


“If They Give Their Mind to HIV, They Don’t Last as Long”: An Explanatory Model of HIV Infection in a Limited-Resource Setting Informs Person-Centered Care

Global Qualitative Nursing Research
Volume 9: 1–14
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DOI: 10.1177/23333936221097112
journals.sagepub.com/home/gqn


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Abstract

Explanatory models describe individuals’ perceptions of their illness experiences, which can guide culturally relevant care. We constructed an explanatory model of the experience of living with human immunodeficiency virus (HIV) in the Dominican Republic. Following qualitative descriptive methodology, we conducted interviews in Spanish using a semi-structured interview guide developed using Kleinman’s explanatory model framework. Two bilingual researchers coded interview transcripts following conventional content analysis. We used deductive codes from Kleinman’s framework and inductive codes external to the framework to construct the codebook. We arranged codes by shared meaning into categories and constructed themes that reflected shared findings from inductive categories and deductive codes. Twenty-six persons living with HIV participated. They provided rich descriptions of their experiences represented by four cross-cutting themes, which informed the explanatory model. By incorporating this in-depth understanding of patients’ illness experiences into care delivery, nurses can cultivate culturally meaningful and trusting patient-centered partnerships that improve health.

Keywords

explanatory model, HIV, Dominican Republic, Caribbean, health beliefs, person-centered care

Resumen

Los modelos explicativos describen las percepciones personales de las experiencias de vivir con una enfermedad, lo cual puede guiar una atención médica culturalmente relevante. Hemos construido un modelo explicativo a partir de la experiencia de vivir con el virus de inmunodeficiencia humana (VIH) en la República Dominicana. Siguiendo una metodología descriptiva cualitativa, realizamos entrevistas en idioma español basándonos en una guía de entrevista semiestructurada desarrollada dentro del marco del modelo explicativo de Kleinman. Dos investigadores bilingües codificaron las transcripciones de las entrevistas siguiendo un análisis de contenido convencional. Empleamos códigos deductivos del marco de Kleinman y códigos inductivos ajenos al marco para crear el libro de códigos. Organizamos los códigos por significado compartido en categorías; construimos los temas a fin de reflejar los hallazgos compartidos de las categorías inductivas y los códigos deductivos. Participaron veintiséis personas que viven con VIH. Brindaron descripciones abundantes de sus experiencias representadas por cuatro temas transversales, los cuales informaron el modelo explicativo. Al incorporar en la atención médica este entendimiento profundo de las experiencias de los pacientes de vivir con una enfermedad, el personal de enfermería puede desarrollar relaciones centradas en el paciente culturalmente significativas y de confianza que mejoran la salud.

Palabras clave

Modelo explicativo, VIH, República Dominicana, el Caribe, creencias sobre la salud, atención centrada en la persona

Received June 1, 2021; revised March 4, 2022; accepted March 19, 2022

Despite significant improvements in the management of Human Immunodeficiency Virus (HIV) globally, HIV infection remains a persistent health threat, especially in limited-resource settings such as the Caribbean (Challacombe,

2020). Nine Caribbean countries, including the Dominican Republic, are among the top 25% of countries with the highest HIV prevalence (Hintzen et al., 2019). In the Dominican Republic, HIV prevalence in the general population is ~1%,



(UNAIDS, 2019) while prevalence rates among key populations are much higher. Although current data is limited, it is estimated that men who have sex with men in the Dominican Republic have an HIV prevalence of 5% to 7% (Coelho et al., 2021), female sex workers a prevalence of 2% to 4% (Deschamps et al., 2016), transgender women an HIV prevalence as high as 17%, while transgender female sex workers may have prevalence as high as 27% (Budhwani et al., 2017; Deschamps et al., 2016). Additionally, rural areas have higher HIV prevalences than urban areas (Montgomery et al., 2020), as do areas with more tourism, likely as a result of sexual tourism (Padilla et al., 2010).

Stigma and discrimination against persons living with HIV (PLWH) are pervasive in the Dominican Republic and negative experiences from this marginalization are common (Budhwani et al., 2017; Rael et al., 2017; Yam et al., 2020). Stigma and discrimination are among the predominant drivers of worse HIV-related health outcomes, as they can lead to riskier sexual behaviors, reluctance to disclose status, underuse of healthcare services, delayed care seeking, and mental health concerns (Carrasco et al., 2017; Rael et al., 2017; Yam et al., 2020). Other factors including low educational attainment and/or low health literacy as well as exclusion from the largest employment sector, the tourism industry, also contribute to suboptimal outcomes for PLWH in the Dominican Republic (Barrington et al., 2017; Hintzen et al., 2019; Palumbo, 2015). Although employment-related discrimination is illegal under Dominican Law 135-11 (2011), it is common for employers, especially in the tourist industry, to screen potential employees for HIV without consent and deny employment if testing indicates HIV infection (Milner et al., 2019; Rael et al., 2017).

