

AIDS Stigma in the Puerto Rican Community: An Expression of Other Stigma Phenomenon in Puerto Rican Culture

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Abstract

Puerto Ricans have been disproportionately affected by the AIDS epidemic in the United States (CDC, 2000). Although the Puerto Rican community is known to be family-centered, often their infected members have had to face their illness without family and community support. A central assumption in this paper is that a compelling cultural phenomenon exists in the Puerto Rican community when it is faced with HIV/AIDS. It is strongly linked to the culture's deep religious and spiritual roots that seem to take hold within the context of the meaning Puerto Ricans give to HIV/AIDS. These roots have pushed the HIV and AIDS illness into the realm of sin and evil. This culture's inability to condone the shameful and sinful behaviors associated with HIV/AIDS, the fear of casual transmission, and the fear of bochinche (malicious gossip) have driven many infected persons to keep their diagnosis secret in order to avoid the inevitable rejection from family and community.

Keywords: Acquired Immune Deficiency Syndrome; stigma; culture; family; Puerto Rico.

El Estigma del SIDA en la Comunidad Puertorriqueña: Una Expresión de otro Fenómeno de Estigma en la Cultura de Puerto Rico

Compendio

La comunidad puertorriqueña en los Estados Unidos ha sido desproporcionadamente afectada por la epidemia del SIDA (CDC, 2000). Aunque es una cultura centrada en la familia, frecuentemente sus miembros infectados enfrentan su enfermedad sin apoyo de la familia o la comunidad. Una idea central de este trabajo es que existe un fenómeno cultural importante en la comunidad puertorriqueña al enfrentar el VIH/SIDA. Está fuertemente atado con las raíces culturales basadas en la religión y la espiritualidad que parecen controlar los significados asociados al VIH/SIDA. Estas raíces han empujado al VIH/SIDA al reino del pecado y la maldad. La inhabilidad de esta cultura de aceptar las conductas catalogadas como bochornosas y pecaminosas, el miedo al contagio, y el miedo al bochinche (chisme malicioso) han hecho que muchas personas mantengan su diagnóstico en secreto para evitar el rechazo de la familia y la comunidad.

Palabras clave: Síndrome de Inmunodeficiencia Adquirida; estigma; cultura; familia; Puerto Rico.

Although Hispanics comprise 14% of the United States population, they account for 19% of AIDS cases diagnosed since the beginning of the epidemic (Office of HIV/AIDS Surveillance, 2004). Among Hispanics, Puerto Ricans are at risk several times greater than whites and other Hispanics throughout the country (Center for Disease Control [CDC], 2000). This data suggest that Puerto Ricans have been disproportionately affected by the AIDS epidemic and are experiencing a profound impact in their communities throughout the country. One study shows that the Puerto Rican infected person often struggles with the challenges of his/her illness without the support of family and community (Roldán, 2003). These figures also indicate that current AIDS prevention programs are not reaching this community. In order to help and serve this population, we need to understand the cultural attitudes, values and beliefs

that influence the Puerto Rican community's view of HIV/AIDS and how these may affect the community's response to a member with AIDS.

Background

This paper is based on findings from a qualitative study conducted with Puerto Rican people living with HIV/AIDS (PWHAs) in Chicago. The sample included 16 PWHAs adults and 3 PWHAs partners (six females and thirteen males). Because some participants only spoke Spanish, the informed consent was provided in both English and Spanish. Special consideration was given to the possibility that the interviews could evoke discomfort or anxiety in some participants. In the event this occurred, additional support and/or intervention were offered. Interviews were semi-structured and tape recorded. I was the primary interviewer which necessitated a high degree of interaction with participants. General questions during the interviews with participants focused not only on their experience with HIV/AIDS, but also how they experienced their family's response to their

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illness. Cultural attitudes, beliefs and values, and self-perceived acculturation levels were examined through topics such as attitudes about homosexuality, drug use, premarital and extramarital sexual relations; beliefs about HIV transmission; attitudes about gender roles (machismo² vs. marianismo³); and level of interaction with others outside of their culture. Data were collected, organized, and analyzed according to the grounded theory method for qualitative research detailed in Straus and Corbin (1998).

While the number of participants in this study is small and represents a limited geographical area in Chicago, this research aimed to capture depth and richness rather than broad representation. This sample also represented the population most at risk for HIV/AIDS in Puerto Rican communities – the injection drug user. The findings provide important knowledge about the experiences of the sample participants.⁴

Although this paper illustrates the psychological transformation in Puerto Rican HIV/AIDS individuals previously documented by Shelby (1992, 1995), it focuses primarily on the cultural context within which this transformation occurs. These individuals fiercely avoid the effects of the stigma attached to their illness by keeping their diagnosis secret. In my study, I found that often Puerto Rican PWHAs experience rejection and isolation by family and community. The data suggests that there is an interaction between Puerto Rican cultural values and belief systems and the stigma Puerto Rican people attribute to HIV/AIDS. This interaction is at the root of the breakdown of the family system.

