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Dominicanas Redefining HIV in San Pedro de Macorís

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Abstract

This study explored the social support among women impacted by human immunodeficiency virus (HIV) living in the Province of *San Pedro de Macorís, República Dominicana*. Social support is one way that social networks can influence health status. Social networks impact health behaviors and overall health outcomes which include infectious diseases, morbidity rates, and mortality rates. Social networks can promote health and minimize risky behavior: “cohesive, supportive networks may themselves blunt stressful experiences and enable people to resist risky behavior and maintain healthier choices” (Berkman, Kawachi, & Krishna, 2014, p. 248). Qualitative methods were used to explore how social support systems impacted the personal experience of women living with HIV. Each Dominican woman described her own moral trajectory ranging from non-acceptance of HIV as an incurable disease to acceptance of living with HIV as a health condition in everyday life. The thematic analysis indicates that social support was instrumental for each woman throughout her journey and process of coming to terms with her HIV diagnosis and taking control of her life. Family, God, the Clínica Esperanza y Caridad (Clinic) and the support group were forms of social support frequently expressed in their narratives and represented their social networks.

Keywords: social support, Dominican Republic, human immunodeficiency virus

Dominicanas Redefining HIV in San Pedro de Macorís

The World Health Organization (WHO) estimates 35 million people were living with human immunodeficiency virus (HIV) in 2013, and 50% of those infected with the disease are women (World Health Organization [WHO], 2013). The Dominican Republic (DR) has one of the highest HIV infection rates in the Western Hemisphere according to the most recent data from the Pan American Health Organization (PAHO) (2012). The United Nations Programme on human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS) states that the main form of HIV transmission in the Caribbean region has been through heterosexual relationships putting women at risk for acquiring HIV (UNAIDS, 2005).

Women bear most of the burden of disease associated with HIV/AIDS and other sexually transmitted infections (STI's); gender norms among other factors drive this global burden of disease (GBD) (Hawkes & Buse, 2013). According to 2010 data collected in the DR, an estimated 48,550 people are living with HIV/AIDS (Government of the Dominican Republic [GODR] and the US Government [USG], 2011). Although the HIV prevalence has stabilized between 0.8-1.1% for the general population, Dominican women have an almost three times greater HIV prevalence, 2.3%, when factoring in poverty (the lowest quintile) and four or less years of education (GODR USG, 2011). “Poor Dominicans comprise 36 percent of the general population and 48.4 percent of the HIV positive population”; uneducated women make up 8.3 percent of the population (GODR USG, 2011, p. 6). These statistics illustrate an urgent need for population health education, prevention and treatment of HIV/AIDS in the Dominican Republic.

Statement of Purpose

The purpose of this study was to explore the social support among women impacted by human immunodeficiency virus (HIV) living in the Province of *San Pedro de Macorís, República Dominicana*. Social support is one way that social networks can influence health status. Social networks impact health behaviors and overall health outcomes which include infectious diseases, morbidity rates, and mortality rates. Social networks can promote health and minimize risky behavior: “cohesive, supportive networks may themselves blunt stressful experiences and enable people to resist risky behavior and maintain healthier choices” (Berkman, Kawachi, & Krishna, 2014, p. 248). Qualitative methods were used to explore how social support systems impacted the personal experience of women living with HIV.

Literature Review

“Gender inequality damages the health of millions of girls and women across the globe. It can also be harmful to men’s health despite the many tangible benefits it gives men through resources, power, authority and control” (WHO, 2007, p. xii). The WHO Department of Gender, Women and Health (WHO DGWH) (2009) and the Women and Gender Equity Knowledge Network (WHO WGEKN) indicate that in comparison to men, women do not have equal access to quality health care services. Although, the life expectancy for women is higher than for men in most countries, the overall quality of life for women is lower. Some countries are working to provide women access to high quality health services. In other countries social, economic and political factors create barriers that decrease access to health services (WHO Department of Gender, Women and Health [WHO DGWH], 2009). Health equity and social determinants of health are influential factors in determining the health of women at local, national and international levels (Braveman & Gruskin, 2003; Braveman, Egerter, & Williams, 2010).

Health Equity is the “absence of systematic disparities in health between social groups who have different levels of social advantage/disadvantage that is wealth, power, or prestige” (Braveman & Gruskin, 2003, p. 254). To overcome barriers resulting from social disadvantages it is essential to have good health and wellbeing (Braveman & Gruskin, 2003). In theory, all people have the same opportunity to live a healthy life, but in actuality this is not the case for many women. A single mother with three children under the age of five living in poverty will not have the same opportunities to access quality health services as a single man living in a middle-income community. Health inequities exist for socially disadvantaged people, among others, those living in poverty, women, and minorities. Social factors that impact health outcomes are identified as the social determinants of health (Braveman & Gruskin, 2003).

The World Health Organization Commission on Social Determinants on Health (WHO CSDH) (2009, pg. 9) defines social determinants of health as:

The complex, integrated, and overlapping social structures and economic systems that are responsible for most health inequities. These social structures and economic systems include the social environment, physical environment, health services, and structural and societal factors. Social determinants of health are shaped by the distribution of money, power, and resources throughout local communities, nations, and the world.

Social determinants have a large impact on the health disparities that confront women. Women living in low-income communities face the greatest risks (Kieny, 2013). To improve the social and economic conditions in which they live, it is important for them to have good health. Braveman and Gruskin (2003) suggest that this poses an ethical and social justice concern. The WHO states that all persons should have “the highest attainable standard of health” (Braveman &

Gruskin, 2003, p. 255). Women living in poverty are denied this human right because they lack equal opportunities to necessary social factors that enable good health to be accessible.

When a woman is unable to achieve optimal health status, a negative impact follows for the woman, her family, and her community. The World Bank is a leading advocate for gender equity in the international community because of the positive correlation between gender equity, women's health and economic development (Moss, 2002). There has been emerging evidence over the last 10 years that suggests the powerful impact female equity can have on individuals, families, communities, nations and the international community as a whole (Dollar & Gatti, 1999). The entire family benefits when women have an equal say in the decision making in their own household with respect to education, work and the distribution of resources (Moss, 2002). Equity for women influences the nutrition, reproductive health and overall health of the family (Dollar & Gatti, 1999).

“The unnecessary disease and suffering of the disadvantaged, whether in poor countries or rich, is a result of the way we organize our affairs in society. Failing to meet the fundamental human needs of autonomy, empowerment, and human freedom is a potent cause of ill health” (Marmot, 2006, p.1). Sir Michael Marmot explains the connection between health and the environment for human survival. His epidemiological research has largely contributed to the establishment of the WHO CSDH. The WHO CSDH (2008) was established to motivate public health leaders to identify action steps and implementation strategies to improve health outcomes for those living in poverty. The WHO CSDH (2008) handbook is a powerful tool for individuals, communities, governments, and non-governmental entities to take action and accept accountability for monitoring health inequities across the globe. The sustainability of the human

race, particularly in low-income and middle-income communities, is dependent on creating healthier environments (Kieny, 2013).

Sexual health is a concern for many women living in poverty globally. Hawkes and Buse (2013) state that “at the level of sexual relationships through community norms and national and international structural and policy drivers, 19 gender norms reinforce the vulnerability of girls, women, and transgender people to adverse sexual and reproductive health outcomes” (p. 1784). The role of gender and the specific health impact on women is not an automatic consideration when developing local, national or international public health policies (Hawkes & Buse, 2013). This is an important point to consider since “gender inequalities ensure that the consequences and health implications of unsafe sex are borne mainly by women, men who have sex with men and transgender people” (Hawkes & Buse, 2013, p. 1784). Gender serves as an important influence on health behaviors and knowledge (Hawkes & Buse, 2013). This is reflected in *San Pedro de Macorís* among HIV infected women.

Background

The DR resides in the Caribbean sub-region and shares the island *Hispaniola* with Haiti located to the west. The island of *Puerto Rico* resides to the east, the Atlantic Ocean is to the north, the Caribbean Sea is to the south, and *Cuba* and the United States are located to the Northwest of the DR as shown below in Figure 1 (Dohn & Dohn, 2011). *Santo Domingo* is the capital and is located along the southern coast of the DR. *San Pedro de Macorís* is about 79 km east of the capital, where the qualitative study was completed.

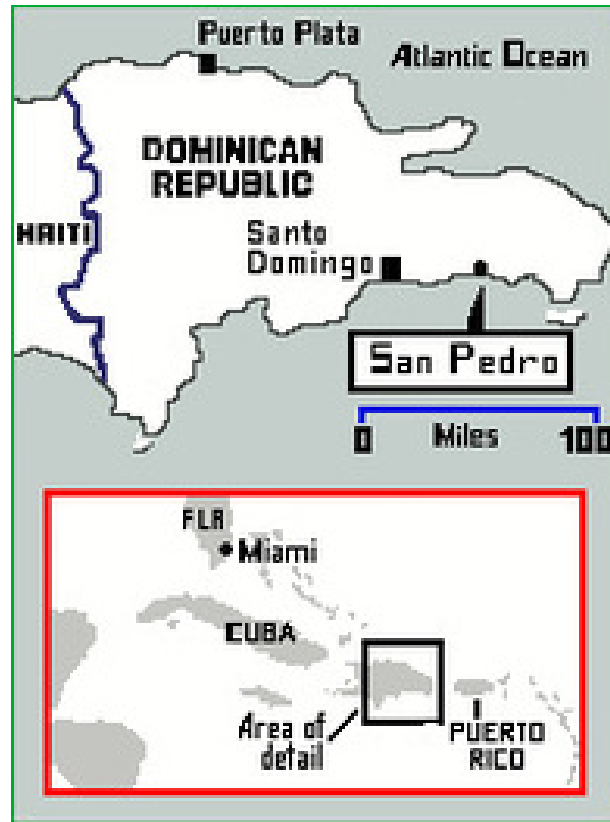


Figure 1. Map of the Dominican Republic.

According to 2009 data, the population in the DR is 9.69 million, the gross domestic product is \$51 billion and the gross domestic product per capita is \$5,321. The official language is Spanish and the country is 95% Christian. The ethnic groups are broken down into 73% Mixed, 16% European and 11% African. The completion rate for six years of compulsory education is 70% and the literacy rate is 84%. The life expectancy for men is 71.3 years and 73.1 years for women (GODR USG, 2011). The HIV prevalence rate is about 1 in every 200 people or 0.44% of the Dominican Republic general population (Dohn & Dohn, 2013). More women are dying from HIV than men, 943 deaths versus 883 deaths per year according to data collected in 2010 from the Institute of Health Metrics and Evaluation (IHME) (Figure 2).