Several studies globally demonstrate individuals' experiences living with HIV and/or cultural perceptions of HIV influence their willingness to take antiretroviral therapy and seek and/or engage in care (Fagan et al., 2012; Jaiswal et al., 2019; Katz et al., 2015). As an example, overall distrust and experiences of mistreatment in the medical community combined with the belief that HIV is man-made and that the government is withholding a cure was associated with higher HIV risk among a sample of Black Americans (Bogart et al., 2019). In South Africa, many PLWH believe antiretroviral therapy is only for the very ill, which delays care-seeking and early treatment initiation (Katz et al., 2015). In the Dominican Republic, PLWH may identify witchcraft or

sorcery as a method of HIV transmission and potential cure and cite stigma and fear of rejection as barriers to care seeking, which can lead to reluctance to initiate or sustain antiretroviral therapy (Stonbraker, Smaldone, et al., 2017; Zulliger et al., 2018). Because optimal adherence to antiretroviral therapy improves treatment outcomes including substantially prolonging life, improving quality of life, and reducing, or eliminating, transmission (Bor et al., 2021; Onu, 2021), understanding how to promote optimal antiretroviral therapy adherence among diverse cultural groups is imperative to continued progress in curbing the HIV epidemic. As patients' powerful and culturally distinct perceptions of illness strongly influence treatment decisions and likelihood of adhering to antiretroviral therapy, it is necessary for clinicians to understand their patients' unique beliefs and perceptions so they can encourage treatment decisions in a way that is meaningful to their patients.

Kleinman's explanatory model framework has been widely used to guide researchers to explore individuals' illness experiences (Kleinman et al., 1978; McSweeney et al., 1997). He articulates that the "study of patient explanatory models tells us how they make sense of given episodes of an illness, and how they choose and evaluate particular treatments" (Kleinman, 1980). Kleinman clarifies that while the word, "disease" refers to a biological, chemical, or psychological abnormality, "illness" refers to the psychological perceptions of the disease or symptoms as they are experienced (Kleinman, 1980). Notably, explanatory models are not consciously constructed, thus they are fluid, may be disorganized, and can change over time (Kleinman et al., 1978; McSweeney et al., 1997). By creating explanatory models, we gain insight into patient's illness experiences and can elucidate places where clinicians can effectively intervene to improve self-management (Laws, 2016; Oetzel et al., 2015). Explanatory models are particularly relevant to nurses, as their position within the clinical team ideally situates them to incorporate patients' beliefs and preferences into care plans (McSweeney et al., 1997). However, all members of a care team can use explanatory models to ensure they offer culturally congruent and person-centered care, which can lead to better engagement and improved outcomes (Jaiswal et al., 2018; Rathert et al., 2013). The purpose of this study was, therefore, to construct an explanatory model of the illness experience of PLWH in the Dominican Republic.

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Methods

Qualitative descriptive methodology guided this study (Colorafi & Evans, 2016). We chose this naturalistic approach to scientific inquiry as it leads to a rich understanding of perspectives and experiences, which is particularly useful when the goal is to arrive at a deep understanding of illness experiences (Colorafi & Evans, 2016; Sandelowski, 2000).

Study Setting

The Dominican Republic is a Spanish-speaking nation with a population of ~11 million located in the Caribbean on the Eastern side of the island of Hispaniola, which it shares with Haiti (Wiarda & González, 2021). Despite significant economic growth in recent decades, mainly from an increase in the tourism sector, rates of poverty in the Dominican Republic consistently hover around 30% (Oviedo-García et al., 2019). Our study took place at Clínica de Familia, located in the city of La Romana on the Southeast coast of the country. Clínica de Familia is a Dominican non-governmental organization and primary care clinic that offers care, treatment, and support to over 2,500 PLWH through almost 20,000 visits annually. As La Romana is a large urban center in the Dominican Republic, Clínica de Familia is the largest clinic that specializes in HIV prevention, treatment, and care in the Eastern region. Thus, clientele with limited resources from both rural and urban areas travel great distances to receive services. We conducted all interviews in private offices within the clinic.

Recruitment and Participants

We used a nonprobabilistic, purposive sampling approach to recruit participants for interviews following their final visit in a parent longitudinal study that included 50 participants (Stonbraker et al., 2021). Inclusion criteria for the parent study were: (1) adult PLWH (age \geq 18 years); (2) a detectable viral load (\geq 40 copies/mL) at any point in the year prior to enrollment. For the current study, we aimed to recruit between 12 and 30 participants from the parent study as our sample was relatively homogenous and we were using a focused interview guide. When these two conditions are satisfied, it is anticipated this sample size will be sufficient to uncover the breadth and depth of participants' experiences (Guest et al., 2006; Thorne, 2016). A Dominican research assistant completed participant recruitment.

Interviews

Recognizing the researcher is the instrument in qualitative descriptive studies, (Xu & Storr, 2015) one female bilingual (English/Spanish) nurse scientist (SS) trained in qualitative research methods and global public health, who has substantial experience working with the adult PLWH in the Dominican Republic, conducted the interviews in Spanish.

We acknowledge her positionality as a white woman, academic, and non-Dominican may have influenced what participants shared during interviews (Manohar et al., 2017). However, the interviewer (SS) has worked at the clinical site for nearly a decade as a student, volunteer, and employee and has substantial experience with the culture and local linguistic nuances. In addition, she implemented interview techniques such as practicing awareness, using accepting body language, and verifying understood content to create an open, non-judgmental, and supportive environment to encourage participants to freely and honestly explore their feelings and experiences (Basberg Neumann & Neumann, 2018). She had no relationship with participants prior to interviews.