Flaskerud and Ruiz-Calvillo (1991) suggest that traditional beliefs about the prevention, cause and treatment of illness often attributed to peoples of Spanish, Mediterranean, and Hispanic origins are those influenced by the Hippocratic doctrine of humoral balance. The theory of humoral balance proposes that health is a state of balance among body humors causing the body not to be excessively dry, wet, hot, or cold. Religion, having faith, regular confession, penance, and devotion to God, the Virgin, and the Saints are believed to result in both spiritual and physical well-being and good health. Hispanics place a high value on spiritual matters. Therefore, classifying the causes of illness into natural and supernatural categories is common in their community. Natural illnesses are those caused by exposure to cold, damp, and impurities, lowered resistance,

and improper diet. Supernatural approaches to health promote beliefs such as sinful acts can cause diseases, and miracles performed by God can cure them. Pares-Avila and Montano-Lopez (1994) caution that the accuracy of these generalizations about cultural beliefs and values may vary as a result of the acculturation process, individual personality differences, or subgroups variations. In my clinical experience, however, Hispanics who are more acculturated tend to retreat to this way of thinking when under stress or facing serious illness.

I also caution the accuracy of the following generalizations about Puerto Ricans but believe some understanding of the Puerto Rican family is necessary to fully appreciate the lived experience of the Puerto Rican PWA. Providing the cultural context is crucial because one cannot begin to understand the contradictions observed in the Puerto Rican community when it comes to HIV/AIDS without exploring the Puerto Rican's reality of HIV/AIDS and their explanatory model for this illness.

Puerto Rican families are characterized as people who, in times of stress, turn to their families (Garcia-Preto, 1982; Morales & Bok, 1992). The Puerto Rican family is described as loving, caring, and nurturing. Family members are expected to come to the aid of those members experiencing a crisis. In terms of cohesion and adaptability, Puerto Rican families encourage interdependence with emphasis on the group rather than the individual. Families value unity, family ties, and intense relationships. The family ensures safety, protection, and caretaking for life *as long as the person remains within the cultural norms*. Therefore, separations are experienced with profound grief and reunions are cause for celebration (Garcia-Preto, 1982). Typically, Puerto Ricans are also moralistic and traditional in family values. These characteristics have endured despite family disruptions caused by poverty, dislocations from rural to urban settings, and migration between the United States and Puerto Rico.

Although the majority of Puerto Ricans in Puerto Rico and the United States are Roman Catholics, spiritism is a widespread belief system in Puerto Rican communities. Often the beliefs regarding health and illness have roots in the world of spirits and humors (Flaskerud & Ruiz-Calvillo, 1991; Harwood, 1977; Hohmann, et al., 1990). Spiritism is a belief system that serves as a religion which posits that the world is inhabited by both good and evil spirits. Good spirits are responsible for good luck and health. Evil spirits are responsible for sickness and suffering (Delgado, 1979). Illness and suffering may also be attributed to evil influences exacting punishment to those who engage in sinful acts.

Morales and Bok (1992) and Garcia-Preto (1982) emphasize that Puerto Ricans PWA constitute a distinct ethnic group. They also suggest that individuals who engage in behaviors that put themselves at risk of contracting HIV/AIDS such as drug abuse, prostitution, and

² Machismo: System belief that men are superior and must always be in control in all situations, including family life and sexuality.

³ Marianismo: System belief that women should be in a submissive position and like the virgin Mary, always suffering and unselfish.

⁴ A more detailed description of the study's methodology can be found in Roldán, 2003.

homosexuality are ostracized within the Puerto Rican community (Ayala & Diaz, 2001). The negative attitude toward these behaviors often leads to social denial, which these authors believe makes prevention of at-risk behaviors more difficult. Most importantly, the culture's condemnation of these behaviors forces the Puerto Rican person to keep his/her diagnosis secret from family and community.