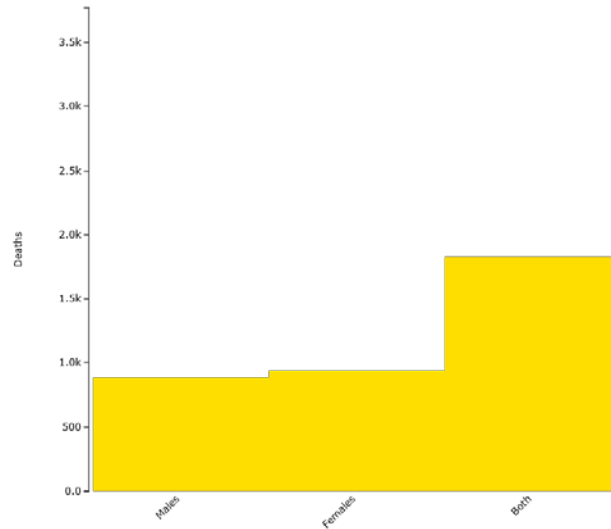


Figure 2. HIV deaths for men vs. women.

The Province of *San Pedro de Macorís* is made up of six municipalities and is mostly urban but also includes rural areas. Sugar cane is one of the main sources of economic growth for the area and attracts many individuals from within other parts of the DR and outside of the country such as from Haiti to work (Wikipedia, 2013). The women that participated in the study came from 12 *barrios* (neighborhoods) in *San Pedro de Macorís* (Figure 3).



Figure 3. Map of 12 *barrios* of *San Pedro de Macorís* in which the women in the study lived.

Methods

An inductive interview approach was used to learn more about the existing support system for women living with HIV and how it impacts their health. A rapid ethnographic assessment triangulated semi-structured qualitative interviews, participant observation, and review of current data (Trotter II, Needle, Goosby, Bates, & Singer, 2001). The qualitative interviews included 19 women living with HIV and 10 health professionals that provide services to the HIV community. Digitally audio recorded interviews were conducted and analyzed in the original Spanish without the use of a translator. This study did not include a survey or a questionnaire; rather, the study used a conversational style interview, allowing for themes and topics to emerge from the participants' responses. The investigator conducted the interviews guided by questions that explored in depth the social support experiences of the participants infected with HIV (Appendix 1). The investigator prompted for further responses with phrases such as "Tell me more about that..." or "Is there anything else..." in order to allow the participants to explore the areas they saw as most significant. The qualitative interviews would come to an end when the participant had nothing further to share.

Confidentiality was maintained for all participants. Numbers linked only to the consent forms were utilized in place of names to identify all study materials. Pseudonyms were used to protect the participants' identities. Both the Institutional Review Boards of Wright State University (Appendix 2) and Clínica Esperanza y Caridad (Appendix 3) approved this study, and each participant gave signed informed consent (Appendix 4) before participating.

During March 2015, I conducted a total of 24 qualitative interviews. All of the interviews lasted on average about 60 minutes. Interviews were conducted with 29 participants in all. A total of 19 women and one man (the husband of one of the participants) living with

HIV were selected based on a convenience sample created through the assistance of the AIDS Peer Counselor who works at the Clinic. She is also the president of Grupo de Auto-Apoyo Esperanza (an HIV/AIDS support group) that is sponsored through the Clinic. All qualitative interviews were conducted during a home visit, at the Clinic, or at one of the local public health offices. The AIDS Peer Counselor accompanied the researcher for the two home visits and was onsite at the Clinic for all other interviews; though the conversations took place only between the participant and the researcher.

Another 10 interviews were conducted with health professionals that are directly involved with HIV/AIDS care and programs in the community. The interviews involved a more eclectic, heterogeneous group including five public health professionals, three health administrators, one nurse, and one doctor. These health professionals described their own perspectives on the social support and social networks of women living with HIV/AIDS in the DR.

Participant observation complemented the qualitative interviews. The participant observation occurred while speaking with staff members at the Clinic and sitting in the waiting room or other offices within the Clinic. Traveling with the AIDS Peer Counselor to conduct interviews in the home, traveling in Dr. Luisa's car with the Clinic staff and the WSU team to visit health promoter groups, and exploring some of the more rural neighborhoods afforded additional opportunities to observe and collect more information.

Findings

A case study approach was used to interpret all of the data (Yin, 2008). The individual interviews involved direct conversations with 17 women living with HIV and two group interviews with staff from the Clinic and the local public health office. When the women talked

about their stories of living with HIV they shared some common experiences that are described as ‘turning points’ and include Unearthing HIV, Challenges with HIV, Living with HIV, and Redefining HIV. Each woman described her own moral trajectory ranging from non-acceptance of HIV because it is an incurable disease to her acceptance of living with HIV as a health condition in everyday life. The women expressed their initial reactions when they first became cognizant of their diagnoses with HIV infection, the challenges associated with it, how it is to live with HIV, and how their perspective shifted over time to the present day.

Unearthing HIV

Unearthing HIV includes the initial reactions of the women when they first learned of their HIV diagnosis. Reactions included fear, denial, disbelief, non-acceptance, a sense of hopelessness, and the desire to end their lives. This was exemplified through the excerpts of Elena, Nari, and María. Elena’s story below illustrates this journey from when she first learns that she has been diagnosed with HIV and how she responds to the news.

Elena’s story.

Elena enters through the accordion partition door where I am sitting, a small room in the back of the HIV clinic at the *Clínica Esperanza y Caridad* where the staff work and counsel patients after examining them. The room is no bigger than the size of a small closet with a small desk, a light, files, and papers stacked on and below the desk. There is a shelf in the very back wall that has an oscillating fan installed above it to cool the room and keep mosquitoes that might be infected with Dengue or *Chikungunya* from landing and biting. Clara has provided me with a mosquito swatter as another form of defense in case the mosquitoes become a nuisance.

Elena has a warm, down to earth demeanor and radiates positive energy when she walks in and sits down across from me. She has a big smile and is very open about telling her story.

She has an 18-year-old son with her late husband and has since remarried in the last two years to a good friend. Elena does not know for sure how long she has had HIV; her deceased husband was the one that gave her HIV and he was unaware that he had the disease. She became aware of her HIV diagnosis in a unique way. In 2000, her first husband passed away because of a motorcycle accident. While he was in the hospital, the staff ran a series of blood tests including an HIV test. The hospital provided her with the results, but did not tell her that he was HIV positive. I suspect they assumed that she already knew. Two years had passed before Elena reviewed the results and read that her husband was HIV positive. She was very confused when she first discovered his test results and she was in denial. She believed that it had to be an error because she knew that she did not have HIV. How was it possible for him to have the disease? She had no prior reason to suspect that she would have been HIV positive. She eventually decided to get tested and found out that she too was HIV positive.

Once Elena had unearthed her HIV, she knew that it had to be from her husband's actions. She had not had sexual intercourse with anyone else during their marriage or prior to their relationship. Her husband had been in another relationship and had three children previously. This made her angry and scared. She was convinced that she had AIDS and that she was going to die. Additionally, she was confronted with the reactions of her community. Her neighbors kept their distance from her because of the fear that they too would be infected by the virus. She explained to me that she was not treated poorly by members of her community, but I would argue that she was. Elena suffered discrimination within her own community through people choosing not to communicate or contact her because of her HIV status. Elena became isolated from her community and it had ill effects on her health. She became depressed and possibly the discrimination explains her transition into a depressive state.

Elena's range of emotions from anger, to sadness, and then to depression was not unique to just her story. Nari also expressed initial reactions of fear and hopelessness when she found out that she had HIV and saw how the people living in her neighborhood responded to her.

Nari's story.

I arrive along with Clara in Santa Fe and in the home of Nari where I am greeted with smiles on the faces of her family: her son who looks to be in his early 20's and a 2-year-old grandson walking around in a diaper. I know that I am receiving this warm greeting because I am accompanied by Clara, the AIDS Peer Counselor from the Clinic. Clara is absolutely adored by Nari, and you can see how her face lights up instantly when we walk through the door. Nari lives in a shack completely made out of corrugated sheet metal with a dirt floor. Her home has two small rooms, and outside the back entrance we can hear a rooster crowing throughout our conversation. Nari is a slender woman who appears to be in her 40's. She has lived with HIV for over 15 years. She shared with me her first reactions to her diagnosis:

At first it was hard, hard, hard. The people here were talking and talking and talking.

Oh...but look at how she is? She doesn't even want to eat. And that made me want to cry and I felt bad and I wanted to die. It is because I thought this was it...because I wanted my life to end. I thought that my life was ending...I thought that my life was ending on many occasions. I wanted to die...I wanted to die...I was crying all of the time.

Nari experienced a lot of suffering in the beginning when she first learned of her disease; she felt unaccepted by her community and that she was being judged for what she was going through at the time. This made Nari feel that her life was out of her control. María expressed this same sentiment in her narrative.

María's story.

María has three children between the ages of 21 and 39 years old. María shared with me her initial reactions to finding out about her diagnosis. She knew that something had to be really wrong with her test results when a team of doctors walked into her room at the hospital. She remembered feeling very dizzy and sick. The last thing that she recalled is that they provided her with a referral to the Clinic.

The first person that María shared the news with was her sister-in-law. María was angry and sad; she remembered feeling out of control and screaming. She did not want to accept the news and she felt that her situation was hopeless. María moved into a deep depression and believed she did not have the will to continue living. The depression made María contemplate suicide and that was the turning point when she sought support from her family. Her family helped her reach the Clinic for further assistance. Her family was concerned for her mental and physical wellbeing. She was so thin, that she looked like she was on the brink of death by the time she arrived at the Clinic. Unearthing HIV for the first time poses many hardships and challenges for these women, and in more than one way. Not only do they have to deal with a life threatening illness with no established cure, but they are also faced with the stigma and discrimination that surrounds the disease.

Challenges with HIV

Challenges with HIV are the existing barriers that include access to employment, health care and nutritious foods. It refers to the hardships that surround HIV such as physical symptoms, mental stress, stigma and discrimination. It also refers to the unintended consequences caused by the support systems for women infected with HIV. The narratives of Nari, Angela, and Samantha exemplify these challenges.

In order to illustrate the lack of support for Nari and many women living with HIV in the province of *San Pedro de Macorís*, it is important to understand the transportation system. I traveled on the *guagua* with Clara for almost 30 minutes; this is their local bus which is a van that picks people up and jams as many people as they can into it (Figure 4). These are privately owned vans licensed through the transportation department and organized by the transportation labor unions. It is the cheapest form of travel in the city and between close municipalities. We sat on the bus for 15 minutes while the *cobrador*, the one who collects the bus fares, left the van and went searching for passengers. When he returned to the van, he had not acquired any new passengers. This standard operating process of the *guaguas* is one of diminishing returns and that the current passengers get frustrated as the time passes and new passengers become less likely.