Semi-structured Interview Guide. The interviewer used a semi-structured interview guide to lead interviews, which were audio recorded with participants' consent, and professionally transcribed to produce verbatim transcripts. Our interview guide followed best practices for the development of a line of inquiry that included: (1) internal testing by the research team; (2) expert assessment by specialists outside the research team; and (3) field-testing with potential participants (Kallio et al., 2016). We included seven of the eight open-ended questions recommended by Kleinman to elicit details of explanatory models (Kleinman et al., 1978) adapted for our clinical context and added four clarifying questions for a total of 11 questions in the guide. We omitted Kleinman's question, "What do you call your problem? What name does it have?" because HIV is a well-defined, frequently used, and acceptable term in the Dominican Republic. To test this assumption, we coded any language participants used to talk about HIV during analyses, which led to analysis of 12 questions associated with Kleinman's framework (Table 1).

Data Analysis

Two bilingual researchers, SS and GS, coded transcripts using conventional directed (manifest) and inductive (latent) content analysis. GS is a non-Dominican Latina woman and native Spanish-speaker who was raised and educated in the United States but has also lived and worked in the Dominican Republic. Analyses were conducted in Spanish to assure consistency with participants' intended meaning and original wording (Sandelowski, 2000). Coders first read through transcripts to immerse themselves in the data (Creswell, 2013). They then conducted directed coding in which manifest codes reflecting the components of Kleinman's framework were operationalized and identified in the transcripts. Inductive coding was performed to identify latent codes that emerged from the remaining transcript text using an iteratively developed codebook (Graneheim & Lundman, 2004; Kleinman et al., 1978; MacQueen et al., 1998). To create the codebook, coders independently coded initial transcripts and then met to compare codes; these codes served as the initial codebook which guided

Table 1. Questions to Elicit Details of Explanatory Models (Kleinman et al., 1978).

KLEINMAN'S questions to elicit details of patients' explanatory models	Adapted question and additional clarifying questions
1. What do you call your problem? What name does it have?	Not included in questions but coded for in analyses.
2. (etiology) What do you think caused your problem?	What do you think caused your HIV, or how did you get the virus?
3. (time of onset) Why do you think it started when it did?	Why do you think it started when it did? Or, why did you come to the clinic to get an HIV test? 3a. Is there a reason you got HIV at that specific time in your life?
4. (pathophysiology) What does your sickness do to you? How does it work?	What do you think HIV does to your body? Or, how does HIV work?
5. (course) How severe is it? Will it have a short or long course?	How severe is HIV? 5a. How long will it last?
6. What do you fear most about your sickness?	Does anything scare you about having HIV?
7. What are the chief problems your sickness has caused for you?	What are the main problems HIV has caused in your life?
8. (treatment) What kind of treatments do you think you should receive? What are the most important results you hope to receive from treatment?	What do you think of the medications that they give here in the clinic? Do you do anything to manage HIV besides take the medications provided here? Which treatments are the most important? 8a. What results do you expect from taking your medications? 8b. How long will you be taking your medications?

Note. The five major components of explanatory models are indicated in parentheses next to the corresponding question.

subsequent coding. Discrepancies in coding were resolved by discussion until consensus was achieved (Graneheim & Lundman, 2004; Sandelowski, 2000). Cross-cutting themes were identified through this coding process. NVivo Qualitative Data Analysis software was used to manage the data (QSR International, 2020). Representative quotes of main findings were selected for this article and translated into English by SS and confirmed by GS.

Qualitative Rigor. We followed validated techniques to enhance rigor with a focus on establishing trustworthiness of findings (Guba, 1981; Thomas & Magilvy, 2011). Credibility was enhanced via prolonged engagement with participants during their nine-month enrollment in the parent study, frequent peer debriefings, and member checks (Creswell, 2013). To address transferability, we provide a thorough description of our participants and several detailed exemplar quotes to demonstrate the richness of the data (Guba, 1981; Richards & Hemphill, 2018; Thomas & Magilvy, 2011). Our use of a codebook fostered dependability (Richards & Hemphill, 2018; Thomas & Magilvy, 2011). Confirmability was achieved through an audit trial to document decisions about the analysis (Richards & Hemphill, 2018).

Ethical Approval

The Columbia University Irving Medical Center Institutional Review Board and the Consejo Nacional de Bioética en Salud (CONABIOS), the ethical review committee in the Dominican Republic, approved this study under protocol numbers AAAR9023 and 016-2018, respectively. All participants completed written informed consent.

Results

Twenty-six participants completed interviews, which lasted a mean of 44.2 minutes (range 21–70.2). Participants were 50% female, 96% Dominican, and had a mean age of 42.5 years \pm 9.41 (range: 26–65 years) (Table 2).

Findings From Directed Content Analysis

In this section, we present the results of the directed (manifest) content analysis of key questions from Kleinman's explanatory model framework. A list of the subcodes and associated exemplar quotes from each question can be found in Supplemental Table 1.

What do you call your problem? What name does it have? Participants referred to HIV in many ways. Several simply said "HIV," while others used words such as, "it" or "this thing." A few participants referred to a "virus" or "the virus," while others called HIV their "illness," "condition," or "infection." A few participants used the words HIV and acquired immunodeficiency syndrome (AIDS) interchangeably, while several articulated there is a clear difference between the two. Some participants used more negative expressions to describe HIV. For example, one called HIV "el quebranto" (37y, Female) which translates to "the thing that breaks you," or "the devastation."

