;35:654–663.
16. Charmaz K, Smith J. Grounded theory. In: *Qualitative Psychology: A Practical Guide to Research Methods*. J Smith, ed. London: Sage Publications, 2003:81–110.
17. Charmaz K. Premises, principles, and practices in qualitative research: Revisiting the foundations. *Qual Health Res* 2004;14:976–993.
18. Charmaz K, Belgrave L. Qualitative interviewing and grounded theory analysis. In: *The SAGE Handbook of Interview Research: The Complexity of the Craft*, 2nd edition. J Gubrium, J Holstein, A Marrasti, K McKinney, eds. New York: Sage. 2002, pp. 347–366.
19. Squires A. Methodological challenges in cross-language qualitative research: A research review. *Int J Nurs Stud* 2009;46:277–287.
20. Chen HY, Boore JR. Translation and back-translation in qualitative nursing research: Methodological review. *J Clin Nurs* 2010;19:234–239.
21. Van Nes F, Abma T, Jonsson H, Deeg D. Language differences in qualitative research: Is meaning lost in translation? *Eur J Ageing* 2010;7:313–316.
22. Douglas SP, Craig CS. Collaborative and iterative translation: An alternative approach to back translation. *J Int Mark* 2007;15:30–43.
23. Ivers LC, Chang Y, Jerome JG, Freedberg KA. Food assistance is associated with improved body mass index, food security and attendance at clinic in an HIV program in central Haiti: A prospective observational cohort study. *AIDS Res Ther* 2010;7:1.
24. Brody LR, Jack DC, Bruck-Segal DL, et al. Life lessons from women with HIV: Mutuality, self-awareness, and self-efficacy. *AIDS Patient Care STDS* 2016;30:261–273.
25. Mosack KE, Abbott M, Singer M, Weeks MR, Rohena L. If I didn’t have HIV, I’d be dead now: Illness narratives of drug users living with HIV/AIDS. *Qual Health Res* 2005;15:586–605.
26. Brown KM. Afro-Caribbean spirituality: A Haitian case study. In: *Vodou in Haitian Life and Culture*. MC Bellgarde-Smith. New York: Pallgrave MacMillan, 2006: 1–26.
27. Murray GF. Bon—Dieu and the Rites of Passage in Rural Haiti: Structural Determinants of Postcolonial Theology and Ritual. In: *The Catholic Church and Religions in Latin*

- America. TC Bruneau, CE Gabriel, M Mooney, eds. Montreal, 1984.
28. Slomka J, Lim JW, Gripshover B, Daly B. How have long-term survivors coped with living with HIV? *J Assoc Nurses AIDS Care* 2013;24:449–459.
 29. Barroso J. Reconstructing my life: Becoming a long-term survivor of AIDS. *Qual Health Res* 1997;7:57–74.
 30. Hunter LM, Reid-Hresko J, Dickinson TW. Environmental change, risky sexual behavior, and the HIV/AIDS pandemic: Linkages through livelihoods in rural Haiti. *Popul Res Policy Rev* 2011;30:729–750.
 31. Ezeonu I, Koku E. Crimes of globalization: The feminization of HIV pandemic in Sub-Saharan Africa. *Global South* 2008;2:112–129.
 32. Mason M. Sample size and saturation in PhD studies using qualitative interviews. Paper presented at: Forum qualitative Sozialforschung/Forum: qualitative social research. Oxford: Oxford Books, 2010.
 33. Allen JD, Mars DR, Tom L, et al. Health beliefs, attitudes and service utilization among Haitians. *J Health Care Poor Underserved* 2013;24:106–119.
 34. Stangl AL, Grossman CI. Global action to reduce HIV stigma and discrimination. *J Int AIDS Soc* 2013;16(3Suppl 2):18934.
 35. Oliphant E, Amodei N, Villela-Perez VA, Mammah R, German VF, Meissner P. The use of survival stories to empower HIV+ women of color. *Int J Bus Hum Technol* 2015;5:13–19.

Address correspondence to:
Lindsey K. Reif, MPH, MS
Center for Global Health
Weill Cornell Medical College
402 East 67th Street
New York, NY 10065

E-mail: lir2020@med.cornell.edu