Figure 4. Picture of a local *guagua*.

Nari lives very far from the Clinic and has to take two buses from her home, which becomes more expensive than taking an alternative form of transportation such as the *motoconcho* or “motorcycle taxis” (Figure 5). The *motoconchos* will take you directly to your destination without additional stops, but the cost is generally much greater. The transportation system highlights the challenge for HIV patients who must access the system often because of

the frequent healthcare visits needed to treat their condition. The physical symptoms that accompany HIV, such as weakness, pain, and nausea, complicate the transportation challenges.



Figure 5. Picture of *motoconchos* (motorcycle taxis) waiting for fares.

Transportation is just one example of the hardships that confront women living with HIV in the DR. Another challenge that was revealed during our conversations was the extreme fear of others learning about their disease. Each woman's fear is part of the widespread stigmatization towards HIV found in each *barrio* and the country as a whole. The justified prominent experience of fear for these women had an unexpected consequence. All of the women that I spoke to had moved out of their existing community into a new neighborhood. They wanted a fresh start in order to protect their identities and avoid the stigma associated with HIV. Angela's story highlights this precedent very well. She had recently moved to the *Barrio La Estación* from the *Barrio Mexico*.

Angela's story.

Angela's home is very different from Nari's. She lives on the top floor of a building in *La Estación* where the windows are looking over a very busy street filled with motorcycles, trucks, construction workers, and lots of people. It is hot inside her home. The noise from

outside makes it hard to hear and it elicits the feeling that we are in the center of everything happening in that neighborhood. As I walk into her home, I notice how welcoming her place makes me feel with the warm, colorful reds and oranges painted on her walls, and how nervous she appears. Angela is much more reserved, and she comes across as a quiet, yet strong, woman. She has been living with HIV for 14 years. She is happy to see Clara which puts her at ease for the moment. I do my best to make her feel more comfortable. At one point during our conversation she begins to cry; she is very afraid for her daughter and how others might treat her poorly because of Angela's disease. Her daughter is 8-years-old and has been fortunate to escape discrimination. However, Angela is still very concerned. She knows from personal experience that HIV is not something accepted in her community.

After the tears are wiped away and she feels safer, Angela opens up more about her story. I observe another side of her; she is more confident and focused. She begins to explain her belief why HIV is not accepted in her community. She attributes this to the lack of HIV education. She strongly believes that education is the only way to change the stigma and to confront the misperception of HIV as only an infectious disease, while failing to see the person behind the disease. In Angela's view, it is important for people to first understand that there is a difference between HIV and AIDS. She believes people need to be better educated on HIV as a health condition. She sees a clear division between what she refers to as the haves and the have not's; a line dividing people who have the health condition and those without it. The ones who do not have the health condition think they know and understand what it is, but according to her, they have inaccurate information.

Upon reflecting on Angela's story, I think of how powerful it can be for individuals to have the accurate information available to them. It can change their beliefs and attitudes about

their own health. The myths surrounding HIV/AIDS contribute to such a negative view of this disease. One common belief is that once you have HIV that you automatically have a death sentence (Centers for Disease Control, 2011). Many of the women that I spoke with had this initial belief, but later learned that in fact there are action steps one can take to prevent death. For instance, another woman expressed that she was concerned about sharing items such as silverware, plates, and dishes for fear of spreading HIV to her family or friends; the same fear that Elena experienced from her neighbors. The myths about HIV can result in self-stigmatizing the individual and self-isolating her from the community. This possible impact is similar to the effect discussed by Bathje and Marston (2014) of public stigmatization on individuals with a mental health diagnosis. “The process of stigmatization involves labeling differences as undesirable and can result in social exclusion, disempowerment, and discrimination” (Bathje & Marston, 2014, p. 1713). In the narratives, the women expressed the fear of other finding out about their HIV diagnosis and how they would be discriminated against in their everyday life.

Under the umbrella of public stigmatization, Corrigan, Larson, and Kuwabara (2010) describe another consequence that can result for individuals: self-stigmatization. This is “the process in which a person with a mental health diagnosis becomes aware of public stigma, agrees with those stereotypes, and internalizes them by applying them to the self” (Corrigan, Larson, & Kuwabara, 2010, p. 1713-1714). This same concept could be applied to women living with a diagnosis of HIV and can have devastating effects for the health and wellbeing of women living within the HIV/AIDS community. It can create silos between them and their community and can be a barrier to instrumental, emotional, social or informational support (Berkman et al., 2014).

During my short stay in the Dominican Republic, I observed that Dominican women identify strongly with their neighbors and members of their community. The community

members work in a communal way and take care of each person as part of one “big family”.

When a woman is no longer accepted within that community, it is difficult for her to thrive. The stigma and fear associated with HIV in a community can have a negative effect on a woman’s health. She becomes isolated and can move into a state of depression.

Angela and Clara described another recurring challenge for HIV infected women. According to them, many individuals living with HIV experience employment discrimination because of their health condition. They are unable to work because of the physical side effects of having HIV and consequently many lose their jobs; when they are stable and can return to the workforce, they are unable to obtain jobs because of this existing discrimination in the workplace. Both Angela and Clara believe that there are no rights or protections of people with HIV in practice. Angela believes that the HIV community needs to continue to fight for their rights and protections and to prevent discrimination in the workplace.

Clara provided an example of the worst form of abuse that she has observed with employers. Many employers have instituted blood tests and health screenings as a part of their application process for hiring. Clara shared that they are dishonest with their applicants and tell them that they are not qualified for the job as soon as the blood test results return. They do not state that the applicant was not hired because of HIV, but rather they explain in general that the applicant does not meet the necessary job qualifications. Angela supported, confirmed that this type of abuse by employers is occurring when she shared a similar experience with her friend that also has HIV.

Her friend went to apply for a job and came to learn that a new law exists that allows for companies to require health tests as a part of the application process. When the results of the health tests showed that he was HIV positive, the person was not hired. They did not tell him

that he was not hired because of HIV specifically, but rather that he was not qualified for the position. Angela believes her friend was denied the opportunity to work because of the stigma associated with HIV. She believes that the current law provides a way for employers to screen for applicants that have HIV and eliminate them as potential candidates. These labor practices have a direct impact on women and their families. If women are not able to work and contribute towards their family's income, this will impact how they can provide the basic needs: food, clothing, shelter, and other important needs to improve their health such as transportation costs to and from the Clinic to receive ongoing care and treatment.

Clara added that there are groups and existing efforts to raise donations to support families with HIV, to assist them in finding employment, and addressing other social factors of their health through the Clinic and other organizations that support the HIV/AIDS community. According to Clara, however, many of these funds or donations have been reduced drastically. These are some of the realities confronting persons living with HIV, forcing people to look elsewhere for support and care.

The example above that Angela shares not only provides insight into the emotions associated with learning about her HIV diagnosis, but also the new social and economic hardships she could be confronted with due to her disease. Many of the narratives include the negative economic impact to the women and their families as a direct result of having HIV. With many of the women when they began their search for employment or when they approached their current employer, they were highly confidential about sharing any information about their health condition. In many of the stories shared with me, the challenge was that they were already unemployed and the stigma associated with HIV was an additional barrier for them to identify employment opportunities. Those that had jobs quickly lost them due to either being

too sick to work or were fired after their employer found out that they had HIV and did not want them working because of the fear and stigma associated with the disease. The resulting economic impact was a reoccurring theme for many of the women.

Much of this is attributed to the HIV law that both Angela and Clara refer to in our conversations; the 2011 Law 135-11 that was passed by the Dominican government. It was recently updated in 2014 to remove the criminalization aspects of the law (Congreso Nacional de la República Dominicana, 2011) and as an unintended consequence resulted in more discrimination. The popular understanding of the law shared by Angela and many of the women with whom I spoke with does not coincide with the intention of the law or what it states. The law is clear in its language that it is illegal to discriminate in the workplace against people solely for their HIV status or diagnosis. There are legal ramifications for companies that violate this. It appears that some companies have found ways perhaps to go around the law. They have instituted health screenings to ensure any future employees are able to perform the necessary job duties. These health screenings include blood tests that can identify if an applicant is HIV positive.

Although Clara and Angela acknowledged that a law is on paper to provide legal protections against discrimination for persons living with HIV in the work place, in practice the rights are not always respected and the law is not enforced. This form of institutionalized discrimination in which the law is in place, but the content is ignored represents a form of structural violence (Farmer, Nizeye, Stulac, & Keshavjee, 2006). The HIV population is facing discrimination because of social, economic and political factors that are embedded in society. The existing injustice and harm impairs their quality of life and can be avoided (Farmer et al.,

2006). Samantha's story reinforces this harm and impact to her quality of life. She explained her employer's reaction to her HIV diagnosis in her narrative.

Samantha's story.

Samantha starts telling the story about her job where she cleans houses. When her employer found out that she had HIV she said, "I don't want you to work for me if you have AIDS and I don't want to get it from you." Samantha emphasizes that the owner of the house did not want her to touch the same plates as she because she didn't want to be infected. This was the first time she had experienced discrimination associated with having HIV and it made her feel very bad.

Conversely, there were some stories that included women working at the time of the interviews. Laura, Leticia, and María were the only three that have remained employed since learning about their HIV condition. Although they have all three succeeded to attain and maintain work despite having HIV, their explanations were different. For both Laura and Leticia, their employers or colleagues are not aware that they have HIV. In Laura's case, she is self-employed and has her own law firm. She had not informed anyone that she works with of her HIV condition and had no intention of sharing that information. Laura prefers to keep her illness confidential both in the work place and within her community. Leticia works at a factory and they do not require any blood tests prior to working or once employees are hired. She said that she has not shared with anyone at her work that she has HIV and therefore she has not had any challenges with maintaining employment.

María's story contrasts with the other two because she has been very open with her workplace about her HIV. She works in a factory and has a female supervisor who has supported her from the beginning and still supports her today. Her supervisor treated her in a

different way than might be expected. She is not fearful of the disease and has been very supportive and understanding. Her supervisor does not give María a hard time if she needs to take time off from work when she is ill or needs to attend to a doctor's appointment. María views her workplace as another form of support. For all three women, their experiences with employment appear to be more the exception than the rule. Many of the women expressed in their narratives the existing challenges that surround their health, their family, their social surroundings, and civic duties and responsibilities as a part of their everyday reality.