What do you think caused your HIV, or how did you get the virus? Many participants did not know how they got the virus and never suspected that they had HIV. Several indicated they became infected because they were "not taking

Table 2. Demographic Characteristics of Study Participants (N=26).

Characteristic	n (%)
Gender identifies with	
Male	13 (50)
Female	13 (50)
Married or in a stable relationship	
Yes	9 (34.6)
No	17 (65.4)
Country of birth	
Dominican Republic	25 (96.1)
Haiti	1 (3.9)
Currently resides	
City of La Romana	13 (50)
Another city	12 (46.2)
Countryside	1 (3.9)
Education	
No formal education	2 (7.7)
Some primary school	9 (34.6)
Finished primary school	1 (3.9)
Some high school	8 (30.8)
Finished high school	4 (15.4)
Any school past high school	2 (7.7)
	Mean (\pm SD)
Age (years)	42.5 (\pm 9.4)
Monthly household income (RD\$*)	13,727 (\pm 16,064)
Average number of people living in the household	2.4 (\pm 1.2)
Time living with HIV (Years)	6.4 (\pm 6.1)
Time attending the clinic (Years)	5.9 (\pm 6.2)

*At the time of data collection, 13,727 Dominican Pesos (RD\$) was equal to USD\$274.54.

care of themselves,” or were “*careless*” (e.g., having condomless sex). Other participants provided specific details regarding the mode of transmission or precise person who infected them.

Why do you think it started when it did? All participants remembered when they first received their diagnosis, but most were unsure of when they contracted HIV. When asked why they decided to get tested, most indicated that it was coincidental to seeking care for another medical concern, symptoms they were experiencing, or pregnancy, while others knew they had been exposed to HIV or were following recommendations from friends or family members to get tested.

Is there a reason you got HIV at that specific time in your life? Most participants indicated there was not a specific reason. Other participants indicated the timing of their infection was related to their lifestyle choices, coincided with another event such as the birth of their child, or that the timing of their infection was part of God’s plan.

What do you think HIV does to your body? Or, how does HIV work? Many participants indicated the virus’s action in the body depended on how well you take care of yourself. This

care included taking your HIV medications exactly as the doctor prescribes, eating healthy, and not “*pasando malas noches,*” which directly translates to “passing bad nights” and refers to having late, wild, and/or drunken nights. Some participants described the action of HIV inside the body with scientifically precise explanations, while others mentioned their physical symptoms. A few participants had very negative comments regarding the function of HIV, such as, “*it destroys.*” Others communicated they do not think HIV does much “*inside*” of them or simply did not know.

How severe is HIV? Participant responses regarding disease severity varied greatly, with some saying it is not serious at all and others saying it is extremely serious. Similar to question four, most participants clarified that severity of HIV depended on how well you take care of yourself.

How long will it last? While some did not know how long HIV “lasts,” others indicated that the infection would last forever (i.e., until death). The most common response was that only God knows. Other responses indicated that HIV duration is idiosyncratic, depending on the person, how well they take care of themselves, and how well they respond to treatment.

What do you fear most about your sickness? Most participants indicated they were initially very fearful of HIV but found that their fear dissipated over the course of their illness and once they accepted their diagnosis. Participants who still felt fear stated they were afraid of dying or of a premature death. Others felt scared about being in relationships or having children, expressing concern that they would pass HIV to those individuals. Participants were also afraid someone would disclose their diagnosis, that they would experience negative physical manifestations of the disease (e.g., wasting), and/or would experience rejection or discrimination because of their infection.

What are the main problems HIV has caused in your life? Participants encountered a wide variety of problems from having HIV; of which, the most common was not being able to find a job. Additionally, most had experienced rejection from their family or loved ones and/or societal discrimination. Several were immensely impacted by depression and sadness associated with their diagnosis and others were too embarrassed, or too afraid, to have intimate partners. Some experienced guilt from having the virus or having infected someone else. Participants also indicated HIV prevented them from traveling or had altered their future plans.

What do you think of the medications that they give here in the clinic? Do you do anything to manage HIV besides take the medications provided here? Which treatments are the most important? Participants described antiretroviral therapy as healthy and as a good - or the best - treatment. They also provided evidence of the success of antiretroviral therapy, including that they were “still alive,” experiencing less symptoms, were stronger and healthier, able to live a normal life, and had lower viral loads. Some participants also indicated positive results by saying they wanted to keep taking their medications so they can keep living for their families or loved ones, especially their children and/or grandchildren. Although many indicated they use home remedies, most participants denied their use for HIV. Most also denied knowing about or believing in Vodou, a religious tradition with African roots common in Haiti and parts of the Dominican Republic. One participant, whose father was a Haitian “witch doctor” indicated Vodou is real with a pantheon of Gods that represent good and evil. He further articulated that he believes in a different God, not in the Gods of his father, and does not believe any God can cure HIV.

What results do you expect from taking your medications? Participants expressed optimism that adherence to their HIV medication would allow them to get better, regain their health, and/or have a longer and in some cases more meaningful, life. A few participants provided scientific responses regarding the results they hope to achieve by taking antiretroviral therapy, such as having an undetectable viral load.

How long will you be taking your medications? Consistent with expected benefits of taking antiretroviral therapy,

participants indicated they will take their medications always, for an eternity or until death, for as long as God wants or until God cures them, or until the doctors say they no longer need to.

