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What the rest of the world should know about HIV: Perceptions from adults living with HIV in the Dominican Republic

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HIV-related stigma is a pervasive social phenomenon with an extensive global reach that can lead to high disease burdens and poor health outcomes by reducing the likelihood of getting tested, seeking and adhering to treatment, or disclosing status to sexual partners or others (Stangl, Lloyd, Brady, Holland, & Baral, 2013). Numerous interventions to address stigma have been designed and conducted worldwide, but are rare in the Caribbean (Sengupta, Banks, Jonas, Miles, & Smith, 2011; Stangl et al., 2013). In the Dominican Republic, the prevalence of persons living with HIV (PLWH) is 1.0% with around 66,000 individuals living with the virus (Joint United Nations Programme on HIV/AIDS, 2015). Stigma is a driving factor behind the HIV epidemic in the Dominican Republic, as homosexuality, sex work, and other social conditions are heavily discriminated against, leading many to hide their status and avoid testing and treatment (Rojas, Malow, Ruffin, Rothe, & Rosenberg, 2011). Steps must be taken to address stigma and discrimination, which are well documented, ubiquitous, and consistent barriers to appropriate health care in the Caribbean (De Boni, Veloso, & Grinsztejn, 2014). Stigma reduction can benefit PLWH by improving

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prevention behaviors, leading to earlier testing and treatment, and improving the quality of health care they receive (Sayles, Ryan, Silver, Sarkisian, & Cunningham, 2007).

Strategies to reduce HIV-related stigma vary based on intervention aims and target populations and, although many have been shown to be effective, the quality of the studies has been questionable and much room for growth in this complex research area has been noted (Sengupta et al., 2011; Stangl et al., 2013). Suggestions from the research have included expanding the scope of interventions to reach multiple societal levels and wider populations (Brown, Macintyre, & Trujillo, 2003; Sengupta et al., 2011; Stangl et al., 2013). Similarly, the authors of one recent study conducted in the Dominican Republic found that educating the larger community was a necessary component of HIV-related stigma reduction (Rael et al., 2016). Another recent study in the Dominican Republic considered using social cohesion as a method to reduce stigma by combating societal norms (Carrasco et al., 2016). Formative research that seeks generalizable knowledge to inform the design of stigma reduction interventions is needed and must include the viewpoints of PLWH (Nyblade, Stangl, Weiss, & Ashburn, 2009; Sengupta et al., 2011). Unfortunately, PLWH in constrained resource areas with limited education backgrounds may not be able to contribute to the research agenda because of their geographic location or insufficient efforts of the scientific community to involve them. Providing PLWH a channel to share experiences with those outside their social spheres can allow others to learn and enable PLWH to participate in the research agenda related to stigma reduction activities. Thus, the purpose of our study was to explore what PLWH in the Dominican Republic want the rest of the world to know about HIV and to identify the messages that this population felt were the highest priorities to share.

Methods

Study Setting

Our research took place at Clínica de Familia in La Romana, Dominican Republic, a primary care clinic located in the southeast Dominican Republic. The Clinic was founded in 2004 through the International Family AIDS Program (IFAP) Global Health Program at Columbia University (<http://www.cumc.columbia.edu/education/ifap-global-health-program>). It maintains an affiliation with Columbia and is independently licensed by the Dominican Ministry of Health to provide outpatient health care. In 2015, free HIV testing, treatment, and support were provided to about 1,800 PLWH (21% of the patient population) in more than 17,000 visits of varying types (Clínica de Familia, 2015). Patients who attended the Clinic lived in urban and rural areas across the eastern provinces of the country.

Ethical Approval

All study activities were approved by Columbia University Medical Center's Institutional Review Board and by the ethical conduct of research committee in the Dominican Republic, Consejo Nacional de Bioética en Salud. Verbal informed consent was obtained from each participant.

Design

Our study used a cross sectional design in which surveys were administered in Spanish via semi-structured interview (development reported elsewhere; Stonbraker, Castillo, et al., 2016), with adults attending the Clinic in fall 2015. All patients who met eligibility criteria (Spanish-speaking, older than 18 years of age, and living with HIV infection) who presented at the clinic during the study period were approached about the study by clinic providers. Those interested in participating were referred to the on-site researcher who further explained the study and completed interviews if participants consented, thus yielding a convenience sample.

Survey Item

This brief research report focuses on a single item from a larger study about the health information behaviors of PLWH, the results of which are reported elsewhere (Stonbraker, Befus, Lerebours Nadal, Halpern, & Larson, 2016; Stonbraker, Castillo, et al., 2016). During survey administration, we asked the question, *What things do you want your friends, family, or members of the community to know about HIV?*, with the additional prompt, *Could you please tell me two things that you wish the rest of the world knew about HIV?* Participants were encouraged to provide at least two responses and up to three were recorded for this item.