In response to these challenges, many of the women turned to God. Some of the women shared that God was their initial form of support and helped them to cope with the fact that they have been diagnosed with a deadly disease. This was the case for Nari and María as discussed throughout their narratives. The lack of an existing cure for HIV is out of their control. Angela expressed this when she shared what she would like to see change with her life and with HIV. "I want a cure." In the face of this loss of control, God can be seen as an important coping mechanism to overcome the challenges of living with HIV. Samantha confirmed the supportive role of God in helping her to overcome the challenges in her life. God provided her with direction and guidance. She realized after learning about her diagnosis that she had to come up with a solution to make money and a way to keep going in order to take care of her husband and her two children who were very young at the time; her son was two years old and her daughter only eight months old.

Samantha's story confirms that God and religion can be seen as a form of support. God is a consistent presence woven in and out of the narratives expressed by each woman. God is perceived as the first prominent form of support and most important strength to motivate reflection, acceptance, and change in behavior. In my opinion, this could be attributed to the

widespread religiosity in everyday life in the DR. Religion is not legally separate from state as is experienced in many other parts of the world, such as the United States (Dohn, Jiménez, Nolasco, Cabrera, & Dohn, 2014). The perspective of each woman living with HIV is shaped by culture.

Although God and religion was expressed as a form of support, it was also presented as a challenge for women infected by HIV. There can be an opposition between the interests of religious institutions and health professionals working towards improving population health. This was shared during my conversations with some of the staff at the local health department and certain members of the Clinic that are working in collaboration to mitigate the effects of HIV in the communities that they serve. I had the opportunity to speak with three members from the local public health department and one physician from the Clinic during this interview. When I provided the example of a church as part of a potential support system for women, the physician from the Clinic interjected that there is a real difference in perspective between some churches and the health centers related to HIV.

The church often teaches people that they need to be pure and clean in order to be healed from their suffering. This can come into conflict with the interests and intention of healthcare. For example, when the medical facility prescribes medications to treat HIV, some members and leaders within the churches believe that they need to rid their systems of antiretroviral drugs before they can be healed from the disease. The leaders and members attribute a spiritual cause to HIV and not just a biomedical cause. Women can feel conflicted between what the health care sector is recommending versus the religious sector in order to heal. Both are important forms of support for these women and have been expressed in many of their narratives. The health care system is encouraging them to take antiretroviral drugs to treat their HIV, reduce transmission,

and prevent AIDS. In contrast, some churches are saying they need to be clean and should avoid taking these medications in order to be cleansed and healed. This can be a challenge for the health and wellbeing of women living with HIV.

Furthermore the public health professionals at the local health department brought up another challenge with the lack of an existing social support system. They believe that there are no formal or informal organizations that exist to provide social support for women living with HIV. They believe it is necessary for the women to have access to these types of services in order to thrive and improve their overall wellbeing. The public health professionals agreed with many of the women that were interviewed that there is still a lot of discrimination and stigmatization associated with the disease. The discrimination is happening within families, communities and the labor sector. One of the public health workers provided an example of discrimination within one of the neighborhoods that the local public health office serves. If a child attends school and his mother has HIV, that child is being impacted by the stigma and discrimination associated with HIV. Children and their parents do not want to be associated with a child that has a family member with HIV.

This type of discrimination is not as obvious from the etic perspective (Geissler & Pool, 2005). In other words, as an external person not living within the community that you are studying, you might make assumptions about the types of existing discrimination because you are observing the situation through your own perspective from the outside (etic). However, from the local or emic perspective, the reality that exists within that community might be that they are experiencing discrimination on another level, through their children (Geissler & Pool, 2005). This is in addition to the self-stigmatization, employment discrimination and public discrimination experienced through the members of their community where they live

neighborhoods because of their HIV. The current institutions represent a form of structural violence for the HIV community (Farmer et al., 2006).

Physical symptoms caused by HIV were another common challenge that was expressed in many of the narratives. María described in detail the physical pain and her physical appearance before she arrived at the Clinic. She felt nauseous, vomited often, and had diarrhea. She was very thin and unhealthy. Clara confirmed when María first visited the Clinic she was very thin and the staff was concerned. Once María started receiving comprehensive treatment through the Clinic, she started to feel much better. She felt that the Clinic was taking care of her along with her disease. The narratives highlight another turning point that often accompanies HIV, the challenges that the disease brings into daily life. The stories illustrate the various hardships and unintended consequences that these women have experienced since finding out that they were diagnosed with HIV. Each woman that I interviewed shared some form of challenge that they faced, continue to face, and will face as long as they are living with HIV.

Living with HIV

Living with HIV describes each woman's transition from suffering to learning how to modify aspects of her life to improve her health and wellbeing. They acknowledged the challenges that accompany HIV, but are no longer burdened by them. They are receptive to education and multiple forms of social support. Angela and Nari talked about their experiences; Angela referred to the support group that is offered through the Clinic as a way to provide social support to HIV patients. She found commonality amongst members of the group and received validation from them. The challenges ascribed to HIV only partially represent the life of someone living with HIV. Eventually the person moves beyond her diagnosis and starts to

acquire new ways of molding her life to better meet the health needs demanded by HIV. This is described in the narratives of Angela, Estrella, and Nari.

Angela explained that education is the answer to help the person move out of self-stigmatization and become aware of existing support and ways to improve her health. HIV is no longer viewed as an incurable disease but rather as a manageable health condition. Angela believes that before providing HIV education to community members, the individual living with HIV has to first be educated with the facts. When she first learned about her HIV, Angela felt disempowered. She was depressed and sad and began isolating herself from her family. The isolation occurred because she thought that if she was near them she would automatically infect them with HIV similar to other infectious diseases. She explained that her own ignorance caused her to react out of fear and uncertainty. Angela believes that if she was better educated on the facts of HIV, she would have responded in a different way. She believed in some of the myths that are associated with HIV such as it can be transmitted in a similar manner to influenza. She believed that she could not share plates, spoons, and glasses with anyone nor sleep in the same room.

The self-stigmatization that Angela displayed initially was due to a lack of education. Estrella shared the same belief as Angela with respect to education as the crucial component to changing the stigma and discrimination associated with persons living with HIV. Estrella is from the *Barrio, Buenos Aires*, and she has worked as a health promoter through the Clinic for the past five years. She described the value of education below in her narrative.

Estrella's story.

Estrella refers to people in her community as lacking knowledge, communication, and education about HIV; in turn, they respond very ignorantly. “When they speak of HIV, they

speak of death, they speak of tragedy not of a health condition.” She commented that the discrimination is magnified in her community because there is no privacy. Neighbors are involved in the lives of other community members. From my observations and from the narratives that were shared, collectivism is an important aspect of Dominican society. There are advantages to this because the community puts the wellbeing of all of the members over one member. This holds true as long as each member of the community is following the accepted social norms. Challenges arise if behaviors, actions, or characteristics do not follow these expectations established by the collective community. The stigma associated with a person diagnosed with HIV puts her at risk of becoming isolated from the collective social support offered by that very warm, loving community. This was the fear that was expressed in each of the narratives. All of the women discussed their efforts to protect their identity and mitigate the risk of others finding out about their HIV condition. If the women were to access the community resources, it could reveal their status and that revelation risked making those resources unavailable. In other words, it would put them at risk of losing access to the support needed to live within any community.

Furthermore, Estrella shared that her role within the community is to educate individuals living with HIV and the community members about HIV as an acceptable health condition rather than a feared disease. She provides them with the facts and information they need to know and understand about living with HIV. Estrella tailors her message to the different groups to address their different concerns. At the time of the interview, she expressed that the community is much more accepting of HIV and those living with the condition than previously. She has seen a positive change within the past five years through her work as a health promoter. She believes if you speak with someone about a topic openly it changes the understanding and acceptance of

that topic. It is also important to speak on their terms, in a way that people can hear it and understand it; she believes that you need to grab their attention. Education and communication in her opinion are crucial to changing the beliefs and attitudes that individuals attach to HIV. She also believes that God puts us all on this Earth for a reason. She believes that reason for her is to educate the community on the facts of HIV.

Moreover, in Estrella's opinion there is not a very good network in place to support people living with HIV. A network exists but it is evolving very slowly and there is not sufficient funding to support these efforts. She provided the example that she has conducted her own research online to identify more resources but has been unsuccessful. She believes this is due to the fear people have in the community about HIV. Since they lack the factual information in order to understand HIV as a health condition, they refuse to support the cause. All of the education that Estrella received was provided to her through the Clinic. The Clinic appears to be the prominent source of information and education for the HIV community in *San Pedro de Macorís*.

Angela also shares in Estrella's vision of education as a way to change the stigma associated with HIV; she also experienced this through the Clinic. It was when Angela came across the Clinic that her perception changed. They educated her on what types of precautions she needed to take and dispelled the myths in order to protect others from becoming sick like herself. Over time, she learned more about her condition and how to take care of herself which made her feel less isolated and different. "I was just like anyone else." Once she was able to distinguish the facts from the myths, it enabled her to accept her condition better and for others to accept her HIV as a health condition rather than a disease. Fear subsides for the person living with HIV and for others.

Angela shared from her personal experience how she responded to people expressing a certain beliefs associated with HIV. In her opinion people make many assumptions about living with HIV; for example, if you have HIV, your children must have the disease as well. She views this type of situation as an opportunity to educate people on the facts versus the myths associated with HIV. Angela shares her personal experience as a form of education. She had a cesarean section delivery in order to avoid transmission of HIV to her daughter. She learned about how she could prevent perinatal HIV transmission through the Dominican national program against vertical HIV transmission. She believes that HIV education enables others in her community to better understand her condition and to accept her as a person. Once they have the facts, they respond more positively and remove judgment on her and others within the HIV community.

Moreover during my interview with Angela, I had the opportunity to observe the relationship between Angela and Clara. It was clear that Clara had established a strong, trusting relationship with her. In my opinion, this trust has motivated Angela to make changes to her daily life in order to improve her health and not allow the HIV to progress to AIDS or even worse death. By Clara showing her respect and dignity, Angela felt cared for and empowered to take charge of her own health. She further explained how Clara gave her hope and motivation to keep moving forward in her life. She became very emotional when sharing this part of her experience of living with HIV. In particular Angela highlighted the significance of Clara in her life. Clara is viewed as her sister, her daughter's aunt, a person that cares for her like a family member, and a friend showing unconditional love and support. Clara was present when Angela described their relationship and she agreed with what Angela expressed and added that she considers Angela and her daughter an extension of her family. "She is our child." Clara said this in reference to Angela's daughter.

Angela is thankful and appreciative of all of the staff at the Clinic for providing her with the necessary education and support in order for her to take action steps towards improving her health. She referred to the Clinic as her “second home” and she believes that other HIV patients hold the same view. Angela experienced a transformation at the Clinic. She initially saw it as just a medical center to treat her HIV. This traditional view was quickly changed and because of the quality of care that she received, the Clinic transformed from a medical center to a place filled with staff ready to take care of the whole person.

