Religious Practices of People with HIV/AIDS
Why Health Professionals Should Care

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There is a Chinese fortune circulating among cookies that says, "You never hesitate to tackle the most difficult problems." Being driven to conduct interviews with HIV-positive Haitians in Boston makes me a most rightful owner of this restaurant wisdom. HIV/AIDS is one of the most stigmatized illnesses affecting current public health, and its stigmas can have compromising, if not devastating, consequences for HIV-positive individuals and associated communities. Because its modes of risk are related to the exchange of bodily fluids, as during sexual intercourse or with the sharing of drug needles, there is a blame attached to HIV. This blame is transmitted in tandem with the human immunodeficiency virus known to cause AIDS, a syndrome that, remember, has to be *acquired*.

Early epidemiologic reports of this emerging infectious disease coined the "Four H's" as a convenient way for the public to remember which groups were most at risk for HIV and AIDS. This simple mnemonic device has had devastating stigmatic consequences for those it singled out: Homosexuals, Heroin-users, Hemophiliacs,[1] and *Haitians*. The stigma of HIV/AIDS tops an entire list of prejudices that Haitian Americans and recent immigrants encounter in this country. As Joel Piton, a Haitian M.D. and health educator at the Center for Community Health, Education and Research (CCHER) in Dorchester, explained to me: "We [Haitians] already have the stigma of being illiterate, poor, immigrant blacks, and now HIV on top of that? It's just too much."

Stigma and the Practice of Anthropology: Ethics and Methods

Stigma – this is how many Haitian AIDS advocates like Dr. Piton, principal collaborator on this project, account for the long silence in the Haitian community on HIV/AIDS. This is also why my proposal to interview HIV-positive Haitians about their religious practices pre- and post-diagnosis initially met some academic opposition. Concerns were raised. Is it exploitative to do fieldwork on stigmatized people? How could I ensure that the HIV-positive status of those interviewed would be protected? And, logistically, why would anyone *want* to talk to a stranger from Harvard about sensitive and painful, stigmatized subjects? Remember my tendency to tackle the difficult problems: I was exploring the role religion plays in HIV illness, which includes the positive and the negative – the coping and healing that religious practice like prayer can lend to HIV-positive people, as well as the contributions of religion to AIDS stigmas and the acronym's aura of blame. The ultimate question in fieldwork, the one with veto power, was raised: do interviews that probe into religion in the context of HIV probe too far to be ethical? When my proposal went before the Harvard Committee on the Use of Human Subjects (HCUHS), red flags went up on a question that I intended to ask of each participant: *What does God have to do with your HIV?*

There was, however, a simple, logistical concern: how would I ever generate a pool of HIV-positive, Haitian individuals to interview in a way that protected their sensitive status? Enter CCHER – formerly the Haitian AIDS Project (HAP). This Haitian health organization adopted an AIDS-free name because of stigmas and makes its home in an unmarked, three-story house on Washington Avenue outside of Codman Square in Dorchester, where it provides a host of services to Haitians with HIV and AIDS – support groups, case management, programs for substance abuse, counseling and family services, peer education and training, housing advocacy, and meal delivery – as well as a host of events, including a monthly clinical forum on HIV/AIDS prevention and education.[2] When I took my curiosity about religious practices of Haitians with HIV directly to Dr. Piton at CCHER, I was relieved to find not only acceptance of, but *encouragement for* such an inquiry among this segment of the Haitian community. The realm of spirituality and religion in the context of HIV was one area that

CCHER still needed to explore, as part of ongoing community needs assessments that the agency conducts through its research arm, headed by Dr. Piton. After clearing it with the center's director, Dr. Eustache Jean-Louis, M.P.H., and bringing my proposal to a meeting of mental health staff led by Gemima St. Louis, Ph.D., I gained access to a CCHER support group to do a round of preliminary interviews on religious practice with CCHER clients. CCHER arranged ten interviews for me, the results of which they intend to use as a springboard for future research on religious practices in their community. Having disproved certain assumptions – that HIV-positive Haitians would not want to discuss their illness with a researcher, and that conducting interviews with stigmatized peoples is an exploitative enterprise – I set out, with CCHER, to nurture a curiosity about the religious lives of HIV-positive people: a curiosity that seemed welcomed by the project's participants as they spoke freely and quite confidently about their religiosity and the virus.

