



The role of religion in HIV-positive women's disclosure experiences and coping strategies in Kinshasa, Democratic Republic of Congo

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ABSTRACT

Literature from the U.S. has documented the importance of spirituality on the psychological health of people living with HIV/AIDS; however there is little published data on the ways in which people living with HIV/AIDS in Africa turn to religion for support. We conducted 40 in-depth interviews with HIV-positive women who were pregnant or had recently given birth in Kinshasa, Democratic Republic of Congo to inform the development of a comprehensive family-centered HIV treatment and care program. Women described how they relied upon their faith and turned to church leaders when they were diagnosed with HIV and prepared to share their diagnosis with others. The women used prayer to overcome the initial shock, sadness and anger of learning their HIV diagnosis. They turned to their church leaders to help them prepare for disclosing their diagnosis to others, including their partners. Church leaders were also important targets for disclosure by some women. Women's faith played an important role in their long-term coping strategies. Conceptualizing their infection as a path chosen by God, and believing that God has the power to cure their infection comforted women and provided them with hope. In settings like the Democratic Republic of the Congo, where there is a strong foundation of faith, we need to recognize how individuals draw upon their different health belief systems in order to develop and implement coherent and effective prevention, treatment and care strategies.

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Introduction

There has been a growing interest in the study of religion and spirituality and their relationships to mental and physical health in patients with chronic illnesses, including HIV. Estimates suggest that up to one third of people living with HIV/AIDS (PLWHA) may have mood disorders or clinically significant depressive symptoms (Benton, 2008). Studies have shown depression causes biologic changes in endocrine and immune function that may contribute to disease progression and mortality (Leserman, 2008). Research also suggests an association between a history of depression and significant delays in initiation of treatment (Cook et al., 2006; Evans et al., 2005), and adherence to antiretroviral therapy (Campos, Guimaraes, & Remien, 2008; Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999). Depression at the initiation of treatment

was also associated with increased risk of clinical progression to AIDS (Bouhnik et al., 2005); slower virologic suppression (Pence, Miller, Gaynes, & Eron, 2007); and shorter survival (Lima et al., 2007).

Literature from the U.S. has documented the importance of spirituality, defined broadly as prayer, meditation, having faith in God and drawing one's strength from one's beliefs, on the psychological health of HIV-positive individuals. Research has also shown that PLWHA who report greater engagement in spiritual activities report lower emotional distress (Sowell et al., 2000), lower depression (Simoni & Ortiz, 2003), greater optimism (Biggar et al., 1999), and better psychological adaptation (Simoni, 2002). In one study of PLWHA in the U.S. authors found that spirituality was strongly and positively associated with the feeling that life had improved (Braxton, Lang, Sales, Wingood, & DiClemente, 2007). People reporting an increase in spirituality after HIV diagnosis have also been shown to have significantly greater preservation of CD4 cells, as well as significantly better control of viral load, after controlling for other factors (Ironson, Stuetzle, & Fletcher, 2006).

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The literature from Africa on the relationship between religion and HIV has focused on the role that religious organizations and religious ideals have played in HIV prevention, care and treatment efforts. With regard to HIV prevention, religious ideals that promote abstinence and do not support the use of condoms are often portrayed in conflict with the secular prevention strategies that emphasize safer sex strategies (Green, 2003; Pfeiffer, 2004). There is some evidence from Africa documenting that individuals affiliated with specific religious denominations may be at lower risk for HIV than members of other denominations, suggesting a protective effect of some of the more conservative religious denominations (Lagarde et al., 2000; Takyi, 2001). A small body of research has also shown that spiritual beliefs may conflict with recommendations of health care providers in the treatment and care of PLWHA. For example, Ugandan researchers found that 1.2% of 558 HIV-positive individuals initiating ART in a prospective observational cohort study discontinued therapy as a result of their belief that they had been spiritually healed, and thus no longer needed therapy. Four of six of these individuals restarted therapy, but three required second-line salvage therapy (Wanyama et al., 2007). Religious fatalism, or the belief that life is pre-determined by God and that individuals are powerless to change what happens to them, has also been found to negatively influence uptake of HIV testing and other HIV prevention strategies (Parra, Doran, Ivy, Aranda, & Hernandez, 2001; Strebel, 1996). Finally, there is a fear among some religious groups that engaging in issues of HIV/AIDS may indicate that churches endorse the behaviours of stigmatized groups such as sex workers and/or gay men (Adogame, 2007). Thus, leaders of these religious groups have distanced their churches from HIV/AIDS, and this has led to isolation and self-stigmatization of HIV infected members of their congregations (Krakauer & Newbery, 2007; Tiendrebeogo & Buykx, 2004).