Cross-cutting Themes from Kleinman’s Framework and Inductive Content Analysis

We identified four themes by synthesizing codes from Kleinman’s questions with the additional inductive (latent) content analysis of the interviews that reflected experiences and perceptions beyond Kleinman’s explanatory model framework.

Religiosity profoundly influences how HIV is understood and managed. Most participants expressed a deep faith in God and indicated their faith helped them to rationalize and accept their diagnosis, motivated them to keep going, and/or provided hope and a reason to keep living. For example, one participant said:

“At the beginning, I felt bad, very very bad, but now I feel better. I feel better because this is the sickness God wanted me to have. I have accepted it because He is the one who sends sicknesses, and one has to accept it because He is the one who knows” (44y, Female).

Another participant said, *“my God takes care of me, he still gives me more strength and more desire to live”* (65y, Male). Additionally, nearly all participants indicated they ask God for help managing their condition and shared their hope and belief that God performs miracles and will cure them. For instance:

“I always ask God to give me the strength to bear it [life with HIV], and if one day I experience a lot of discrimination, that he gives me the strength to bear that too. And if one day He thinks I deserve it, he can do a miracle and cure me of this indefinitely. I would be so grateful” (42y, Female).

Several participants communicated that their belief in God and belief in doctors/modern medicine were not mutually exclusive, but rather, complementary. For instance, one participant shared, *“if you are connected to the God from above and the God of the land [doctors in the clinic], you are safer”* (42y, Male). Another shared:

“Of course God is going to cure me!’ But I have to complete with the law of the land. The law of the land is to obey you all [clinicians]. . . He gave me His wisdom and I understood that I need to take my medications, come to my appointments, take care of myself, use protection. If it is His will that I am healthy, He will cure me through all of this, because God is all powerful” (33y, Female).

Initial receipt of an HIV diagnosis is a significant event that changes one’s life. The initial diagnosis was a deeply negative moment for most participants as they believed they were

going to die, were not expecting the diagnosis, or were worried about the stigma and discrimination they would face. As one participant shared, “it [initial diagnosis] was terrible, I felt everything. I wanted to die. I cried a lot. I did not want to eat. I didn’t sleep well, I was depressed” (42y, Female). Another recounted, “at the beginning, yes, I do not lie. . . I wanted to die, I didn’t want to exist, I thought they would discriminate against me” (33y, Female). Several discussed how the circumstances in which they received their diagnosis greatly contributed to their negative sentiments in that moment. For instance:

“No, he [the doctor] did not tell me [of the diagnosis], he told my mother first. . . and she did not take it very well. I told the doctor if my mother would have died, it would have been his fault, he should have told me first” (35y, Male).

Despite their initial devastation, most participants indicated that they learned to accept, and live with, the diagnosis over time. One participant shared, “now I have to live a calm life, this really influenced me a lot because, before I lived very. . . [wild], but now I have to live eating well and taking my medications as calmly as I can” (44y, Female). Notably, one participant was very relieved and excited to receive the diagnosis because he had been suffering from a long-term leg injury that would not heal. In discovering he had HIV, he started taking medication and improved his health, which led to his leg healing.

HIV changes relationships and interactions with others. Many experienced rejection and discrimination from friends and family members because of their diagnosis. As one participant shared, “I tell her [sister] I am going to the bathroom and she says to me, ‘look, here is the bleach, there is the other thing, clean the toilet for me. . .’ I do not like the way she treats me” (48y, Female). Because of the associated fear and embarrassment, several participants felt they could not disclose their status and thus, were always keeping a secret. As one participant said, “I have to hide, it is a second life. I have to carry HIV alone. Only here [in the clinic] do I talk about this [HIV]. When I get home, it is different” (31y, Female). Another participant said:

“I don’t want them [anyone] to see me, I come [to the clinic] disguised in many forms, I wear wigs, because I am embarrassed. . . none of my friends or family know [about HIV diagnosis], just the clinic. . . I think I will take this with me to the grave because you know families can cause problems, sometimes they discriminate, or keep you at a certain distance” (42y, Female).

Several participants specified that their diagnosis changed their romantic relationships. Some had positive experiences such as finding their loved ones still accepted and supported them, which gave them strength and motivation. As one said, “when I told her this [HIV diagnosis], she gave me her support, she said there is no problem because of this, that

she wasn’t going to leave me and she has stayed with me” (31y, Male). Another shared:

“I have a girl who knows what I have [HIV] and she loves me a lot, it doesn’t matter to her what I have. When we have relations, we use protection because I take care of her. She loves me a lot and says she wants to be with me no matter what. This gives me a lot of strength to keep going, you know, fighting and wanting to live. . . What kills you is when they walk away or turn their back on you and you feel alone, like you don’t have anybody” (30y, Male).

Other participants had either lost or experienced difficulties with their partner because of their diagnosis. For example, one woman who had contracted HIV because of her husband’s infidelity said, “It was very difficult [initial diagnosis], in fact, this brought our separation. When I found out about this, I never thought about being his wife again” (44y, Female).

Participants who were not in relationships discussed how their conversations around safe sex with new partners changed after their HIV diagnosis and shared that they are now more cautious and only have protected sex. Others indicated being afraid and refused the idea of new relationships or romantic partners all together. For example, one participant shared, “I am afraid to get married, very afraid. . . there are many men who when you say, ‘look, we are going to use protection,’ still say, ‘Ah! You are sick!’” (48y, Female) and another said, “I cannot enjoy the trust of a relationship, but that does not cause me a big problem. I have learned to live with it. . . I don’t want anyone to know about my devastation [HIV diagnosis]” (37y, Female).