I resolved the controversy surrounding the project by formalizing my research methodologies to satisfy the Harvard CUHS, which was concerned about confidentiality of informants and the distress or discomfort that certain questions – the "God" ones – were anticipated to pose. I was required to read a prepared disclaimer statement and to gain the verbal consent of each individual before proceeding with the interviews. According to the HCUHS agreement, I was also required to remind participants that a CCHER counselor would be available if the interview provoked difficult emotions, that they could choose not to answer any question that made them feel uncomfortable, and that they could end the interview at any time. To protect the HIV status of each client – to ensure that respondents' names would not be inadvertently released at Harvard or elsewhere in a group identified as HIV-positive – CCHER staff recruited and scheduled interviews with their own clients, and I went in blind, not learning the first names of the men and women I was interviewing. I had not planned to record the interviews, because it makes interviewees self-conscious even when topics are less sensitive; but, regardless, this method of data collection would not have met the approval of the HCUHS, which ruled that voice recordings contain too many identifiers to reasonably preserve confidentiality. Therefore, as I had first intended, I took only notes on the interviews, three of which required Creole translation from Dr. Piton (one interview: male) and Rachelle, a young CCHER staff member (two interviews: female). The responses compiled on each questionnaire were paired with a demographic sheet that each informant filled out at the beginning of the interview.[3] These two documents – interview notes and the demographic survey – were used to create a transcript that was assigned a number, not a name.

Adhering to these strict HCUHS protocols certainly worked against the research in some ways, and the biggest barrier to better understanding the interviews was having no access to clients for any follow-up with them. Confidentiality is, however, always a concern for people with HIV/AIDS, and since data was being taken out of the CCHER community, to Harvard University, the steps we took to protect the individuals' identities were wholly necessary and reassuring to those who participated.

HIV and Religious Practice

The conversations are surprisingly rich for a small, one-time set of ten interviews, with six women and four men, half of whom were between the ages of forty and forty-five, and all of whom were over the age of thirty-five – the age demographic representing 83 percent of those with HIV/AIDS in the Commonwealth of Massachusetts.[4] All ten participants were born in Haiti. Four of those interviewed had lived in the United States five years or fewer, while the other six had lived here well over ten years each (residencies ranging from thirteen to twenty-one years). Eight of the ten CCHER clients had been living with HIV for more than five years, and half of these fell in the five-to ten-year range. Only two of the individuals had more recent diagnoses of HIV, within the last two years.

The CCHER interviews deal nearly exclusively with Christian religious practices, possibly because a project designed to penetrate the stigmas of HIV/AIDS in a religious context of blame do not also crack deeper stigmas associated with *Vodou*. Another factor contributing to the emphasis on Christian practice in these interviews is the nature of the support group from which CCHER drew at least some of the clients (other interviews were arranged personally by Dr. Piton). At least two of the ten interviewed (both women) participate weekly in a spirituality support group facilitated by Martha Florestal, a social worker preparing for ordination in the African Methodist Episcopal Church, who thus lends an obvious Christian lens to the group's functioning.[5] In two interviews, participants made specific remarks about the nature of the spirituality group, one woman saying that she knew Martha's spiritual group to be very helpful for clients and "very focused." Another woman had a great deal to say about the spiritual direction that Martha herself

has inspired in her own life. When this client's husband died from AIDS, she started to gamble and had struggled with depression for years afterwards. She described this period since her husband's death and her own diagnosis as a confusing time of living "upside-down," and explained, "I used to go to a different church every Sunday, but Martha showed me how to focus and how to really become a Christian." She now attends Pentecostal revival two or three nights a week and says that being a Christian has helped to reduce her reliance on antidepressants. Two others reported that they were involved in CCHER support groups, but it was not clear if they attended Martha's group focused specifically on Christian spirituality and religiosity. It should also be mentioned that Dr. Piton himself is a highly visible and active member of his own Christian congregation, the Church of the Nazarene (Codman Square). This is to say that there are Christian resources available at CCHER that perhaps heighten the emphasis of Christian religious practices in the context of HIV/AIDS for these CCHER informants.