On the other hand, there is substantial evidence of the important role that religious organizations are playing in providing treatment and care services in Africa (Hearn, 2002; Tiendrebeogo & Buykx, 2004). It has been documented, for example, in a recent report commissioned by UNAIDS that 70% of health services in the Democratic Republic of Congo (DRC) are delivered by churches and church related institutions, 50% of hospitals in the DRC are owned and managed by local churches, and the Roman Catholic Church alone provides 25% of all HIV/AIDS care including home based care and support of orphans in the DRC (Haddad, Olivier, & De Gruchy, 2008). Religious organizations have a long history of providing health services in resources constrained settings, and this has certainly been the case of HIV/AIDS treatment and care in sub-Saharan Africa. Receiving less attention in the literature is the role of religion and spirituality on the psychosocial well-being of HIV-positive communities in Africa.

This study was conducted in Kinshasa, the capital of the DRC. The DRC is the second largest country in all of Africa and the largest in Central Africa. The DRC's population is among the poorest in the world. In 2008, the DRC ranks 168th out of 177 countries in the Human Development Index, a composite indicator compiled by the United Nations Development Programme (UNDP, 2008). Despite the economic collapse of the country and internal conflict, HIV prevalence in the DRC appears to have remained fairly stable for many years and decreased more recently (Buve, Bishikwabo-Nsarhaza, & Mutangadura, 2002; Edmonds et al. 2008). Between 1986 and 1989, HIV prevalence among antenatal women in urban areas was between 5.8 and 6.5 percent (Batter et al., 1994; Ryder et al., 1989). Between September, 2004 and August, 2007, the prevalence at 21 antenatal clinics in Kinshasa offering prevention of mother to child transmission programs to 84,830 pregnant women ranged between 2.64% and 1.34% (Edmonds et al., 2008).

Methods

In collaboration with colleagues at the University of Kinshasa School of Public Health and the Ministry of Health we have conducted clinical, behavioral and prevention research on HIV and other infectious diseases in the DRC since 2004. The research includes a focus on pediatric and adult HIV care and treatment, prevention of vertical HIV transmission, and positive prevention among adolescents. This qualitative study was conducted to inform the implementation of Sango-Plus, a family-centered primary HIV care and support program. The Sango-Plus program provides comprehensive HIV care and treatment services including anti-retroviral therapy, family planning services, psychosocial support and nutritional counseling and support to HIV-positive women and their first degree relatives. Thirty-two antenatal care (ANC) clinics throughout Kinshasa can refer HIV-positive pregnant women to the Sango-Plus program. The clinics include 11 facilities managed by the Catholic Church, 16 managed by the government, and 5 managed by the Protestant Church. While many of the clinics in Kinshasa are run by religious organizations, individuals who seek services from these clinics need not be members of these religious organizations to receive services at the clinics. The clinics run by religious organizations have the reputation of providing good quality and affordable services throughout Kinshasa. In selecting clinics for their care, women consider proximity, cost and perceived quality of care, rather than what organization finances and manages the clinics. ANC clinics were selected as the point of entry into the Sango-Plus program because HIV testing is routinely offered during pregnancy in the clinics, and because we have been offering prevention of mother to child transmission (PMTCT) services in these clinics for several years. Prior to launching the Sango-Plus program we wanted to better understand how women shared information about their diagnosis with their families because the program was relying on women sharing their HIV diagnosis with their families and encouraging the families to join the program. We designed this research to explore women's experiences with HIV status disclosure and male partner involvement in HIV prevention, care and treatment. In the process of asking women about their experiences with HIV status disclosure and coping, women spontaneously talked about their religious beliefs and their ties to the church. This paper describes the ways in which women's faith and their religious leaders helped them with disclosure of their HIV status and coping with their HIV status.