Data Analysis

Responses to the survey item were analyzed in Spanish by a bilingual nurse researcher using conventional content analysis. In this inductive qualitative approach, codes are allowed to emerge from the data and then grouped into categories according to meaning (Hsieh & Shannon, 2005). Codes and categories were reviewed and confirmed by a second bilingual nurse researcher experienced in conventional content analysis. Discrepancies were discussed until consensus was reached. Results were translated into English for the final manuscript. Translations were completed by one bilingual researcher and were then verified by two additional bilingual researchers.

Results

Participant Characteristics

As previously reported (Stonbraker, Befus, et al., 2016; Stonbraker, Castillo, et al., 2016), the average age of participants ($N = 107$) was 40.8 years (range = 19 – 75) with an average time living with HIV of 7.7 years (range = 0.17 – 20). The majority of participants self-identified as heterosexual (88.7%), 2.8% indicated they were men who have sex with men, 2.8% were bisexual, 1.8% were transgender women who have sex with men, and 3.7% reported that they were no longer sexually active. The highest level of education was some high school or higher for 32%, all or some primary school for 57%, and 11% reported having no formal education at all. Most were female (60%) and lived in La Romana (58%), while the rest lived in another city (31%) or outlying areas (11%).

Participant Responses

During interviews, 87 of the 107 participants provided 162 responses regarding what they would like the rest of the world to know about HIV. Individuals who elected not to give an answer to this question expressed how the world had not done anything for them, so why should they do anything for the world? Some participants also mentioned that they did not want to share for fear someone would find out their diagnosis despite assurances of confidentiality. Participant responses fell into five categories: (a) how HIV may be transmitted and prevented ($n = 68$ responses), (b) general information regarding HIV ($n = 34$ responses), (c) The experience of having HIV ($n = 23$ responses), (d) get tested and get treated ($n = 19$ responses), and (e) do not discriminate against those who have HIV ($n = 18$ responses). Representative quotes of main ideas from each category are presented in Table 1. Most respondents (83%) expressed feeling that they were living a normal life as long as they took their medications, while a few (17%) expressed that having HIV was a grave, deteriorating experience ($n = 15$). Respondents from each of these two groups were represented in each of the five main categories discussed below.

How HIV may be transmitted and prevented—Participants commonly mentioned that they want people to know more about HIV transmission and prevention so they always protect themselves, as participants did not want the same thing to happen to others. Similarly, participants emphasized that you always have to protect yourself and be careful of who you trust because it is not obvious who has HIV. Participants were eager for others to know more about transmission so that people would not be so fearful about being near them. Specifically, they want people to know that the virus is not as easy to get as people may think. For example, one individual emphasized that one cannot contract HIV from hugging or shaking hands.

General information regarding HIV—Participants responded that they wanted the rest of the world to know more about HIV in general. As one participant said, people should know “todo sobre el VIH (everything about HIV).” They wanted people to understand that HIV is a real condition, it exists, it is dangerous, and that no one wants to have it. Participants also shared that HIV was not immediately fatal like it used to be. They also emphasized that it was just a virus, similar to or possibly less harmful than, other diseases such as diabetes or cancer.

The experience of having HIV—Participants communicated that having HIV was isolating and that it was not something that people asked for, nor was it something that anybody wanted or deserved. It could be painful and might literally be a fight for life itself. Yet, participants consistently stressed that HIV was a “normal” condition and that they could live long, healthy lives provided they were adherent to a medication regimen. Some wanted to communicate that living with HIV was harmful to the body but emphasized that you had to move forward and fight in order to stay alive.

Get tested and get treated—Participants voiced the importance of knowing where to access treatment in case of infection. They also mentioned that if you get HIV, you should go straight to Clínica de Familia or to a hospital, as physicians could help. They emphasized

the necessity of early testing and treatment because it was better to know your status and seek treatment than to not know. Multiple participants discussed how important it was to listen to your physicians because if you took your medications as prescribed, you could live a long, normal life.

Do not discriminate against those who have HIV—Participants expressed numerous concerns about the stigma and discrimination that they had experienced from their friends, family, and community. Many indicated that they wanted the rest of the world to understand that the general public looks at PLWH very negatively and as multiple participants pointed out, “no tiene que ser así (it does not have to be like this)”. They also expressed wanting the rest of the world to have less fear of PLWH and to not treat them so poorly.