For the Puerto Rican PWHA, the HIV/AIDS experience has its own distinct characteristics and qualities which are unique to this culture. As mentioned earlier, Puerto Ricans have been experiencing the devastating effects of the AIDS epidemic for almost twenty years. Many have suffered multiple losses going back at least two generations. The primary mode of transmission of HIV/AIDS *"I've been surrounded by drugs since I was 16 years old. My older brothers used and were dealing."* *"I started doing drugs when I was 9 years old. I used to go to shooting galleries to get high. I'm 40 years old now."* *"I've been an addict for 20 years. I have gone through several rehab programs, too. I've tried to get off this stuff"*. In this community has been through injection drug use. In the mostly poor urban Puerto Rican communities throughout the United States, the pervasiveness of drugs and drug use appears to be tolerated and accepted as a way of life. Several participants stated: Families often express compassion toward the drug abuser in their family and community.

Although HIV/AIDS has also become pervasive in their communities, Puerto Ricans are responding in a way that runs contrary to this culture's strong values of close family ties, unity, and intense relationships. Although families of injection drug users have experienced much disappointment, worry, and frustration with their drug addicted members, they tend not to withdraw their support. Not until family members contract HIV/AIDS does the family support become threatened.

Roland (1988) describes a different organization of the self which helps to illustrate how the experiential sense of self is of a "we-self." Self-esteem would be closely linked to strong identifications with the reputation and honor of the family and other groups. It is called the familial self. According to Roland (1988), the familial self is a basic inner psychological organization that allows women and men to function well within the intimacy relationships of the extended family and community. It involves intensely emotional intimacy relationships where emotional connectedness and interdependence is emphasized.

Given that the Puerto Rican family develops from a relationship-centered culture, the HIV/AIDS crisis then has transformed the relationship-centered culture dramatically. It has left their infected members with extreme feelings of disconnectedness, rejection and abandonment. PWHA are

then faced with a developmental challenge which is an anomaly in their culture. They are, perhaps for the first time, pushed into more autonomous, independent functioning. They have to face HIV/AIDS alone without the safety and security of the family.

Development of the Theoretical Proposition

In the case of HIV/AIDS, the culture's strong religious and spiritual roots seem to take hold within the context of the meaning Puerto Ricans give to this illness. These religious and spiritual roots seem to have pushed the HIV and AIDS illness into the realm of sin and evil and underlie the stigmatization of the HIV/AIDS illness in this community. The inability to condone the shameful and sinful behaviors associated with HIV/AIDS and the fear of casual transmission have driven many of these families to push away their infected members. I contend that the family's and the community's negative response to their infected member is due to the culture's condemnation of behaviors associated with HIV/AIDS.

Therefore, immense psychological stress is experienced when someone in the Puerto Rican community is diagnosed with HIV/AIDS. Risking the loss of family support puts the Puerto Rican PWHA in a despairing situation. Feeling vulnerable, frightened, confused, and ashamed, the infected person wishes and expects to be surrounded by the safety and security of the family. This wish only gives rise to angry and resentful feelings because the Puerto Rican PWHA, expecting to be judged and rejected by both family and community, is subjected to suffering in silence.

As a result, living with HIV/AIDS makes unusually tough demands on the Puerto Rican PWHA. Many are fending off depressive, angry feelings which they believe can only debilitate them further. *"When you're sick, it is necessary to maintain a state of peace. Tension and stress makes one depressed and affects the immune system."* In addition, the mental energy that is required to defend against these feelings is often overpowering. In their daily lives they must cope with their mortality and their fantasies about death without losing hope and giving into feelings of despair. For most participants, beliefs about death were rooted in their Catholic upbringing, and they often expressed a loss of hope for redemption because of their sinful acts. PWHA will not only face death alone and die in secret; they will also be condemned to burn in hell (Roldán, 2003).

Because Puerto Rican PWHA cannot depend on the customary support of the family, their support system may just include his/her partner. It may or may not include children, parents, or siblings. The fear of rejection and humiliation has forced PWHA, and sometimes his/her nuclear family, to separate from extended family. They feel forced

to function more autonomously in order to protect themselves and their families from the stigma associated with the HIV/AIDS illness. Thus, keeping the secret is of paramount importance.

Due to the Puerto Rican community's attitude toward HIV/AIDS, facing the reality of their illness is complicated by a very strong code of secrecy. Underlying this code of secrecy is the fear of *bochinche* (malicious gossip). *Bochinche* is perceived as harmful, intrusive, and destructive; yet it is a part of the social fabric of the Puerto Rican community. It is often fueled and driven by misinformation and fear. Statements common among participants were: "*They find out somebody is HIV and they start talking.*" "*They have nothing good to say.*" "*Shit, you're still human.*"