Data were collected in Kinshasa from July, 2006 through December, 2006. Forty in-depth interviews were conducted with HIV-positive women who were pregnant or who had recently given birth. We purposively sampled HIV-positive women who had been through the HIV testing process at an ANC clinic so that we could examine their experiences in-depth. We selected women according to specific demographic characteristics that we wanted to have represented in the sample, including marital status (married by civil or traditional ceremony, not married but in a committed relationship, and single which included divorced and widowed) and residential status (living alone, living with partner, living with extended family). Women were recruited from a sub-sample of 11 of the 32 ANC clinics involved in the Sango-Plus program, including 4 clinics managed by the Catholic Church, 4 managed by the government and 3 managed by the Protestant Church. Trained health care providers recruited women during routine clinic visits. Interviewers provided women with information on the study and obtained consent from women who were eligible and willing to participate. The interviews were conducted in Lingala and lasted between 45 and 60 min. Interviews were semi-structured based on an interview guide that outlined the general topics for discussion and suggested probes. All interviews were audiotaped, transcribed

and translated into French for analysis. To insure quality control of the translation process, a systematic sample of 10% of all transcripts was translated by two independent translators.

Deductive codes were developed and two trained research assistants fluent in French applied codes to all transcripts using Atlas.Ti (Version 5.0), a qualitative data analysis software program. Code reports were generated and reviewed by the data analysts. Interpretive codes were then applied as themes emerged during the analysis process. To facilitate cross-case analysis, matrices that summarized and displayed the data by topic were created. The study was designed to explore women's disclosure and coping experiences, and through the questions on these topics our interviewers uncovered the importance of women's faith and their ties to the church. While we did not explicitly ask about the role of religion, 37 of the 40 women we interviewed spontaneously talked about the importance of their faith as it relates to their disclosure experiences, to their coping strategies or both. This study was approved by Institutional Review Boards at the University of North Carolina at Chapel Hill and the University of Kinshasa School of Public Health.

Results

During the interviews we asked women to talk about their experience learning their HIV status and disclosing their status to others. Through their narratives we learned about the significance of women's faith and their ties to the church in their efforts to come to terms with their infection.

Description of the sample

A total of 40 women between the ages of 20 and 42 years were interviewed. Sixteen women were pregnant at the time of the interview, one woman suffered a miscarriage, and the remaining 23 women had delivered within the past 12 months. All but two women reported having at least one child. The median number of children per woman, not including women's current pregnancy, was 2.6, with a range of 0–6 children. A total of 22 women were married, 8 women were in committed partnerships but not married and 10 women were single. Five women reported that they were on antiretroviral therapy (ART). Among the 40 women we interviewed, 38 learned their HIV status for the first time when they were tested in their current pregnancy. Two women learned of their status during a previous pregnancy.

Learning their HIV-positive diagnosis

Most women did not know that they would be offered the opportunity to test for HIV during their antenatal care. While women consented to test for HIV, many talked about feeling emotionally unprepared to learn of their HIV-positive diagnosis. Most women were shocked and sad when they learned about their HIV-positive diagnosis. Women used prayers to help them overcome their shock and sadness. Women also turned to church leaders for advice and support in this early stage.

"That really disturbed me. I asked God if he would give me peace because I totally missed peace. The day I came when I was told about it (my HIV status) I really missed peace. But I came home, remained shut in the room and I cried to God. I asked him why this happened to me...I prayed and read the Bible and God told me to be calm, nothing will happen." – Pregnant woman in committed relationship

"...when they found out that I had that disease it was a big problem and surprise to me. This was a problem that could kill me because of the emotions. But the health care people who had

given me the results, they tried to give me some advice to show me how I can live long. That coincided with the meeting with God's helpers, I talked with them, they gave me advice, gave me hope toward God. Today I live. I am at least in peace." – Post-partum married woman

Some women were angry when they learned of their HIV diagnosis. After seeking advice from church pastors and praying, these women were able to find peace and overcome the anger.