Discussion

When given the opportunity to share experiences and opinions with the rest of the world, most participants were eager to communicate their ideas. As health care providers, it is our responsibility to listen to patient perspectives in order to frame conversations that would directly address concerns and tap into motivations to appropriately guide adherence and other self-management activities. Participant responses fell into five interrelated categories, the main thrust of which was that PLWH in the Dominican Republic want the rest of the world to know and understand more about the virus in general, its transmission, and the importance of timely testing and treatment. They wanted people to protect themselves, to not be so fearful when around PLWH, and to not discriminate. These categories could be used to involve the words and opinions of participants to further advance clinical communication, stigma reduction research, and targeted intervention design. As has been previously discussed (Nyblade et al., 2009; Stangl et al., 2013), the next steps in this research trajectory must be to consider methods to scale up stigma reduction interventions across multiple societal levels in order to reach the broader community.

Unfortunately, a duality exists in how best to provide education regarding HIV to the rest of the world. A possible drawback to normalizing the condition is that widespread acceptance would hinder prevention efforts as beliefs regarding the efficacy of highly active antiretroviral therapy have done (MacKellar et al., 2011). Despite this drawback, stigma reduction can have numerous positive health benefits for PLWH, including improved prevention and treatment behaviors, reinforced positive values such as courage and resourcefulness, as well as improved health care services (Carrasco et al., 2016; Sayles et al., 2007; Stangl et al., 2013). Also, when communities accept HIV as a chronic condition like many others, there might be less discrimination toward PLWH, which would generate numerous physical and mental health benefits for these individuals (Sengupta et al., 2011).

For some participants, the opportunity to communicate with the rest of the world was an empowering experience as they were rarely, or may never have been, asked about their thoughts. That the majority of those who responded to this question chose to highlight the need to inform others about prevention was in direct contrast to individuals in the study who chose not to respond. That almost 20% of participants chose not to share anything with the rest of the world because of profound feelings of betrayal and fear of discovery, even in a

confidential situation, emphasized the extent and impact of the negative experiences with which these individuals must cope. Health care settings that provide care to PLWH should consider providing opportunities to their patients to share experiences in meaningful ways, such as in safe collected spaces or in group therapy sessions, where their input and ideas are valued (Carrasco et al., 2016; Rael et al., 2016). Additionally, researchers and clinicians should further identify methods in which patient input can enhance education and generate positive change in wider society on topics such as stigma.

That participant responses generally fell into two categories, those who were more accepting of their condition and those who were more distraught from it, highlighted the different ways that participants perceived the diagnosis and indicated that some people may need more support services than others. Health care providers must remain vigilant to this while they work with PLWH. Furthermore, that a majority of the participants appeared to have reached an acceptance of the diagnosis by expressing that, with treatment, they could live a normal life just like any other person, was a testament to human resiliency and showed that effective support and treatment could lead to positive outcomes for PLWH.

There were limitations to our study. Participants were recruited using convenience sampling from a single clinic, and findings, therefore, may not be generalizable to other settings. Social desirability bias may have influenced participants to report the answers that they thought the interviewer wanted to hear and may have prevented them from sharing their actual sexual orientation. A strength of the study was that patients were given an opportunity to express themselves to the broader community in a confidential way. The Clinic will be using a selection of these quotes during sexual education classes with adolescents in schools near the study site to further enable the words of participants to reach the local community. Similarly, these quotes can help nurses, other health care practitioners, and community members to lead stigma reduction activities in ways that put the experiences of PLWH front and center.

Conclusions

Much of what PLWH in the Dominican Republic want others to know about HIV relates to education and awareness. They want the rest of the world to know more about the virus in general, including how it is transmitted and prevented, as well as where and how to get tested and treated. Through increased knowledge and understanding of the condition, it is the collective hope of these individuals that others avoid contracting the virus and that they seek testing and early treatment if necessary. Finally, many participants expressed that others should not discriminate against those living with HIV. The quotes and ideas from this study may be used to include PLWH perspectives in the formation of future research activities.

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Table 1

Representative quotes of main ideas from each category of responses in answer to the question: “What things do you want your friends, family, or members of the community to know about HIV?”