Nari also views the Clinic as a “second home” and form of social support. She expressed in her narrative that it was not until she discovered the Clinic that her suffering began to end. She credits finding the Clinic and the end of her suffering to God; “I have overcome it thanks to the Lord.” The people working at the Clinic took care of her and treated her holistically. Often in biomedicine, the patient is not seen as a person, but rather as a disease that has to be treated. This process of bracketing oversimplifies the process of treating the whole person and eliminates the patients’ subjective experience of the illness or condition (Geissler & Pool, 2005).

Nari, Angela and all HIV patients receive ongoing, comprehensive care through the Clinic. The Clinic has an overarching umbrella of services in addition to regular visits with a doctor. Patients receive services from an onsite psychologist, obtain their medications from the pharmacy, attend regular support group meetings provided by the Clinic and facilitated by the AIDS Peer Counselor, and receive home visits from the AIDS Peer Counselor to ensure that they are following-up on mutually agreed upon plans to improve their health. The AIDS Peer Counselor ensures that the patient is attending routine visits as needed to the Clinic, taking her medication and that she is eating well. She also checks in on how the patients are feeling both

physically and emotionally, assessing how their economic situation is progressing, and other follow-up questions related to everyday life based on the mutually agreed upon plan.

The support group that Nari and other HIV patients attend holds regular meetings at the Clinic to educate patients on how to take care of themselves and prevent the spread of HIV to others. In addition to providing health education, the support group is a way to identify with others going through a similar experience. Bringing together a range of different health services that address the physical, mental, and social factors of health makes Nari feel well taken care of, and she acknowledges the fact that it has motivated her to take better care of herself.

But look... it is because I met these people. After I got to know people who were taking care of me and supporting me, giving me strength, giving me encouragement...that helped me a lot...and everybody accepted me as I am and everyone loved me and my home was a place where people would come visit me.

Nari describes in the quote above that the love, support, and care that she received from the Clinic slowly transformed how she approached her own health and made her feel empowered to share her story with others as well as not feel ashamed of her condition. This experience motivated Nari to educate others in her church community and as a consequence it has assisted in changing their attitudes and beliefs on HIV. Instead of judging her as a person infected with HIV, they accept her as a person living with HIV.

Furthermore, the Clinic provided support for Nari during this challenging time in her life. The doctors treated her in addition to the disease. The doctors explained to Nari what she needs to do in her everyday life to take care of herself. They treated her illness with medication and empowered her with education. They referred her to the psychologist and an outreach worker to provide an opportunity for Nari to share her feelings around this new health concern in her life.

It also connected Nari with a support system within the Clinic. She experienced a personal transformation from the moment she walked into the Clinic; no longer was she alone in this process. She experienced a sense of normalcy with her HIV and that others understood what she was going through at this stage in her life.

Redefining HIV

Redefining HIV describes the process of transformation from perceiving HIV as an incurable disease to acceptance of living with HIV and establishing a new identity. Christy and Elena shared their experiences; Christy described how her neighbor loved and accepted her. She took care of her and looked out for her overall wellbeing. She cooked for her, she cleaned her house, and she asked how Christy was feeling. Her neighbor was part of her support system and she empowered Christy to find value in her own life.

Christy's story.

Christy radiates very high energy and has a very upbeat personality. She emanates a positive spirit when she speaks. She explained that she has always been full of life. She has two boys that she has to take care of because their father, her husband, passed away. She said that the only time she was depressed was when he passed because she did not know what she was going to do in order to take care of her children. She did not have her mother or other family members to provide support. Christy only had her in-laws that supported her and her children during this time.

Christy is from the *Barrio Villa Providencia*. She described her neighborhood as tranquil and close knit. She is surrounded by many people in her apartment complex and she has mixed feelings about living within such a small community. On the one hand, she never feels alone and feels like she is cared for within her community. She described one neighbor in particular that

has been there from the beginning supporting her, not judging her based on her diagnosis. Christy described how her neighbor loved and accepted her. She took care of her and looked out for her overall wellbeing. She cooked for her, she cleaned her house, and she asked how Christy was feeling. Her neighbor was part of her support system and she empowered Christy to find value in her own life. “She kept me motivated and wanting to move forward in my life.” Even when Christy had days where she was depressed or felt physically ill, her neighbor was there supporting her and lifting her up so that she could put one foot forward in front of the other. This was not the case with others living in her neighborhood. Christy described the other neighbors as people who like to know all of the happenings within their neighborhood. According to Christy, this curiosity creates a lot of *chisme*, which means “gossip”. She wishes that she could have more privacy from her other neighbors.

Christy shared her experience of learning about her HIV. It happened shortly after the passing of the father of her children. He had just died from AIDS and at that time she was unaware of the cause of his death; he had never told her. She had actually found the results of some of his blood work at the hospital and that is when she learned how she contracted the illness. She said that it was strange because the results did not say positive but rather reactive. And she was thinking reactive; that must be something good. However, when she went to the doctor, the doctor told her that the results were positive and that meant he had HIV.

Thinking about her own health history with HIV, she remembered how difficult it was to physically move; she had to stop and rest because she felt sick. Her sons finally took her to receive care and that is how she became connected with the Clinic. She described her experience at the Clinic as having an entire support system behind her, helping her. She did not feel alone and Christy mentioned Clara, the doctors, the psychologist, and the members of the support

group as instrumental to helping her overcome her disease. It was through the support group that she found others that she was able to relate to and that could understand her story.

Christy explained that the staff at the Clinic took care of her in many different ways. They helped her overcome her depression and *tristeza*, meaning “sadness”. She shared that at her lowest point she believed that she was going to die. The support group and the staff at the Clinic empowered her to put one foot in front of the other and believe that her life was worth living despite her HIV diagnosis. She said that from the moment she found out about the results for her former husband and for herself, the Clinic was there for her both physically and emotionally. She reflects back to the support group and how they were motivating her from the beginning. They encouraged her to share her condition with her children. She no longer needed to feel ashamed of her condition and to keep it a secret from her family. Once she had been more open with her family, her support was greatly enhanced. Her children really took care of her and were making sure she was eating well, taking her medicine, and going to her medical appointments. She had the support and love from her children. Apart from them, her cousin knows and she has been helpful to her when needed. Her sisters are not there for her as much as she would like but at least she has her cousin. She also mentioned her sister-in-law is there for her within her family support; she is like her real sister. In addition to her own family, she views the Clinic as her “second family”.

Christy expressed that her only real fear over the past 20 years involving her HIV diagnosis involved her youngest son between the ages of 17 to 21 years. For three years, her son was asking his mom if he could be tested for HIV. She did not want to know the results and was fearful of what the outcome would be. She had a vaginal delivery with him and it was at the time that she was unaware of her HIV status; therefore he was at risk for contracting HIV.

Eventually, Christy took him to be tested thanks to the support of the Clinic, and she thanked God that the test results were negative.

Christy ended our conversation with a *new* theme. She wanted to talk about the fear she has as a woman to find another relationship. She wants to love someone else and have someone else love her. She wants to find someone that can take care of her and someone that she can really trust. She shared that she had fallen in love one time since her husband passed away. However, he became scared of her HIV condition and believed he was not prepared to take care of her and her condition. They eventually stopped dating and Christy was left feeling confused and sad. Christy is at a loss of how to navigate this part of her life. She is worried about being alone for the rest of her life. She is hopeful, but scared to pursue future relationships because of her health condition. She believes it will be a challenge to find someone that will be willing to care for her because of the stigma associated with HIV, the fact that she been married beforehand, and the unknown future of her health condition. She mentioned that this is a theme that has been discussed in the support group and she has found it helpful to speak to others that share the same concerns. Despite these concerns, the support of the group has empowered her to remain positive and to be open to the possibility of future relationships.

Christy further explained that since she was diagnosed with HIV, about 20 years ago, she has seen the level of consciousness rise in her community related to HIV. There is more acceptance and tolerance regarding the condition. In her opinion there has been a decrease in stigmatization surrounding HIV from the time that she found out she had HIV. She believes this is due to the increase of education and understanding of HIV.

After reflecting on the conversation with Christy, in my opinion a combination of three things might take place in order to empower each person living with HIV and to assist her in

accepting a life with HIV. First, her attitude and beliefs about HIV influence her level of acceptance of the disease. Second, her ability to be self-aware of HIV as a health condition as part of the identity of the person rather than the entire identity of the person. Third and final, established support systems need to be in place that offer an integration of emotional, instrumental, appraisal and informational support (Berkman et al., 2014).

Furthermore, Elena shared how her family helped her to redefine HIV and give more value to her own life. Elena talked about how she became empowered in order to overcome her illness. She embraced a positive attitude and consciously chose to fight for her life. She was able to accomplish this because of her support system. She explained that watching her mother experience cancer was instrumental in shaping her belief system about her own HIV condition. Her mother had breast cancer and was very sick. Elena would leave her house at 5:00 a.m. every day to visit her mother and make sure that she was getting out of bed and living her life to the fullest as long as she was capable. This was how her mother wanted it. Her mom had a positive attitude and seemed to have a good quality of life, despite having cancer. Watching her mother respond to her illness in a positive manner motivated Elena to continue living her life to the fullest.

According to Elena, she perceived her mother as someone who embraced a positive attitude towards both her health and her life in general. “If you cry, cry, cry and do not want to fight for your life against the disease than you will surely die.” She explains that she felt this way at only the beginning. Elena knows what it feels like to be at such a low point and she believes that no one is able to take you out of this place; it is up to the individual and she has to be ready to change. Elena talked about how she became empowered in order to overcome her

illness. She embraced a positive attitude and consciously chose to fight for her life. She was able to accomplish this because of her support system.

However if you decide to look at your condition from a different perspective...as a fighter...you decide to not allow it to control your life...you decide that you want to defeat the virus and to continue living...then you will survive.

Diego Torres wrote a song in 2001 called *Color Esperanza*, which means “The Color of Hope”, that many HIV/AIDS advocates have adopted as their champion song to continue putting one foot in front of the other and believe that “yes, we can” overcome this or as the saying is recognized in Spanish as *¡sí, se puede!* Figure 6 below is an example of a Dominican HIV/AIDS activist group marching in support of HIV rights.



Figure 6. HIV/AIDS rights activists in the Dominican Republic.

Elena’s story is empowering. Instead of looking at her life and defining it by having HIV, she chose to view her life as living with HIV but not limiting her from continuing to pursue other aspects of her life. She does not view herself as victim of HIV, but rather she is a person, with an identity that is separate from HIV. Elena continues to provide another way that she is validated through her changed outlook on living with her health condition. She described an experience with members of her community wanting to share a meal in her house. They drank

from the same cups, ate from the same plates, and used the same silverware. They were accepting of her. She described her community as a “large family”. Each member of the community takes care of each other in an unconditional way. Family was instrumental in helping Elena to redefine HIV.