"I felt very angry, especially that I had accepted to get married in purity (a virgin), trying not to go into debauchery. But why did this sickness happen to me? Then in seeing these two children that I have already, who can take care of them in my absence? This is what deeply touched me. I even told myself to hurt myself before death overtakes me. But by meeting the men of God and the health care people, that strengthened me. I have forgotten all that. I have given my life to the only one who is guiding me." – Pregnant woman in committed relationship

Disclosing HIV diagnosis to others

After dealing with the initial shock, sadness and anger of learning about their HIV-positive status, women were faced with the prospect of having to share the news of their HIV diagnosis with others. Among the forty women we interviewed, 18 had not disclosed their HIV status to anyone. Fourteen women disclosed their status to their partners, and one woman reported that while she had not disclosed her results to her partner someone else had informed him of her HIV status. Eleven women said they had disclosed their HIV status to someone other than their partner, and seven women disclosed to both their partner and someone else. Among the 18 women who had disclosed to someone else, seven women said that their pastor or another leader within their church was one of their targets for disclosure. Among these seven women, two of the women had disclosed only to their pastors, and not to a partner or anyone else.

The women who had talked to their pastors or other church leaders about their diagnosis said they did so because they felt that they could trust them to keep their HIV status confidential.

"By the way, in my pastor, I have confidence and I am sure that he keeps the secret. He is our shepherd and he helps us any time in prayer, and he has the advice to comfort us. He has always comforted me by saying this 'You are innocent, concerning the contamination (infection) and God is able to take care of you and cure you.'" – Post-partum woman in committed relationship

Women also said they wanted to disclose to their pastors so that their pastors could pray for them. They believed that their pastors had the power to influence the course of their illness.

"Ah, I had decided to divulge it to him so he would pray in my favor, because also he has the gift...I say 'Ah my God! Can I live five more years? Can I live ten years?' God gives me the grace to live until the day which he, himself, will judge to take my soul." – Post-partum married woman

In discussing their decisions regarding disclosure, 12 of the 14 women who had disclosed to their partner specifically mentioned the role of either their pastor or their faith in preparing them to disclose to their partners. They turned to their pastors or to God through prayers to give them the courage they needed to disclose their status to their partner, and to calm their partner so he would not get angry when he heard the news.

"First, I have put everything in a prayer. I have prayed a lot, asking God to give me the courage to be able to talk to him about it." – Post-partum woman in committed relationship

"I have only asked God to touch his heart so that he could accept everything I was going to tell him. That he does not get angry, that he does not lose his temper. It's like that that I made him sit down and started to explain to him that problem." – Post-partum woman in committed relationship

Among the 18 women who had not disclosed to anyone, eleven said that they wanted the knowledge of their HIV status to remain a "*secret between them and God*." They didn't feel they could trust other people with the information of their diagnosis.

"It is only God who knows. I would not know how to do it (disclose to others). You see it is God and he alone knows. It is one that remains a secret." – Post-partum woman separated from partner

"If I speak to somebody, it is so that he will do what? In this world, one cannot trust anybody, if it is not God." – Post-partum married woman

Developing long-term coping strategies

Through these interviews we also learned about the long-term strategies women used to cope with their HIV diagnosis, and the role that women's faith plays in this process. Several women talked about their belief that God had chosen this path for them. Conceptualizing their infection as a path chosen by God helped women cope with the knowledge of their status.

"So every sickness is mortal. The finality of all according to the plan of God is that nobody will live eternally. One cannot worry. Let us look at God who will be able to give us more days in order to raise the children that we have." – Pregnant married woman

There were also women who believed that God could cure them of their illness, and this belief provided women with hope.

"I have glorified God by saying, 'Thanks God.' I have said, 'Go and cure the sickness which is in my body. Even if it is hidden I don't know where, you, you are going to act in my heart.' I have faith that I am already cured." – Pregnant woman in committed relationship

"I have confidence in God. Even if one says that I have the sickness, in the name of God I will be cured because I did not hurt anybody. The sickness exists but one must believe in God and he will act. I put my hope in God with all my assurance...One had informed me and I said that even if the sickness is in my body, I still believe and I have my Jesus Christ. He is going to take away this blood that is contaminated. I have no problem with anybody. I do not know how I caught that sickness. It is only God who knows." – Pregnant married woman

The belief in the power of God to cure HIV was supported by this woman's HIV counselor. The counselor encouraged the woman to pray, implying that God may have the power to cure her of her infection.

"The counselors had also recommended to pray a lot, because the laboratory can show that I have the virus, but where the wisdom of man is limited, the wisdom of God starts." – Pregnant married woman

There were other ways that pastors and women's faith in God provided support to them as they coped with their HIV status. A few women talked about advice that they received from pastors and other leaders in the church regarding their health care. For example, in this interview the woman explains how her pastor told her not to rely only on God, but that she must also remember to take her medication.