The mind shapes the HIV illness experience. Participants described how the mind is the most powerful part of the body and that it directly influences peoples’ perceptions of HIV, if they accept the diagnosis, and how they live with it. One participant said:

“You know, the mind moves the whole body. . . there are people who are disabled, and they don’t give their mind to it, there are people who are blind, and they don’t give their mind to it, and there are people who have HIV, and they don’t give their mind to it. But, if they give their mind to HIV, they don’t last as long” (41y, Male).

Another believed HIV acceptance and management was easier for him because:

“Of the academic level that I have, because of studying and understanding . . . I know a little bit more about things. For those who do not have much understanding, they think this [HIV] is a thing from another world, that they can die tomorrow” (49y, Male).

Participants’ attitudes toward HIV varied greatly, ranging from not caring about their situation, to having fully accepted it and/or being glad they do not have a more serious condition,

to feeling awful, horrible, or sad/depressed. One participant said, *"I am going to tell you something, I would rather have HIV than cancer, than a tumor"* (29y, Female), another shared, *"up until now, I feel fine, I feel the same energy, the same strength"* (35y, Male), while another indicated, *"I still feel dejected and all that. It is like I still do not believe that I can live like this, I do not believe it. . . I do not feel anything good"* (48y, Female). Some participants revealed that their feelings toward HIV fluctuate. For instance:

"Sometimes one feels bad, sometimes one feels good. 'What is the part that is good?' When you are taking your medications and maintaining your self-esteem high. . . the other part is sometimes when you think 'how did I get this?' And I fall into depression thinking, 'oh my God, I am going to die, I am going to last a certain number of years, and then at any moment I can die.' Another thing is the discrimination and all that. Those are the parts that are bad" (42y, Female).

When asked, participants who had accepted the diagnosis found benefits to living with HIV, such as having met good people at the clinic, being able to teach others about HIV and other sexually transmitted infections, discovering which of their friends and family truly loved them, and living better lives. In most cases, a "better life" indicated they were healthier, less "wild," and take better care of themselves. For example, *"I will tell you, the only benefit is now that I know I am like this, I am like calmer. I am more careful. I am not crazy in the street like before"* (31y, Male). Participants who demonstrated less confidence and acceptance, however, felt strongly that there are not any benefits to having HIV. For example, *"I don't think there are any benefits because this brings sadness to people"* (44y, Female).

Several participants mentioned not overthinking was critical to living a normal and healthy life. They shared that when people *"give their mind to"* HIV or think about it too much, it can be rapidly detrimental. As one participant said, *"the only thing there is, is to confront reality. If you confront reality, you will live for 1,000 years. But if you are with this thought [HIV] all the time, well you aren't going to last even 15 days"* (41y, Male). Another commented,

"when people give their mind to HIV, they destroy their mind and their peace. If you do not think about it and take your medications calmly, you will realize you do not have anything. If you start dwelling on it, there you go getting depression, getting inconsolable, and from there you go down, down, down" (40y, Female).

How Gender Influenced Participants' HIV Experiences

Overall, responses from male and female respondents were quite similar. Of 61 subcodes corresponding to the 12 coded questions associated with Kleinman's framework, only nine did not contain responses from both male and female

participants (Supplemental Table 1). The most noteworthy difference was that only male participants indicated HIV had not caused them any life problems. Conversely, only women reported problems such as having to keep their diagnosis a secret, having changed their life plans, and not being able to travel. In addition, only women reported contracting HIV from forced sex or feared disclosure of their status either directly by a confidante or indirectly through physical manifestations of the disease. Also, only women reported not knowing how HIV works in the body and that they received HIV at a specific time because it was God's plan.

An Explanatory Model of HIV in the Dominican Republic: Bringing It All Together

Through our inductive and deductive analyses, an explanatory model of the experience of living with HIV in the Dominican Republic emerged. This deeply personal phenomenon begins with the initial diagnosis, which is generally a tremendously impactful, devastating experience as those receiving this news are instantly afraid not only for their own life, but also for the lives of their loved ones. Additional sentiments such as guilt, betrayal, loss, and rejection are also common during this period. If people can receive their diagnosis in a supportive environment and can choose who learns about their diagnosis, and when, it can alleviate some of the initial impact. Over time, as people attend medical appointments, adhere to antiretroviral therapy, and process their situation, most come to accept their diagnosis and adapt to their new life with HIV. Though fears of rejection or discrimination, unwanted disclosures, and work and/or relationship stressors are ever present, people learn to live normal lives that are at a minimum tolerable and at best, enjoyable. A person's mental state including inherent intellect and resiliency, outlook on life, self-esteem, and level of education also contribute to their ability to adapt to, and live with, an HIV diagnosis. Laced through this experience is a deep belief in God and His powers. Through this profound connection, PLWH find a justification for their situation, support and guidance to live with it, and perhaps most importantly, hope, which motivates them to live long, healthy, and fulfilled lives with friends, family, and romantic partners.