Avoiding *bochinche* requires one to expend much psychic energy because of the fear of being subjected to the humiliation, shame, and rejection of others. In many ways, fear of *bochinche* seemed to organize the lives of the participants in my study as they continually struggled to maintain their diagnosis secret from loved ones and community. It is a daily preoccupation and worry about what others may think or say. Keeping the diagnosis secret functions as a self-protective measure against the destructive forces of *bochinche*. As one participant stated, "*My family thinks he has cancer. I will keep his secret until he dies. I will bury his secret with him.*" In addition, there is the fear that the family will become the target of *bochinche*. This is the driving force behind keeping the HIV/AIDS diagnosis secret. A participant stated, "*My parents don't know. Don't want to unnecessarily cause them trauma.*" This concern overrides any anxiety PWHAs have about himself/herself and is the source of much distress in this community. For instance, one participant declared, "*You know Puerto Ricans; they're bochinchosos (gossipers). Make a mountain out of a mole hill.*" Another participant stated, "*We don't tell anyone [about being infected] to avoid bochinche and have people drag us through the mud.*"

Bochinche appears to be a necessary evil in the Puerto Rican community in Chicago and on the island as well. It symbolizes the intense social interactions this population enjoys and dreads. *Bochinche* seems to be a form of communication which keeps people involved with one another. There is a sharing of life's joys and sorrows with others in the community. As a result, people respond by offering help and comfort. *Bochinche* also seems to be experienced as something invisible with supernatural qualities and powers. Everyone fears it. Yet, everyone does it. It is feared because in matters that are considered evil, *bochinche* rears its malevolent head. It brings with it destruction and shame

Bernal y Del Rio (1982), a psychoanalyst practicing in Puerto Rico, attempts to dynamically explain *bochinche*. He suggests that the geographical closeness, the extended family, and the intense social contacts of the Puerto Rican people are what make the psychoanalytic situation special in Puerto Rico. Given these features, he reports that any of his analysands "can get for the asking a more-or-less benevolent but thorough biography of mine" (Bernal y Del Rio, 1982). However, when it comes to HIV/AIDS, PWHAs and his family struggle with the fear that a malevolent biography (*bochinche*) would be spread throughout the community. The fear is rooted in the inescapable shame and humiliation *bochinche* will bring to PWHAs and his/her family should the diagnosis become public knowledge. It is also the motive behind the collective secrecy in the community (Roldán, 2003). Fimbres (1993) refers to how the Hispanic family's fear of not only what the neighbors will say and even do often prevents them from acknowledging a member has died due to HIV complications. *Bochinche* then becomes a metaphor for the AIDS illness. It is almost as if the greater fear is of becoming infected with *bochinche*.

There is a sense that one is helpless from the onslaught of *bochinche*. PWHAs express anger and frustration about having to keep their illness a secret. They overwhelmingly blame an external source for their community's struggle with the disease. *Bochinche* is also blamed as the source of the Puerto Rican community's ignorance regarding HIV/AIDS. Although there is much available information about AIDS, the Puerto Rican community is still greatly misinformed. Because misinformation is fueled by *bochinche*, when it comes to HIV/AIDS the Puerto Rican community reacts with fear and panic. Therefore, PWHAs feel helpless when faced with the possibility of someone finding out his/her secret.

PWHAs experience their family's revulsion and fear but do not feel these feelings can be openly expressed. They cannot tell their families how it feels to be treated "like a leper". Another participant lamented, "*They say and do stupid things. They're still afraid of contracting the disease. I have seen a lot of ignorance when it comes to AIDS. People turn away. It's sad*". There seems to be some great prohibition about speaking and expressing these feelings to family members. In fact, there is evidence of a giant collusion among family members. Perhaps this is due to cultural inhibitions regarding taboo subjects such as sex or behaviors considered sinful (Marin, 2003). Also, open communication related to topics such as feelings of loss and shame seems to be discouraged. Bardach (1995) similarly found that when confronted with the illness of AIDS, open communication within the Hispanic family seems

to break down and instead a “conspiracy of silence” is adopted.

This lack of communication often leaves PWHAs feeling isolated and abandoned. Although families do not cut off all contact with the infected person, interactions tend to change dramatically. Many participants interviewed have been subjected to countless painful experiences of rejection by immediate family, friends, and strangers. One participant stated, “*They don’t know the facts about the disease, so I don’t know if they’re going to have a separate glass or plate for me.*” Another infected participant added, “*Since I found out I had the virus, I isolate myself. I don’t visit family or friends like I used to.*” The intense connection and intimacy PWHAs enjoyed within the family prior to disclosing his/her HIV/AIDS diagnosis no longer exists. PWHAs feel his/her family’s anxiety and fear when in their presence. Even customary ways of greeting one another are modified. No longer can they enjoy the physical contact so casually offered to other members of the family. These experiences lead to feeling very vulnerable, and in order to protect themselves from further hurt, PWHAs often choose to distance themselves from their family. Although my study data (Roldán, 2003) suggest that participants did not experience out-right rejection by family, these experiences invariably left them feeling unwanted.