In addition to family helping to redefine HIV, the Clinic offers the opportunity for all of their HIV patients to attend a monthly support group that provides the following benefits: health education and workshops; to share their story and connect with others experiencing a similar situation; to receive validation for their own feelings that come up while trying to cope with HIV; and lastly to provide a safe, fun, environment where HIV does not have to be the only thing that defines their lives. For example, Clara explained that sometimes the group plans outings to the beach to just relax and to socialize with others. They would not incorporate a specific theme on HIV, but maybe discuss how to have fun and how to take care of yourself in order to best manage stress. The group has helped change attitudes about identifying the person as having a disease and redefining HIV as a health condition. Angela has learned so much about her condition, about herself, and about how to move forward. “Whatever question I had or doubt, the group educated me on it.” She learned there how to take care of her condition when she was pregnant. She felt very fortunate to have had that information before having her daughter.

For Angela, she is able to redefine her condition because of the support and education that she received through the support group offered at the Clinic. The support group is comprised of other HIV patients, Clara as the facilitator, and family members or friends that provide support to the patients. The number of people varies from month to month depending on their schedules, the type of workshop being offered, and the activity that is planned for the session. Angela viewed the group as a form of social support, providing her strength because

now she had knowledge, tools, and social-emotional support to help her work through the discovery of having HIV and how to adapt her lifestyle to improve her health. Angela saw the group both as her social support and a place that provided her and others education. It seemed to really empower her. According to Clara when I spoke to her as a follow up from the interviews, the Clinic provides health education in each of the sessions and individualizes the various topics to meet the needs of the members of the group. She facilitates the discussion and selects a different health education topic for each session.

Discussion

The moral trajectory went through the following four stages for the Dominican women impacted by HIV and who participated in this study: 1) Unearthing HIV: It begins with an awareness that she has HIV and the sensation of disbelief, denial, non-acceptance of the disease and the feeling of hopelessness and wanting to die; 2) Challenges: It then transitions into understanding how HIV impacts her life, what kind of challenges emerge, what kind of barriers, stigma and discrimination that exists; 3) Living with HIV: The path changes as she is learning to adapt to this new way of life, analyzing and acknowledging the challenges that go along with HIV but receiving education and support to combat those difficulties associated with HIV; 4) Redefining HIV: Finally, each woman moves into acceptance of living with HIV as a health condition with a person and redefining her identity (which is unique to each woman) as it relates to living with HIV. This journey can vary from individual to individual and the duration might be longer in one stage of the process depending on her experience.

The challenges for women living with HIV in the Province of *San Pedro de Macorís* are concrete and also exist as part of their new reality. Christy did not share with her neighbors because she feared that they were incapable of accepting her because of her health condition.

She has never received a negative reaction from them; in fact, she believes that they are unaware of her HIV condition because they greet her and are kind to her. She still chooses not to share with them her situation; she only shares with the one neighbor that was mentioned above in the beginning of the interview.

The responses to these challenges shape how they redefine HIV on a personal level as well as on a community level. Christy also shared how she perceived the existing challenges surrounding HIV also as opportunities for creating a new personal identity. This is an empowering approach to a disempowering illness. The different forms of social support for Christy and many of the women who shared their stories might perhaps explain the success of these women learning to adapt their lives to HIV and overcoming the worst case scenario, death.

Social support is instrumental for each woman through her journey and process of coming to terms with her HIV. Family, God, the Clinic and the support group were forms of social support expressed in their collective narratives. One aspect that enhances the negative impact of HIV is the lack of community life or family support. The stress might be overwhelming without a social support system in place, and evidence has demonstrated the negative impacts on health associated with high levels of stress (Berkman et al., 2014). Social support is broken down into the following four subgroups “emotional, instrumental, appraisal, and information support”. Emotional support relates to “the amount of love and caring, sympathy and understanding and/or esteem or value available from others” (Berkman et al., 2014, p. 243). Berkman et al. (2014) explains that emotional support is most often given by a family member or by an intimate partner but can be provided from other sources.

This was typical of what I observed and heard from the narratives that were shared with me. The women described when their family members and friends provided them with

emotional support it helped them to accept their own condition. In addition to family, both the faithful from the churches and the Clinic provided emotional support. Many women turned to God or to their church to seek understanding or value with their life. God was seen as a source of strength and empowerment for many of the women. God came first and through Him, they were able to understand that HIV is part of their journey and part of the plan God has for them. It was a way for them to validate and explain this traumatic situation taking place in their life at this time. They were doing it for God because He has their best interest at hand. They believed that God would be there supporting them no matter how low or hopeless they felt.

Samantha's reference to God is a good illustration of how she responded to a difficult time in her life by being more empowered and determined instead of allowing the situation to make her feel defeated. She attributed her ability to overcome a challenging period of her life through the support she felt from God. There appears to be a common thread among the narratives shared by each woman living with HIV. Initially, they are faced with a life threatening condition and then through the spiritual strength they obtain, their HIV experience becomes manageable. In many narratives this type of emotional support results in a positive outcome. It motivates them to take care of themselves first and to continue to take care of others within their families. They have a purpose to keep moving forward despite the challenges that are associated with HIV.

One area to conduct further research is to explore the motivation behind improving one's health when diagnosed with a life threatening disease. Each woman expressed in her narrative a desire to continue living and improving her health in order to care for someone outside of herself. She has other responsibilities that drive her to move forward in her life. In some instances, she has children and a husband and in other cases she has another family member or

friend that needs her to be strong, stable and healthy in order to provide for that person. They appear to have a strong motivation to overcome the challenges confronted when living with HIV in order to serve a larger purpose. For example, Christy shared, “I have to take care of my family so I have to live; this is part of God’s plan. He is providing me the strength to continue.”

Many of the supportive aspects expressed from the narratives about religion, church and God were also characteristic of the Clinic. The staff at the Clinic validated their illness narratives, listened to them, empathized with them, and empowered them to love and care for themselves. The Clinic was referred to as the ‘second home’ or ‘second family’ for many of the women. It provided a welcoming, familiar place where they could be accepted and provided unconditional love, similar to what might be expected for parents and the relationship that they have with their children. Often times, the women living with HIV experienced this type of family support but when they did not, the Clinic filled in the gap. The staff at the Clinic provided unconditional love to many of the women and strengthened those that were receiving emotional support already from their family and close friends.

From my observation, Christy’s story represents this form of emotional support. She felt like someone cared for her life and her existence, and that fueled her to keep moving to improve. This is an observation that I had after speaking with each woman. Each had felt loved, respected, and cared for as a person first and then as a patient. The Clinic did not represent the typical biomedical experience that is frequently seen in the United States health care systems.

The Clinic also provided instrumental support or “help, aid, or assistance with tangible needs such as getting groceries, or getting to appointments, phoning, cooking, cleaning, or paying bills” (Berkman et al., 2014, p. 244). They educated each of the patients about the facts versus the myths of HIV and how to take their medications and to attend ongoing and regular

health appointments. Clara conducted home visits to make sure they had enough food to take with their antiretroviral drugs and the psychologist would call to see how they are feeling and if they needed anything. All of these examples of instrumental support provided through the Clinic can impact the overall wellbeing and health of women living with HIV because they improve access to care (Berkman et al., 2014).

The third form of support is appraisal support; it “relates to help in decision-making, giving appropriate feedback, or help deciding which course of action to take” (Berkman et al., 2014, p. 244). The support group held by the Clinic for HIV patients is the best source of appraisal support based on the narratives and my own observations. It offered an opportunity for testimonies, education, validation and guidance to take place from peer to peer but also from health staff to patients. The support group created a safe place to share fears, concerns and questions and where people can find common understanding. This is a unique aspect offered by the Clinic and demonstrates another anchor within the support system of women living with HIV in *San Pedro de Macorís*.

Christy also discussed the support group as another form of support. She described her experience of when it was her turn to share her story with the group. She was very well received by the other members. They accepted her right away, and they validated her story for her. She has developed strong relationships with each of the members and they keep in touch in between meetings. If someone does not come to the group, they call them up and make sure they are doing well or to find out if they need anything. Additionally, if they have not seen a member for a while there is no judgment when they return to the group meetings. The member is welcomed and they pick up from where they left off the last time they were all together. Christy expressed that each group meeting has a different theme to discuss for that particular day. They learn about

different health topics, HIV and other areas of interest brought forth by the group members. In essence, the members of the group guide the direction of their meetings. They have input into what is discussed and they guide the group's discussion. Each person has an opportunity to express their thoughts and perspective during the meetings. They can share their feelings, concerns, or if they have questions about the assigned topic for that meeting.

Christy shared that one of the themes that they talked about was the death of loved ones. That topic was a very emotional one for her. The anniversary of her husband's death was 15 years ago at the time of our interview. She expressed that even after 15 years it is very difficult for her because she was left with so many memories of him. She hears a song on the radio and she thinks of him; she goes by a place in her neighborhood that reminds her of him; it is difficult because she feels him and thinks of him often.

The final form of support "is related to the provision of advice or information in the service of particular needs" also referred to as informational support (Berkman et al., 2014, p. 244). The Clinic, the support group, and the local public health department provided this type of support for the women living with HIV. The Clinic and the support group provided advice and guidance on how to live with HIV, how to take care of their health conditions. They provided both individual and group counseling to educate and empower the women. The local health department provided population health, education, and support to the HIV community. They are implementing strategies to prevent HIV, protect the rights and dignity of persons with HIV, and to connect the HIV community to comprehensive services that incorporate social determinants of health. They assess legal, political, economic, educational, and social factors that influence the health and opportunities of the HIV community. They are working to accomplish this through

establishing multi-sectoral partnerships at local and national levels that provide services to the HIV population.

Limitations

This study had some limitations. First, the investigator stayed for eight days in the DR and therefore was limited on the amount of time to interview participants and to gather all of the information needed to complete a rapid ethnographic study. The investigator would have liked more time to conduct participant observation, non-participant observation and perhaps a focus group with the patients that attended the support group. The other limitation was the background noise and environmental noise where the interviews were conducted. Many times there was a lot of street noise, the noise of a fan or even animals that made it difficult to hear during review of some of the digital audio recordings. Third, a convenience sample was used due to the short time and that did not provide the opportunity to try to recruit more people to increase the amount of participants in the study. Lastly, even though the primary investigator was bilingual in Spanish, there was a lack of full cultural proficiency during the interviews. Some of the interviews involved the key informant, Clara, but most of them did not. At times this resulted in some misunderstandings at first and even in the later interpretation and analysis. However, all information was able to be clarified in the end.