Prayer Practice and HIV

Those who participated in the CCHER interviews spoke mostly of involvement in Protestant Christian, as opposed to Catholic, churches (eight of ten respondents). They described their major religious practice as *prayer* – either by themselves, with friends and congregants, or under the guidance of religious leaders who sometimes offered special prayers for their particular situation with HIV/AIDS. Prayer was most often said to give one the courage to live with HIV and to inspire confidence and hope for the future. It was also consistently said to increase faith in God.

One man – the youngest interviewed (36–39), and with the most recent diagnosis of just over a year – described his prayer practice as providing relief from the emotions that overcome him: "The difference in my religious life since the virus is that I'm praying more because I'm feeling down and sad. I'm praying more to overcome the sadness." This participant said that of all his religious practices – attending church on Sundays, going to additional prayer services during the week, and joining in other church activities – "Praying helps the most, praying more if I need to. Sometimes I feel sad, and I kneel down on my knees and feel better." A female participant discussed how her prayer practice has helped her to resolve her own most difficult emotion over the diagnosis: anger. "I am a changed woman," she said. "This anger I had is past. I am more patient now. I have more faith and more hope." She told me that she had prayed a lot before, and had ever since she was a thirteen-year-old girl, but that she has prayed even more since her diagnosis in 1992. "I pray in the morning, at noon, and at night. And sometimes I pray in my heart at night when I can't sleep and I'm thinking about my life when I was young and what has happened to me." In some of the interviews, prayer was described this way: as a relief and refuge from difficult emotions and, over time, as a resource for overcoming them.

Others of the CCHER clients described how they approach and articulate their prayers in ways very specific to their health and HIV. These prayers are about antiretroviral drugs, research, vaccines, viral loads, and cures. One, a man more than sixty years old, prays over his medicine each time he takes it: "I think when you pray, God can help you with the disease. When I take out the medicine, morning and evening, I pray. I ask God to help me with the disease, and to have a good result with the medicine." Of course, many also pray for and expect a cure, as one woman, told me: "Praying has helped," she said. "I think that someday I'll be cured. In my prayers, I ask God to take it away. God is answering my prayer – my viral load is now undetectable and my CD4 count is high. As long as I take my meds and see the doctor, I'm good!" This woman believes her prayers to have lifted the load of HIV in the physical sense (God providing the doctors and the medications that establish her health), but she describes how the weight of HIV has additionally been lifted from her mind, soul, or spirit. While maintaining a strict drug regimen, she has been able to detach herself from the idea of having a chronic, incurable illness. "God is taking it away," she repeats. "When I take the medicines, it's like I'm taking a Tylenol for a headache."

Several participants in these conversations demonstrated how prayer provides a link between individual and collective religiosity, particularly as pastors and other congregants offer special prayers for HIV-positive people. The client who has been so shaped by Martha Florestal in her spiritual search said: "I have such a supportive church family. They are with me all the time, supporting me and praying for me. They feed me – they baby me." In her comments we can identify three types of social support being offered: *material* support (meals); *emotional* support (what she describes as being "babied," or receiving comfort); and *spiritual* support (via the prayers and guidance that her church "family" offers). In this example, prayer is the fulcrum of a social support system that goes beyond the typical provisions of material and emotional support to contribute something spiritual or religious.

God and Meaning-Making

Out of these consistent prayer practices, highly evolved notions of God seem to develop, which the CCHER clients have used to make meaning of HIV illness, in the face of the currents of religious stigma in our culture and the lingering belief that AIDS is a punishment from God. It was encouraging to hear the range of positive and creative answers to my controversial question: *What does God have to do with your HIV?* Not a single informant said that HIV was God's punishment.