"It is not a good thing to neglect your medicine to say that you count only on God. It is necessary to fulfill all the methods." – Pregnant woman in committed relationship

Discussion

In this study of women's experiences with HIV testing during pregnancy we found that women's spirituality and their religious leaders were important sources of support to them immediately after they learned their HIV-positive diagnosis, in the process of sharing their diagnosis with others, and in their long-term strategies to cope with their diagnosis. While women were not specifically asked about the role of religion and their faith, 37 of the 40 women mentioned their faith and/or the role of their religious leaders in their disclosure and coping experiences.

These findings need to be understood in the larger context of Congolese society. Religion is an important part of daily lives of most people in Kinshasa. There is a diversity of religious affiliations in the DRC including Catholic (31%), Protestant (30%), other Christian (34%), Muslim (2%), and the remaining individuals practicing indigenous and syncretic religions (Macro International, 2007). Since the civil war in the DRC started in 1998, the country has experienced tremendous social and economic upheaval. It is estimated that at least 3.8 million people have died during the conflict, costing more lives than any other conflict since World War II. In terms of health infrastructure, the mismanagement of public funds during the years of the Mobutu regime (1965–1997), followed by the complete collapse of government infrastructure and the ensuing war have left the medical and public health system fragile. Religious organizations have done more than supplement the failed health system in the DRC. It is estimated that 70% of all health services in the DRC are delivered by churches and church related institutions (Haddad et al., 2008). The importance of people's faith in their understanding of their health and healing, together with the strong presence of religious organizations in the implementation of health and social services, underscores the ubiquity of religion in the health care and delivery system of the DRC.

There has been a call to find more effective approaches to bridge the gap between the HIV prevention, care and treatment efforts and the strong foundation of faith in communities most heavily affected by HIV (African Religious Health Assets Program, 2006). The interviews that we conducted highlighted a number of ways in which women relied upon their religion and turned to their pastors for support during the process of learning their diagnosis and disclosing their status to others. Pastors were the target of disclosure for some women, as was found in another study among HIV-positive community members in Nairobi, Kenya (Miller & Rubin, 2007). Women also described the role that their pastors played in supporting them as they prepared to disclose to others, as well. Disclosure of HIV status has important implications for HIV prevention and treatment efforts. There is evidence that women's efforts to participate in prevention of mother to child transmission programs, adhere to infant feeding guidelines, and prevent unintended pregnancies are difficult without the knowledge and support of a partner (Brou et al., 2007; Buskens, Jaffe, & Mikhathswa, 2007; Medley, Garcia-Moreno, McGill, & Maman, 2004). It is critical that we continue to encourage and enhance opportunities to support disclosure through existing community resources.

Women's narratives also illustrated how their faith was an important source of ongoing psychological support as they learned to live with their diagnosis. A lack of adequate ongoing support can have devastating health consequences for PLWHA. Depression has been linked with higher morbidity and mortality among PLWHA

(Leserman, 2008). In severely resource constrained settings there are often few organizations that provide psychosocial support to PLWHA, and where they exist, they frequently lack adequate funding. This is certainly the case in Kinshasa, where the extremely weakened state has led to a lack of social services for PLWHA. We cannot ignore the role that churches and church leaders are playing in providing support to PLWHA.

While there are obvious benefits that women drew from their faith in God, other studies have shown that religious beliefs may serve as a barrier to treatment and care efforts. These data demonstrated the conviction that women, their religious leaders and even their health care providers had in the power of God. Women talked about praying to God to cure them of their infection. There was also an example of a health care provider who acknowledged her belief that modern medicine may have limitations, and therefore advised her patient to pray to God for a cure. On the other hand, there was an example of a pastor who reinforced the importance of adhering to medications while also stressing the value of prayers. These narratives suggest that women, their religious leaders and their health care providers are negotiating between different health belief systems. While there was no specific example in our data of a clash between these health belief systems, Wanyama et al. in Uganda did find that spirituality was a barrier to ART adherence (Wanyama et al., 2007). Thus, acknowledging and monitoring how women and their providers negotiate between these different belief systems are important in the implementation of treatment and care programs.