Original quote	English translation
How HIV may be transmitted and prevented (68 responses)	
Como protegerse - por ejemplo, no tener muchas parejas.	How to protect themselves – for example, do not have a lot of partners.
Que sepan todo de cómo protegerse.	That they know everything about how to protect themselves.
Que se cuiden para no caer en esto.	That people take care of themselves so they do not end up with this.
No pueden confiar en personas porque algunos pueden decir que estén bien sano pero en realidad tienen el VIH.	You cannot trust people because some can say that they are very healthy but, in reality, they have HIV.
Que el VIH no se pega con besos o comiendo juntos, solo en relaciones sexuales.	HIV does not spread through kisses or eating together, only in sexual relations.
Que se botan estas ideas que va a pegar fácilmente. Si alguien lo tiene y le da la mano no pasa nada.	That they toss out these ideas that it is easy to contract. If someone has it and they shake hands, nothing is going to happen.
Tener más precaución porque eso no es algo que se ve en la cara.	To be more cautious because this [HIV] is not something you see on someone's face.
Que deben protegerse con condones y usarlos siempre.	That they should protect themselves with condoms and always use them.
En cada relación sexual, hay que protegerse, debemos proteger uno al otro, así no hará más VIH.	In every sexual relationship, you have to protect yourself. We should protect one another, this way, there will be no more HIV.
General information regarding HIV (34 responses)	
Tienen que orientarse a que es VIH.	They have to acquaint themselves to what HIV is.
Necesitan saber que es una enfermedad inmunodeficiencia que no mata como otras enfermedades, no es como la muerte.	They need to know that it is an immunodeficiency disease that does not kill like other diseases, it is not like death.
Que se concienticen sobre el VIH. No tienen educación sobre el tema entonces hablan con la lengua desenfadado.	That they become more aware of HIV; they do not have education about the topic so they speak with a loose tongue.
VIH existe y es real.	HIV exists and is real.
Sepa que es un virus peligroso.	Know that this is a dangerous virus.
El VIH ya no tiene cara de muerte como antes.	HIV does not have a face of death like it used to.
Que nada más es un virus y la persona con este puede vivir por mucho tiempo.	That this is nothing more than a virus and a person can live with it for a long time.
Que el VIH no es algo extraordinario, como diabetes es peor.	HIV is nothing extraordinary, like diabetes is worse.
Todo, hay mucho que deben saber del VIH, hay gente que piensan que no tiene remedio y no es así.	Everything, there is a lot they should know about HIV, there are people who think there is not treatment and it is not like that.
The experience of having HIV (23 responses)	
Ahora aíslan las personas con el VIH, ni quieren hablar con ellos.	Now, they isolate people with HIV, they don't even want to talk to them.
Uno no pide por eso, es una lucha por la vida.	One does not ask for this, it is a fight for one's life.
Después que tú lo tienes es normal, como cualquier otra enfermedad. El cáncer es peor, duele y come el cuerpo.	After you have it, it is normal, like any other disease. Cancer is worse, it hurts and eats the body.
Que el VIH no es del otro mundo, es de aquí, no es tan terrible y es posible vivir con la condición.	That HIV is not from another world, it is from here; it is not so terrible and it is possible to live with the condition.
Tener VIH no mata si toman los medicamentos es una vida normal.	Having HIV does not kill, if you take the medications, it is a normal life.
Que el VIH se destruya el cuerpo.	That HIV destroys the body.
Get tested and get treated (19 responses)	
Que se chequean porque es mejor saber si lo tiene o no.	That they get checked because it is better to know if they have it or not.

Original quote	English translation
Que si se sientan alguna cosa que no es normal, que se chequean.	If they feel anything that is not normal, that they get checked.
La gente muere cuando no buscan ayuda. Necesitan saber dónde ir por si acaso, así que pueden buscar ayuda.	People die when they do not look for help; they need to know where to go just in case, then they are able look for help.
Que hacen el chequeo para ver en que estén. Si estén infectados, pueden tomar medicamentos y estar en tratamiento.	That they get tested to see their status, if they are infected, they can get treated and take medications.
El VIH no mata si te lleva su tratamiento pero debe venir a la clínica para saber y recibir medicamentos.	HIV does not kill if you follow your treatment, but you should come to the clinic to know and to receive medications.
Do not discriminate against those who have HIV (18 responses)	
Que no sean tan locos con las personas que tienen el VIH.	Don't be so crazy with the people who have HIV.
A veces te desmoralizan que tienes el VIH porque tú no tomaste la precaución.	Sometimes they demoralize you because you have HIV because you didn't take precautions.
Que no se rechazan, una persona puede quitarse la vida.	That they should not discriminate, a person could take their own life.
Que no tienen que tener miedo de las personas con el VIH.	That they do not have to be afraid of people with HIV.
Entienden mejor porque miran a una persona en el VIH muy malo y no tiene que ser así.	They need to understand better because they look at a person with HIV very badly and it doesn't have to be like that.