The first person interviewed said, point-blank, "God has nothing to do with my HIV," and then explained that "He let me have it, let it happen, to get me to know Him, and to turn me to Him, for a reason." This informant has long been a Seventh-Day Adventist, but despite strong religious practices that predate her diagnosis, she did not enjoy the same connection with God that she does now since living with the virus: "I know God more. Even though I went to church before, and I was always singing and praying, now I have a more intimate relationship with God." Knowing God deeply gives her a different perspective on the virus in her life, a perspective of God's grace: "I don't blame Him for my HIV. Sometimes God takes something bad and turns it to good." One client, who was more philosophically oriented than the others – and the only participant who identified as a Christian (Catholic) culturally, but had no religious practice – first put it this way: "I do not think God is responsible for people getting HIV. People are responsible." And then, sighing, he said, "Poor God – he doesn't have a thing to do with it. God is good."

Others believe that what God has to do with HIV is that God helps people stay healthy with the virus by helping them to cope and by providing medications and services for people with HIV. One woman, thrilled with her health after five years of living with the virus, credits God with helping her to avoid sickness and mental anguish over HIV: "God helps me deal with the illness. If not for God, I could be dead, or I could have lost my mind by now." This sense of gratitude emerges in other comments about how God provides for HIV-positive people with accessible AIDS programming: "God puts the programs like CCHER there, to feel comfortable about talking." God is also thanked in prayer for the medicines that have drastically prolonged life with HIV since the early days of outbreak, when one lived only about two years post-diagnosis. One participant who has been HIV-positive for over a decade admitted: "It's hard to take the medicines, but you have no choice. When other people are dying because they have no drugs, this is the grace of God to find the medicine."

Making meaning of one's illness in terms of God grants, for some, a greater perspective on God's relationship to humanity. Approaching the problem of AIDS from a global vantage point makes it easier for at least one of the participants to see his isolated illness in context: to see himself as one of millions of AIDS sufferers worldwide. When asked about God and HIV, this man said: "God is playing the same role in my illness as he is in the pandemic that affects everyone across the world. We pray to God to have Him help us." This perspective is just one of the ways that God is helping him to "face" his situation in the context of the global community, and the cosmos beyond.

The one idea that connects all these notions of God expressed by the clients is that *God does not give people HIV*. No one suggested that God even created the virus, but rather, that God is forced to cope with having it in the world, like they and so many others are forced to cope with having it in their bodies.

This project, focused specifically on addressing the stigmas of HIV/AIDS, was not deep enough to also get beneath the additional stigmas of *Vodou*. In response to my questions about using *Vodou* to cope with or treat HIV/AIDS, many of the respondents said flatly that, because they are Christian, they either do not practice or explicitly do not believe in *Vodou*. Several others pointed out that going to a *Vodou* priest (*houngan*) or priestess (*mambo*) will not cure you of AIDS, and they said this with the emphasis of people who have watched others succumb to the illness without antiretroviral treatment, for lack of life-prolonging drugs in Haiti, or for making the misjudgment to rely exclusively on *Vodou* for treating HIV illness. Of course, someone who relied exclusively on prayer – for all its perceived benefits – for help might fare similarly, yet Christian prayer did not hold the stigma that *Vodou* did for these CCHER participants.

Perspectives on Prayer: Science versus Religious Studies

In fact, there is a growing acceptance or *curiosity* surrounding prayer in public health and medicine, when utilized as a supplement (not substitute) to Western medical treatment and health surveillance. Recently, the front page of the *Harvard Gazette*, a newspaper always showcasing the newest scientific studies at the university, ran a front-page article about a Harvard Medical School study that found one-third of Americans likely to pray over health and sickness.[6]

Scientific research may have established an interest in prayer as it relates to sickness and health, but, in light of the CCHER interviews, we see that there is still much room for exercising a deeper curiosity about prayer as a religious practice, spiritual journey, and healing process that binds people together and to their God. When prayer is discussed in scientific contexts, it is often from a mind-body perspective that concerns itself with prayer's effects on physiological functioning. Prayer, the act, is assumed to be something static, uniform, and predictable, while its physiological or health effects are approached as the real data. An anthropological, ethnographic, or religious studies curiosity, however, is better explored in the *practice* of prayer itself and in the questions with which we replace our previous assumptions of what prayer actually is to people. These conversations, just ten interviews, offer an intriguing taste of the range of possibilities for exploring the practice of prayer in the context of HIV/AIDS.