Discussion

We constructed an explanatory model of HIV infection among adult PLWH in the Dominican Republic. Although participants provided unique perspectives, there were many commonalities to their lived experiences, all of which confirmed HIV is a complex chronic condition that presents numerous social, physical, and mental challenges. Pervasive stigma and discrimination presented the most potent obstacles to our participants achieving health, obtaining work, and finding or maintaining healthy relationships with friends, family, and/or romantic partners. However, a strong

belief in God, trust in the health care providers at the clinic and antiretroviral therapy, as well as strong interpersonal relationships motivated PLWH to overcome barriers to live normal lives.

Our findings both substantiate other studies on the illness experiences of PLWH and provide new insights, especially in the cultural context of the Dominican Republic. For example, our participants indicated the trauma of receiving their diagnosis slowly eased over time with most indicating they were eventually able to live normal lives if they adhered to prescribed medications. This process, referred to as “identity reformation” or “identity reconstruction,” is when individuals essentially rebuild their identities after receiving the diagnosis of a stigmatizing, or chronic, condition (Aryal, 2018; Ho & Goh, 2017; Laws, 2016). Identity reformation allows people to confront their initial fear and/or embarrassment regarding their diagnosis and establish a new sense of self that promotes function and disease management (Aryal, 2018; Ho & Goh, 2017; Laws, 2016). The presence of this transformation has been observed in other Dominican PLWH (Barrington et al., 2018) as well as Dominicans living with type 2 diabetes (Sadeghzadeh et al., 2021). How quickly individuals complete their transformation likely depends on individual factors such as their frame of mind, self-esteem, level of social and professional support, and/or their level of religiosity. This provides an important contribution to the literature, as clinicians can use this culturally relevant insight to lay the framework for the reformation process by providing professional support as well as information about available resources, disease severity, and expected duration of treatment to patients near the initial diagnosis. Additional research is needed, however, to develop and understand effective methods to help individuals successfully complete the identity reformation process (Ho & Goh, 2017; Laws et al., 2020).

According to participants, a person’s mind is the most important factor in deciding if, when, and how they accept their diagnosis and if they choose to adhere to prescribed medications. This finding is similar to studies among female sex workers living with HIV in the Dominican Republic that found perceived and actual mental health status, including anxiety and depression, influence engagement and self-management (Kerrigan et al., 2021; Zulliger et al., 2018). In our study, participants clearly indicated that “*giving your mind to*” HIV quickly leads to an unhappy life, non-adherence to antiretroviral therapy, and in some cases, rapid death. This concept of “thinking too much” has been identified in the Dominican Republic (Sadeghzadeh et al., 2021), Haiti (Kaiser & McLean, 2016), and in several other sites worldwide (Kaiser et al., 2015). Although translated and experienced differently across languages and cultures, the underlying sentiment of this concept refers to pervasive and anxious thoughts, and may be a proxy for depression (Kaiser et al., 2015; Lewis-Fernández & Kirmayer, 2019). Frequent reports of “thinking too much” led to its inclusion as a

cultural concept of distress in the Diagnostic and Statistical Manual of Mental Disorders; 5th edition (DSM-5) (American Psychiatric Association, 2013). In the HIV context, “thinking too much” is associated with worse outcomes such as suboptimal treatment adherence (Kidia et al., 2015), hypertension exacerbation (Manavalan et al., 2020), and increased mental health diagnoses (Andersen et al., 2015). To help patients manage repetitive thoughts, culturally relevant support, particularly at the time of the initial diagnosis, is needed. Additional strategies that can help PLWH manage overthinking include mindfulness training (Scott-Sheldon et al., 2019), support groups (Nakimuli-Mpungu et al., 2014), interpersonal group therapy (Asrat et al., 2020), social cohesion strategies (Carrasco et al., 2017), and cognitive-behavioral therapy (Brandt et al., 2018).

Like our participants, other PLWH have reported HIV is preferable to conditions such as diabetes, hypertension, and cancer. For instance, Stonbraker et al. identified the same sentiment in a separate study conducted at the same research site in the Dominican Republic (Stonbraker, Arcia, et al., 2017). Sadeghzadeh et al., found that Dominican participants living with type 2 diabetes felt diabetes was worse than HIV because of the extensive lifestyle modifications that diabetes requires for successful management (Sadeghzadeh et al., 2021). PLWH living outside the Dominican Republic express this sentiment as well. For example, in a Nepalese study, participants differentiated between early death from cancer and the chronic nature of HIV and described diabetes and hypertension symptoms and associated lifestyle changes as more unpleasant than those associated with HIV (Aryal, 2018). In a US study, participants indicated that in most cases HIV can be simply managed with one pill a day, while hypertension or diabetes require complex medication regimens and substantial lifestyle changes (Monroe et al., 2013). Similarly, Malawians reported hypertension is equal to, if not more severe than, HIV due to its sometimes unexpected complications, such as strokes (Hing et al., 2019). Our findings contribute to this growing body of evidence regarding the reconceptualization of HIV as a chronic manageable condition. Health care professionals can use this information to provide support to their patients living with HIV, as helping individuals to understand HIV is not a “death sentence,” but rather a manageable condition may encourage antiretroviral therapy adherence and support the identity reformation process among the newly diagnosed.