Conclusion

Each Dominican woman described her own moral trajectory ranging from non-acceptance of HIV as an incurable disease to acceptance of living with HIV as a health condition in everyday life. The thematic analysis indicates that social support was instrumental for each woman throughout her journey and process of coming to terms with her HIV diagnosis and

taking control of her life. Family, God, the Clinic and the support group were forms of social support frequently expressed in their narratives and represented their social networks.

Furthermore, social support is one way that social networks can influence health status. This qualitative study explored and synthesized the exiting social support systems expressed through the Dominican women's narratives and how it has impacted their health. Broad social determinants of health are crucial to understanding the health a population (Berkman et al., 2014, p. 242). Socioeconomic factors, politics, and social network structures influence factors such as personal experience, social support and negative social interactions. "Women aren't the problem but the solution. The plight of girls is no more a tragedy than an opportunity" (Kristof & WuDunn, 2009, p. 100). This call to action is one of the many movements that public health professionals can join to improve health outcomes not only for women but for families and communities across the globe.

The call to action from the WHO CSDH motivates the public health community to demonstrate innovation, critical thinking and a high level of accountability towards addressing health disparities. This poses a challenge for current and future public health professionals, and at the same time it creates incredible opportunities. Public health professionals are trained in a multidisciplinary manner in order to address an entire population's health and wellbeing (Turnock, 2004). This enables incredible opportunities for public health professionals because they are able to address multiple health issues at the same time. Throughout the 20th century, the quality of life has improved globally because of great accomplishments in public health. There has been an increase in life expectancy, a reduction of infant and child mortality, as well as a reduction and/or eradication of communicable diseases (Turnock, 2004). This demonstrates the effectiveness of public health. The level of planning, assessment and intervention implemented

by public health professionals is needed to address the growing public health concerns of the 21st century such as chronic diseases like HIV and addressing the health disparities that exist among different HIV populations. When public health professionals, government, nongovernmental organizations, communities and individuals collaborate to obtain gender equity in health, the results are powerful to reduce overall health inequities (WHO WGEKN, 2007). Perhaps, if health inequities were eliminated, Dominican women living with HIV would receive the direct benefits to their health and overall wellbeing.

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Appendix 1: Questions for Interviews

Prepared Questions for Interviews (English):

1. What do you enjoy most about living in San Pedro de Macorís?
2. How does the community perceive women living with HIV/AIDs?
3. How is it for you living with HIV/AIDS?
4. Describe your support system(s).
5. How has the support group impacted your life?
6. What would you like to see happen in these support groups?

Preguntas preparadas para las entrevistas (Spanish):

1. ¿Qué es lo que más disfruta de vivir en San Pedro de Macorís?
2. ¿Cómo la comunidad perciben las mujeres que viven con el VIH / SIDA?
3. ¿Cómo es para usted que vive con el VIH / SIDA?
4. Describa su sistema(s) de apoyo.
5. ¿Cómo ha impactado el grupo de apoyo de tu vida?
6. ¿Qué te gustaría acontecer en estos grupos de apoyo?

Appendix 2: IRB Approval Letter Dominican Republic

1. Approval document from local IRB (HHS IRB registration number IORG0007257) for the protocol titled “Las Redes Sociales de las Mujeres Viviendo con el VIH/SIDA”, local IRB No. 2014-12, approved for one year as a minimal risk study on 8 December 2014.
2. Signed permission form allowing Emily Surico to conduct her study in cooperation with Clínica Episcopal Esperanza y Caridad.

Clínica Esperanza y Caridad [CEyC]
Comité Institucional de Revisión
Formulario de Aprobación de una Actividad Sociológica o de Comportamiento



Número asignado al protocolo: 2014-12

Fecha sometido: 6 diciembre 2014

Fecha Aprobado: 8 dic 2014 [Aprobación expira en un año: 7 dic 2015]

Título de la Investigación: Las Redes Sociales de las Mujeres Viviendo con el VIH/SIDA

CATEGORÍA DE APROBACIÓN

- Esa actividad no fue aprobada.
- Esa actividad fue referida para una revisión completa por el comité.
- Esa actividad fue aprobada como las siguientes categoría(s):

Categorías de Revisiones Exoneradas

1. Actividades típicas educacionales
2. Pruebas educativas, encuestas, entrevistas o observaciones del comportamiento público (no identificadores ni un tema sensible)
3. Investigaciones que involucran personas políticas públicas (tal como, políticos y candidatos)
4. Revisión de datos, documentos, muestras que son públicos o no tienen enlaces que identifican la fuente personal
5. Evaluación de programas de servicios de beneficio público; monitoreo y evaluación de calidad de servicios de CEyC.
6. Investigaciones de la calidad y aceptación de comida y/o el sabor

Categorías de Revisiones Aceleradas

1. Muestras de sangre rutina y de poco volumen (menos de 25 ml.)
2. Investigaciones clínicas que no incluyen medicinas ni aparatos experimentales*
3. La colección de datos por métodos no invasivos (por ejemplo, entrevistas rutinas clínicas)
4. Datos, documentos, muestras, entre otros, no colectados originalmente por fines de investigación
5. La colección prospectiva de muestras biológicas a través de métodos no invasivos
6. La grabación de audio o video por fines de investigación
7. La compilación de encuestas, entrevistas, y/o historias orales (entre otros) de individuos o grupos

* Todos las medicinas o aparatos han sido aprobado previamente y son disponibles en una farmacia; el uso de las dichas medicinas/aparatos conforme a sus indicaciones aprobados.

CONSENTIMIENTO INFORMADO

1. Documentación de consentimiento:

- Sometido para revisión exonerada. Documentos de consentimiento informado no son necesarios.
- El formulario de consentimiento informado ha sido revisado y aprobado.
- Una excepción o variancia en el consentimiento informado ha sido dado. El proceso de consentimiento informado ha sido revisado y aprobado. La actividad califica por una excepción o variancia porque:
- 1) no hay más de un riesgo mínimo;
 - 2) la excepción o variancia no va a impactar los derechos ni el bienestar de los sujetos;
 - 3) la actividad tiene asuntos logísticos o pragmáticos que vaya a ser estorbados por el consentimiento informado; y
 - 4) cuando es apropiado, sujetos recibirán información pertinente después de participación.
- Una excepción o variancia de documentación de consentimiento informado ha sido dado. El proceso de documentación ha sido revisado y aprobado. La actividad califica por una excepción o variancia porque:
- nada más que el formulario conecta el sujeto y la actividad, y el riesgo principal vaya a ser el perdido de confidencialidad; y/o
- la actividad no presenta más de un riesgo mínimo y no tiene nada que requiere un permiso firmado normalmente.

Revisado por:

Firma:

Fecha: Fecha firmada.

8-12-14

NOTAS

Notas y comentarios. Favor, limitarlos al espacio disponible en esa página.

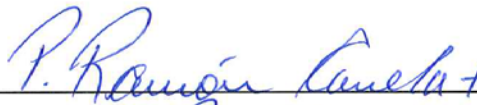
**Master of Public Health Program**

Boonshoft School of Medicine
 Center for Global Health
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 FAX (937) 258-5544
 med.wright.edu/mpH

La Clínica Episcopal Esperanza y Caridad le da permiso a Emily Surico para ejecutar su investigación "Las Redes Sociales de las Mujeres Viviendo con el VIH/SIDA" ["Social Networks of Women Living with HIV/AIDS"] con la Clínica como el base de operaciones. La Clínica va a proveer 1) revisión ético del protocolo por su Comité Institucional de Revisión, 2) los contactos para identificar participantes y 3) algún soporte logístico (tal como "wifi").

Clínica Episcopal Esperanza y Caridad grants permission to Emily Surico to conduct her investigation "Social Networks of Women Living with HIV/AIDS" ["Las Redes Sociales de las Mujeres Viviendo con el VIH/SIDA"] with the Clinic as a base of operations. The Clinic will provide 1) ethical review of the protocol by its Institutional Review Board, 2) contacts to identify participants, and 3) some logistical support (such as use of "wifi").

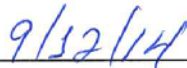
Firma / Signature: _____



Puesto en la Clínica / Position at the Clinic: _____




Fecha / Date: _____




Appendix 3: IRB Approval Letter Wright State University

Office of Research and Sponsored Programs
201J University Hall
3640 Col. Glenn Hwy.
Dayton, OH 45435-0001
(937) 775-2425
(937) 775-3781 (FAX)
e-mail: rsp@wright.edu

DATE: February 24, 2015
TO: Emily Surico, PI, MPH Student
Community Health
Michael Dohn, M.D., Faculty Advisor
FROM: Jodi Blacklidge 
Program Facilitator, WSU-IRB
SUBJECT: SC# 5779
'Social Networks of Women Living with HIV/AIDS'

This memo is to verify the receipt and acceptance of your response to the conditions placed on the above referenced human subjects protocol/amendment.

These conditions were lifted on: 02/24/2015

This study/amendment now has full approval and you are free to begin the research project. If this is a VA proposal, you must still receive a letter of approval from the Research and Development Committee prior to beginning the research project. If this is a MVH proposal, you must still receive a letter of approval from the Human Investigation and Research Committee (HIRC) prior to beginning the research project. This implies the following:

1. That this approval is for one year from the approval date shown on the Action Form and if it extends beyond this period a request for an extension is required. (Also see expiration date on the Action Form)
2. That a progress report must be submitted before an extension of the approved one-year period can be granted.
3. That any change in the protocol must be approved by the IRB; otherwise approval is terminated.

If you have any questions concerning the condition(s), please contact me at 775-3974.

Thank you!
Enclosure

RESEARCH INVOLVING HUMAN SUBJECTS

SC# 5779

ACTION OF THE WRIGHT STATE
UNIVERSITY
EXPEDITED REVIEW
Assurance Number: FWA00002427

Title: *'Social Networks of Women Living with HIV/AIDS'*

Principal Investigator: Emily Surico, PI, MPH Student
Michael Dohn, M.D., Faculty Advisor
Department: Community Health

Expedited Category: 7

The Institutional Review Board has approved the use of human subjects on this proposed project with conditions previously noted. The conditions have now been removed.

REMINDER: FDA regulations require prompt reporting to the IRB of any changes in research activity, changes in approved research during the approval period may not be initiated without IRB review (submission of an amendment), and prompt reporting of any unanticipated problems (adverse events).

Opdi Blockledge
Signed _____ Program Facilitator, WSU-IRB

Expedited Review Date: February 13, 2015

IRB Meeting Date: March 16, 2015

This approval is effective only through: February 13, 2016
To continue the activities approved under this protocol you should receive the appropriate form(s) from Research and Sponsored Programs (RSP) two to three months prior to the required due date. If you do not receive this notification, please contact RSP at 775-2425.