The dynamism of prayer is evident even in this small group of informants, and even though my questions were weighted more toward *whether* one prayed than on *how* one prayed. More must be asked. Yet, these ten voices suggest certain things: that prayer can provide relief from overwhelming emotions and lift the weight of having HIV; that it provides an additional reserve of strength and hope when individuals know that they can count on God for support and for a solution; that it links individuals to communities when people pray together; and that the evolving notions of God facilitated by prayer can grant a broader perspective on individual illness, as it occurs in the context of community and the cosmos – all of which have played some positive role for many of these informants as they cope with and make ultimate meaning of HIV and AIDS.

Perhaps most importantly for the challenges of AIDS' attached blames, I also observe that prayer can facilitate the process of forgiving oneself for having a virus that others think one deserves. Prayer, coupled with the fortunate side effects that the CCHER clients described, seems to provide at least one path to what many of the informants consider their goal: living *confidently*, even openly, with the virus. Because AIDS is still an incurable disease, we usually describe optimal health only as *coping*, but when one evolves to a stage – religiously or otherwise – where it is possible to forgive oneself for having contracted a virus that some view as punishment, here enters the possibility of *healing from* HIV and AIDS, healing in the sense of overcoming – psychologically, socially, and spiritually – its stigmas.

Cultivating Curiosity: Toward Cultural and Religious Competency

I allowed curiosity to guide this endeavor, and it is not an easy or painless thing. Curiosity as an anthropologist requires a willingness to make oneself vulnerable by not claiming to know answers in advance. It requires abandoning the assumptions that pad our egos. Only by letting go of assumptions can you make room for good questions.

Getting curious – could this also be the key to unlocking cultural competency in the practice of health and medicine? It requires an essential vulnerability fully expressed only when one suspends the authority of one's familiar system and theoretical language to place it in the rightful context of one system among many. Curiosity depends on one's willingness to ask questions and *to take someone's answers seriously*: to suspend disbelief, if you have it. In the case of an American doctor or health provider for Haitians with HIV, curiosity might look like this: Why does my patient/client think she has HIV? Why does my patient think he is doing so well/poorly with the virus? To whom does my client turn for emotional support? What is my patient's relationship to his medicines, and what does he think as he swallows them several times a day? From where does my client draw her hope and joy? How does my patient understand life, ultimately? How is this other human being different from me, the health professional? Most importantly, how are we the same?

There are ways to cultivate curiosity if it doesn't come naturally, or, in the case of physicians and service providers, if one lacks time in the patient/client encounter to start the conversations about someone's religious practice and worldview as it informs a culturally specific orientation to health. One can, in the meantime, go to the literature: one can read novels.

Of the scores of brilliant Haitian narratives available, I can suggest two for a start: *Masters of the Dew* (*Gouverneurs de la Rosée*) by Jacques Romain (New York: Macmillan, 1971),[7] and *The Dew Breaker*, by Edwidge Danticat (New York: Knopf, 2004). These books are most inspiring and informative when read together, because of the Haitian timeline and experience that they span, to include both Haitian and Haitian American narratives. Written for international audiences, they provide broad entry perspectives into Haitian culture, religion, and worldview as they have developed through the nation's own painful and triumphant experiences.