Many of the principal problems and fears reported by our participants were associated with HIV-related stigma and discrimination that limited their job opportunities and restricted travel. National and community level policy changes could mitigate effects of these stressors. While Dominican Law 135-11 (2011) prohibits HIV discrimination within the workplace, this is a widespread problem, especially in the tourism industry. Reinforcing infrastructure that allows for the anonymous reporting of violations coupled with more stringent monitoring of violations and enforced

penalties could have a meaningful impact on the lives of PLWH in the Dominican Republic. At the community level or within health care centers, providing resources to locate jobs that do not require HIV testing and assistance with applications and/or interview skills could further alleviate employment-related stressors. Additionally, although the United States' HIV-related travel ban ended in 2010 (United States Department of State, 2009), 48 countries/territories still have similar bans (Joint United Nations Programme on HIV/AIDS (UNAIDS) (2019). However, if PLWH knew that the United States and Europe (commonly desired destinations among Dominicans) do not ban travel for PLWH, it could reduce the stress or feelings of loss that come from believing one is no longer able to travel.

Another noteworthy point from this study is that our participants were very accepting of antiretroviral therapy and indicated they did not use, or in many cases had not heard of, alternative, traditional, or home remedies. This is contrary to previous studies that have identified some reluctance toward antiretroviral therapy, with preference for alternative or complementary remedies, among Latino populations, including Dominicans (Keese et al., 2012; Sobon Sensor, 2019). It is possible that there was a sample bias as our participants were attending a clinic for HIV treatment and were willing to participate in research or that social desirability prevented participants from endorsing nonbiomedical beliefs during the interviews. Interestingly, participants who discussed balancing their spiritual beliefs with the scientific views of the clinic indicated more willingness to adhere to antiretroviral therapy saying they were safer following the laws of "God in the sky and the Gods of the lands [clinicians]." This is similar to findings in Tanzania in which participants indicated belief in a miraculous cure but also willingness to initiate antiretroviral therapy, as it could be God's way of answering their prayers (Zou et al., 2009). This is another important finding that provides a substantive contribution to the literature, as nurses and clinicians can use this work to consider how they might incorporate traditional religious and/or spiritual views into their treatment plans to promote antiretroviral therapy adherence. This integration has been found to enhance trust and lead to better patient engagement (Flores et al., 2016) and may be especially important in the Dominican Republic, where varying Haitian and Dominican cultural and religious views have the potential to conflict with biomedical approaches. In this and other contexts where similar contradictions exist, health care providers can and should attempt to contextualize biomedical treatment as complementary to patients' beliefs to obtain this balance.

To effectively integrate traditional beliefs with current care delivery and more effectively meet the needs of this, and similar, patient populations, nurses and clinicians can—and should—implement person-centered care strategies. Person-centered care is "a holistic (bio-psychosocial-spiritual) approach to delivering care" which clinicians can use to better understand their patients and encourage them to actively

participate in their treatment (Morgan & Yoder, 2012). When clinicians effectively incorporate person-centered care into care delivery, especially in HIV-care, it can lead to better engagement in care, patient-provider relationships, shared decision-making, self-management, retention in care, and treatment adherence, all of which lead to better health outcomes (Flores et al., 2016; Jaiswal et al., 2018; Park et al., 2018; Rathert et al., 2013).

This study had limitations. Social desirability bias may have led to responses that participants thought the researcher wanted to hear (Krumpal, 2013; Latkin et al., 2016). To avoid this, we implemented techniques such as generating rapport, explaining why truthful answers are needed, guaranteeing privacy, and normalizing risk behaviors (Krumpal, 2013; Latkin et al., 2016). Also, we recruited from a single clinic which may limit generalizability. However, member checks corroborated many of our findings, as did the results from other studies conducted at our site and in similar settings, which supports our findings and enhances transferability. Additionally, we did not collect data regarding the high-risk subpopulations our participants pertained to (e.g., men who have sex with men, sex workers etc.), if any, so we were unable to perform subgroup analyses. Future research should explore the experience of HIV through these different lenses.

Conclusions

Adult PLWH in the Dominican Republic describe the experience of living with HIV as an initially devastating event that they adapt to over time, with many indicating they live normal, healthy lives. Individuals with a more positive outlook, an appreciation for both biomedical and spiritual approaches to disease management, and greater social support may be able to complete this transformation earlier or more easily. Despite successful adaptation to their diagnosis, social and societal factors stemming from stigma and discrimination can be a constant source of stress for PLWH. Our study demonstrates the importance of support at the time of initial diagnosis and offers insight into the most desirable information/resources of patients, including the severity and duration of the diagnosis and treatment, rights to employment, and ability to travel. By understanding and respecting cultural beliefs related to illness experiences and treatment preferences and incorporating this understanding into their care, nurses and other clinicians are well-positioned to provide the culturally meaningful person-centered care that establishes the enduring, trusting, and mutually respectful partnerships with patients that lead to better health.

Acknowledgments

The authors would like to thank our participants who were willing to share their very personal experiences to benefit others. We would also like to thank the staff at the clinic who are always tremendously supportive of our research. Without them, this work would not be possible.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The research reported in this publication and the first author were supported by the National Institute of Nursing Research of the National Institutes of Health under award numbers K99NR017829 and R00NR017829. The mentorship of RS was supported by the National Institute of Nursing Research of the National Institutes of Health under award number K24NR018621. The contributions of SB, TRC, and MG were supported by the Precision in Symptom Self-Management Center which is supported by the National Institute of Nursing Research of the National Institutes of Health under award number P30NR016587. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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Supplemental Material

Supplemental material for this article is available online.

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