Appendix 4: Informed Consent Form

The attached Informed Consent Statement printed on WSU MPH Program letterhead was originally composed in the Spanish language with reference to consent forms from other studies that Dr. Michael Dohn used during his 14 years working in the Dominican Republic (2000-2014).

Accordingly, there are no English language originals, Spanish translations, or back translations into English available.

There are

1. the original Spanish language consent submitted to and approved by a local IRB (HHS IRB registration number IORG0007257, local IRB protocol number 2014-12, approved 8 December 2014 – Approval document in Appendix 2) and
2. an English language translation to accompany this submission to the Wright State University IRB.

The original Spanish consent form follows this sheet, with the English language translation afterwards.

**Master of Public Health Program**

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 FAX: (937) 258-5544
 med.wright.edu/mph

Formulario del Permiso Informado para Participantes en la Investigación

Título: Las Redes Sociales de las Mujeres Viviendo con el VIH/SIDA

Dirigido por: Emily Surico, estudiante en salud pública

Email: surico.3@wright.edu

Tel: +1 937 258-5555

Dr. Michael Dohn, supervisor

Email: michael.dohn@wright.edu

Mobile: +1 513 266-9020



Dr. Cristina Redko, directora

Email: cristina.redko@wright.edu

Antes de participar en ese programa, es importante que entienda esta explicación sobre la actividad.

Yo entiendo que:

- **El propósito de la investigación** es entender el impacto de algunos asuntos de género entre las mujeres Dominicanas afectadas por el VIH/SIDA. El enfoque de la actividad es las redes sociales y sus relaciones a la vida de personas viviendo con el VIH/SIDA.
- **Los métodos** son entrevistas con grabaciones audios. Cada encuentro para una entrevista va a durar más o menos una hora (y nunca más de dos horas).
- **Mi participación es voluntaria.** No hay ninguna obligación a participar. No hay penas por no participar. La alternativa es simplemente no participar.
- Además, yo **puedo retirarme de la investigación** en cualquier momento sin problemas ni consecuencias. No hay penas por retirarme.
- **No hay riesgos identificados** de la investigación. Quizá habría riesgos desconocidos.
- **No hay beneficios directos** para mí.
- Los materiales de la investigación (ese formulario, las grabaciones, las notas, el análisis, entre otros) **van a estar confidencial** y accesible solo a los investigadores nombrados arriba. Tal vez se publicarían los datos en resúmenes, artículos, o en otro parte; sin embargo, yo no voy a ser identificado por nombre.

Por ese medio, la firma abajo indica que yo quiero participar en la investigación "Las Redes Sociales de las Mujeres Viviendo con el VIH/SIDA" y estoy dando permiso para mi participación.

Fecha: _____

Firma de participante: _____

Portador(a) del Cedula No. _____

Firma de Testigo: _____

**Appendix 1. English language translation of original Spanish language document.
Informed consent form for Emily Surico’s protocol “Social Networks of Women living with
HIV/AIDS”**

The document is a single page printed on Wright State University Letterhead from the Master of Public Health Program. Letterhead information is not included in this translation. The English translation begins below.



Informed consent form for participants in the investigation

Title: The social networks of women living with HIV/AIDS

Managed by: Emily Surico, public health student Email: surico.3@wright.edu

Telephone: +1 937 258-5555

Dr. Michael Dohn, supervisor

Email: michael.dohn@wright.edu

Mobile: +1 513 266-9020

Dr. Cristina Redko, director

Email: cristina.redko@wright.edu

[A picture of a red AIDS ribbon and a horizontal line separate the page at this point.]

Before participating in this program, it is important that you understand this explanation of the activity.

I understand that:

- The purpose of this investigation is to understand the impact of some gender issues among Dominican women effected by HIV/AIDS. The focus of the activity is the social networks and their relationship to the lives of people living with HIV/AIDS.
- The methods are interviews with audio recordings. Every meeting for an interview will last about an hour (and never more than two hours).
- My participation is voluntary. There is no obligation to participate. There are no penalties for not participating. The alternative to participating is simply to not participate.
- In addition, I can quit [“leave”, “remove myself from”, and “withdrawal from” are alternative translations] the investigation at any moment without problems or consequences. There are no penalties for quitting.

- There are no identified risks of the investigation. Possibly, there might be unknown risks.
- There are no direct benefits for me.
- The materials of the investigation (this form, the audio recordings, the notes, the analysis, among others) are going to be confidential and available only to the investigators named above. It is possible that information will be published in summaries, articles, or in other ways; however, I will not be identified by name.

By this means, my signature below indicates that I want to participate in the investigation “The social networks of women living with HIV/AIDS” and that I am giving consent for my participation.

Date: _____

Signature of participant: _____

Bearer of national identification number: _____

Signature of witness: _____

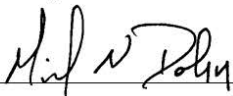
[A horizontal line separates the page at this point.]

Informed Consent ~ The social networks of women living with HIV/AIDS



Spanish to English translation by Michael N. Dohn, MD MSc

24 January 2015



Appendix 5: List of Competencies Met in CE

Tier 1 Core Public Health Competencies Checklist

Domain #1: Analytic/Assessment Skills
Describes factors affecting the health of a community (e.g., equity, income, education, environment)
Identifies quantitative and qualitative data and information (e.g., vital statistics, electronic health records, transportation patterns, unemployment rates, community input, health equity impact assessments) that can be used for assessing the health of a community
Applies ethical principles in accessing, collecting, analyzing, using, maintaining, and disseminating data and information
Collects valid and reliable quantitative and qualitative data
Describes public health applications of quantitative and qualitative data
Uses quantitative and qualitative data
Describes assets and resources that can be used for improving the health of a community (e.g., Boys & Girls Clubs, public libraries, hospitals, faith-based organizations, academic institutions, federal grants, fellowship programs)
Contributes to assessments of community health status and factors influencing health in a community (e.g., quality, availability, accessibility, and use of health services; access to affordable housing)
Describes how evidence (e.g., data, findings reported in peer-reviewed literature) is used in decision making
Domain #2: Policy Development/Program Planning Skills
Contributes to state/Tribal/community health improvement planning (e.g., providing data to supplement community health assessments, communicating observations from work in the field)
Identifies current trends (e.g., health, fiscal, social, political, environmental) affecting the health of a community
Gathers information that can inform options for policies, programs, and services (e.g., secondhand smoking policies, data use policies, HR policies, immunization programs, food safety programs)
Describes implications of policies, programs, and services
Domain #3: Communication Skills
Communicates in writing and orally with linguistic and cultural proficiency (e.g., using age-appropriate materials, incorporating images)
Solicits input from individuals and organizations (e.g., chambers of commerce, religious organizations, schools, social service organizations, hospitals, government, community-based organizations, various populations served) for improving the health of a community
Facilitates communication among individuals, groups, and organizations
Describes the roles of governmental public health, health care, and other partners in improving the health of a community
Domain #4: Cultural Competency Skills
Describes the concept of diversity as it applies to individuals and populations (e.g., language, culture, values, socioeconomic status, geography, education, race, gender, age, ethnicity, sexual orientation, profession, religious affiliation, mental and physical abilities, historical experiences)
Describes the diversity of individuals and populations in a community
Describes the ways diversity may influence policies, programs, services, and the health of a community
Recognizes the contribution of diverse perspectives in developing, implementing, and evaluating policies, programs, and services that affect the health of a community
Addresses the diversity of individuals and populations when implementing policies, programs, and services that affect the health of a community
Describes the effects of policies, programs, and services on different populations in a community
Describes the value of a diverse public health workforce
Domain #5: Community Dimensions of Practice Skills
Describes the programs and services provided by governmental and non-governmental organizations to improve the health of a community
Recognizes relationships that are affecting health in a community (e.g., relationships among health departments, hospitals, community health centers, primary care providers, schools, community-based organizations, and other types of organizations)
Suggests relationships that may be needed to improve health in a community
Supports relationships that improve health in a community

Domain #5: Community Dimensions of Practice Skills (continued)
Collaborates with community partners to improve health in a community (e.g., participates in committees, shares data and information, connects people to resources)
Engages community members (e.g., focus groups, talking circles, formal meetings, key informant interviews) to improve health in a community
Informs the public about policies, programs, and resources that improve health in a community
Domain #6: Public Health Sciences Skills
Describes how public health sciences (e.g., biostatistics, epidemiology, environmental health sciences, health services administration, social and behavioral sciences, and public health informatics) are used in the delivery of the 10 Essential Public Health Services
Retrieves evidence (e.g., research findings, case reports, community surveys) from print and electronic sources (e.g., PubMed, Journal of Public Health Management and Practice, Morbidity and Mortality Weekly Report, The World Health Report) to support decision making
Describes the laws, regulations, policies, and procedures for the ethical conduct of research (e.g., patient confidentiality, protection of human subjects, Americans with Disabilities Act)
Domain #7: Financial Planning and Management Skills
Describes the structures, functions, and authorizations of governmental public health programs and organizations
Describes government agencies with authority to impact the health of a community
Adheres to organizational policies and procedures
Provides information for proposals for funding (e.g., foundations, government agencies, corporations)
Provides information for development of contracts and other agreements for programs and services
Describes how teams help achieve program and organizational goals (e.g., the value of different disciplines, sectors, skills, experiences, and perspectives; scope of work and timeline)
Motivates colleagues for the purpose of achieving program and organizational goals (e.g., participating in teams, encouraging sharing of ideas, respecting different points of view)
Domain #8: Leadership and Systems Thinking Skills
Incorporates ethical standards of practice (e.g., Public Health Code of Ethics) into all interactions with individuals, organizations, and communities
Describes public health as part of a larger inter-related system of organizations that influence the health of populations at local, national, and global levels
Describes the ways public health, health care, and other organizations can work together or individually to impact the health of a community
Contributes to development of a vision for a healthy community (e.g., emphasis on prevention, health equity for all, excellence and innovation)
Identifies internal and external facilitators and barriers that may affect the delivery of the 10 Essential Public Health Services (e.g., using root cause analysis and other quality improvement methods and tools, problem solving)
Describes the impact of changes (e.g., social, political, economic, scientific) on organizational practices

Concentration Specific Competencies Checklist

Global Health:
Identify strategies that strengthen community capabilities for overcoming barriers to health and well-being
Exhibit interpersonal skills that demonstrate willingness to collaborate, trust building abilities, and respect for other perspectives
Identify and respond with integrity and professionalism to ethical issues in diverse economic, political, and cultural contexts
Apply the health equity and social justice framework for the analysis of strategies to address health disparities across different populations
Conduct evaluation and research related to global health
Enhance socio-cultural and political awareness
Apply systems thinking to analyze a diverse range of complex and interrelated factors shaping health at local, national, and international levels