Masters of the Dew, by Jacques Romain, was circulated around the globe when published and "imme-

diately hailed as Haiti's finest novel."[8] In Romain's story you meet the struggling peasants of a rural Haitian village in the throes of drought and the gradual desertification of once-fertile lands. Wide, woeful Délira and her gruff little husband Bienaimé disagree on God's role in their misfortune as they struggle to generate an income and as Délira continually laments the long absence of their only son. *Masters of the Dew* builds from this essential, perhaps universal, conflict about God's orientation to humanity: Is human misfortune and hardship a punishment from God, as Délira dramatically moans, or is heavenly business truly separate from earthly business, as Bienaimé craftily insists? Different perspectives on the existence of HIV/AIDS in relation to the divine usually point to this same, ultimate tension. That the book is broadly about hope – who has the right to have it, and when – lends it another perspective from which to consider the plight of HIV-positive people in our societies.

Edwidge Danticat, a Haitian author collecting acclaim and gaining considerable prominence,[9] wrote her newest book *The Dew Breaker* in dialogue with Romain's Haitian classic.[10] In it, she focuses more on earthly business: violence among the Haitian people and exodus into the diaspora. These short stories are about Haitians who are raised and reside in America, exiles from their homeland. Through the work's poetic perspective and supreme fictional technique of weaving several short stories subtly together, Danticat facilitates an unlikely connection for the reader: one finds oneself in a position to sympathize with a perpetrator of the political violence (called, in Kreyol, a "dew breaker," for coming at first light to abduct) that has driven so many Haitians from their island. *The Dew Breaker* can also be read as a meditation on the religious or spiritual force that still binds the Haitian people together. Working against political betrayal, violence, poverty, terrified flight, and immersion in foreign cultures of the diaspora, Haiti exudes a force that binds the people of its present to its past, connecting them to the island and, ultimately, to Africa, where the ancestors are.

In *Poetic Justice* (Boston: Beacon Press, 1995) Martha Nussbaum urges judges, legislators and policymakers to read novels as a way to deepen their perspective on democracy, based on her observation of the transformative experience that the literary framework facilitates. Connections, or "links of possibility," are made between the reader and the literary characters as one identifies and sympathizes with them, and as the reader imagines what it is like to be them. As a practical suggestion and gateway to cultural competency, I take Nussbaum's lead here. I urge doctors and service providers who treat Haitians in America to read more novels – Haitian ones[11] – to enhance the quality of the public health encounter in America and to foster more curious connections between doctors and patients.

Notes

1. There has been less stigma attached to hemophiliacs who, before blood screening for HIV was possible or thought to be necessary, contracted the virus "innocently" through a blood transfusion.

2. More detailed information on CCHER's comprehensive HIV/AIDS services is available at their website: http://www.ccher.org/page2.htm; accessed 19 May 2004.

3. The demographic survey was based on those that CCHER routinely uses in research (collecting data on sex/gender, age, education, place of birth, and length of time in the U.S.), with the addition of one category for this project: religious affiliation/identity.

4. *HIV/AIDS in Massachusetts: An Epidemiologic Profile March 2004*, chap. 2, "Who Is Currently Living with HIV/AIDS?"p. 18; http://www.mass.gov/dph/aids/research/profile2004/pdf/chap2.pdf; accessed 17 May 2004.

5. The extent to which *Vodou* is incorporated into or accepted in the group is not clear.

6. The study was directed by Dr. Anne McCaffrey. William J. Cromie, "One-Third of Americans Pray for Their Health: But Does It Make a Difference?" *Harvard University Gazette*, 13 May 2004; http://www.news.harvard.edu/gazette/2004/05.13/01-prayer.html.

7. English translation by Langston Hughes and Mercer Cook, second edition.

8. From the introduction to the 1971 edition, by Mercer Cook, p. 9.

9. Danticat is the author of *Krik? Krak!* (1996), for which she was a finalist for the National Book Award; *Breath, Eyes, Memory* (1998), which became an official Oprah's Book Club Selection, and *The Farming of Bones* (1999), for which Danticat won the American Book Award. This is only a selection of her many literary awards and accomplishments in fiction, nonfiction, youth fiction, and editing and compiling ethnic anthologies.

10. Edwidge Danticat, comments at Wordsworth book-signing event, Cambridge, Massachusetts, 23 March 2004.

11. Reading lists and connections to Haitian works of fiction are available on websites like www.kreyol.com and by contacting the author at ddorland@post.harvard.edu.