The religious fatalism described in these interviews may also serve as a barrier to women taking initiatives to prevent and treat their infections. In a study among Mexican-American women in the U.S., Parra et al. demonstrated how religious fatalism served as a barrier to HIV testing (Parra et al., 2001). There were no women in this study who talked about forgoing treatment because of their fatalistic belief that their infection was God's will and/or because of their belief that God could cure them of their infection. However, if we look at other decisions women made, we see the way in which their religious convictions influenced health related decisions. The two women who learned about their HIV status during a previous pregnancy said they had not taken steps to prevent their current pregnancy because they believed that the decision about how many children they should have is in the "hands of God." Given the importance of their faith and their belief in God, recognizing and directly addressing these beliefs in the provision of health services is very important.

This study is not without limitations. The study generates important new questions that need to be explored through further research. First, these interviews were not designed to explore the role of women's spirituality. While the interviewers effectively probed women for more information on their spirituality when it emerged during the interviews, there is more that could have been explored if religion was the only topic for discussion in the interviews. It would be naïve to assume that women experienced their religion in the same way. Additional data collection could help to distinguish differences in how women used their faith to help them through the process of deciding who to disclose their status to and how to support themselves.

Second, since we did not collect information on women's religious affiliations, we were not able to explore whether there were any clear patterns according to different religious beliefs and affiliations. It would be very useful to determine whether different religious affiliations influence outcomes such as disclosure and coping in different ways with a larger and statistically representative sample of women. Other studies have shown that adherents of different churches have distinguishable patterns of risk behaviours for HIV/AIDS, specifically engagement in non-marital sex (Gregson,

Zhuwau, Anderson, & Chandiwan, 1999; Hill, Cleland, & Ali, 2004). There is also some evidence to suggest that different churches have different levels of tolerance and acceptance of PLWHA (Krakauer & Newbery, 2007). Understanding these distinctions between religious affiliations and how they influence disclosure and coping would be the important next step to avoiding conflicting messages and motives between the health care system and the religious sector.

Third, we were limited in the fact that only a small number of the women we talked with were on antiretroviral therapy at the time we interviewed them. Thus, we could not explore in sufficient depth the ways in which their religious beliefs influenced their treatment behaviours. While the experiences of these women do not indicate that their religious beliefs interfered with their treatment behaviours, other research studies in sub-Saharan Africa have shown this to be the case (Wanyama et al., 2007). Exploring these issues with a larger sample of women who have been on ART for a longer period of time would enable us to gain a deeper understanding of how their religious beliefs influenced their treatment behaviours.

Next, given our small sample size and non-representative sampling strategy, these findings cannot be generalized to a larger population of women or to the experiences of men. These findings are drawn from a sample of 40 women from antenatal clinics who were purposively sampled according to certain demographic characteristics. Women from antenatal care were sampled because they represented our target population for recruitment into the Sango-Plus program. In Mozambique, Agadjanian demonstrated how women were at a greater disadvantage in terms of initiating prevention strategies in Pentecostal-type churches as compared to mainstream churches, such as Roman Catholic and Presbyterian (Agadjanian, 2005). Determining whether similar gender differences across different churches are apparent in treatment and care decisions would also be important.

Finally, interviews with pastors and other leaders of churches could help shed more light on their interaction with PLWHA in their congregations. We did not find any examples of women who said they were isolated or ostracized by the church upon disclosing their positive HIV status, however, this has been found by others (Krakauer & Newbery, 2007). Because of the strong foundation of faith in settings like Kinshasa, isolation or ostracism by the church could lead to devastating consequences for PLWHA. Understanding how church leaders interact with PLWHA members of their church and what motivates the advice that they provide to these congregants would be important.

Given the strong foundation of faith in African communities that are heavily impacted by the HIV/AIDS epidemic, understanding how the religious beliefs of individuals affected by HIV/AIDS influence their prevention, care and treatment choices is critical. Our data suggest that while PLWHA, their health care providers and their spiritual leaders have strong convictions in the power and goodness of God, they also believe in the importance of medical treatment and care for PLWHA. Acknowledging and understanding how communities rely upon and tap into these different health belief systems is critical to developing and implementing coherent and effective prevention, treatment and care strategies in these settings.

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