Conclusion

Rolland (1994) suggests that a family characteristic which is generally viewed as dysfunctional under certain circumstances can be adaptive during a health crisis. Systems theory also views a family’s response to stressors or crises in terms of its coping and adaptation abilities. A balance between cohesion and adaptability allows family members to manage and resolve hardships without losing their sense of independence and connection to their families (Walsh, 1982).

There is an assumption in the statement above which alludes to the Western value of maintaining independence while remaining connected to family. This statement does not reflect a unitary Hispanic family systems model or unitary Puerto Rican family systems model. However, it is helpful to look at how some of the family systems concepts compare to what I found in my study. Looking at the Puerto Rican family from a systems perspective, one can identify a characteristic which could enhance their ability to cope with a health crisis. That characteristic is cohesion. Rolland (1994) also suggests that family adaptability is a crucial characteristic for well-functioning family systems. Family adaptability or flexibility is essential in facing the challenges of the more progressive, relapsing illnesses such as AIDS.

However, when it comes to HIV/AIDS, the Puerto Rican family is lower in both cohesion and adaptability making it more vulnerable when facing HIV/AIDS.

The Family Systems-Illness Model that Rolland (1994) developed also suggests that a cohesive family is more likely to be able to cope and adapt in a health crisis. This model views illness as dynamic and with specific phases. Each phase has its own psychosocial demands and developmental tasks which present the family with different challenges. Rolland (1994) suggests that not solving the phase-related tasks of the three major phases (crisis, chronic, and terminal) can jeopardize the coping process of the family. According to this model, the crisis phase begins before the actual diagnosis. The individual or family has a sense something is wrong. This is where the Puerto Rican family remains trapped. Although Puerto Rican PWHAs transition onto the other phases and tasks of living with HIV/AIDS, their families do not.

According to Rolland (1994), in the crisis phase proper, there is a sense of the family pulling together. The family group effort is at a premium during this phase. However, the Puerto Rican family seems not to enter into this experience. My data suggest that the Puerto Rican family may not be able to enter into “the pulling together” experience because of their beliefs about the causes of HIV/AIDS. Rolland (1994) found that a family’s belief about the causes of the illness also organizes their experience and mirrors their belief system. These core beliefs shape the family’s reaction, response and coping strategies.

Similarly, the Puerto Rican family’s core beliefs about the causes of HIV/AIDS and illness in general shape their reaction and give rise to the complicated feelings and fantasies which are culturally derived. These beliefs are what drive the Puerto Rican family to act uncharacteristically distant and un-nurturing when faced with HIV/AIDS. The shame associated with the HIV/AIDS illness interferes with the Puerto Rican family’s ability to face the crisis phase developmental tasks that pull the family together. Using this model to understand the Puerto Rican family’s response to HIV/AIDS, one might say that the Puerto Rican family’s unfinished business from the crisis phase blocks their movement onto the other phases. Since many Puerto Rican PWHAs do not disclose their diagnosis to their families, their families remain stuck in the stage where everyone has a sense something is wrong but no one is talking about it.

In addition, the Puerto Rican community’s strong anti-homosexual attitudes affect the family’s response to PWHAs. These attitudes have religious roots which are connected to behaviors considered sinful. They are also connected to the gender roles and social scripts ascribed to men [machismo] and women [marianismo] in the Puerto Rican

culture. Machismo is a complex phenomenon which emphasizes male superiority and the need for the man to present as masculine and dominant. Men are responsible for the family's safety, well-being and the defender of its dignity and honor. It also involves cultural values such as courage and fearlessness. This machismo code makes it difficult for men to accept help or demonstrate vulnerability. Marianismo is the female counterpart of machismo. It is based on the worship of Mary who is both virgin and Madonna in the Catholic religion. The term connotes the chaste and submissive female whose purpose is to bear children and be self-sacrificing, especially when it comes to her husband and family.

Consequently, behaviors associated with HIV/AIDS such as homosexuality and prostitution tend to be viewed as impure, sinful and evil. Therefore, HIV/AIDS is viewed as a punishment from God for sexual transgressions. This belief would undoubtedly affect how others respond to PWHA. As mentioned earlier, culturally based beliefs regarding health and illness have roots in the world of spirits and humors. If sickness and suffering is believed to come to those who engage in sinful acts, HIV/AIDS then afflicts those who have been sinful and impure. Not so explicit is the fear that PWHA is judged homosexual. Becoming the target of *bochinche* could then put one at risk of being seen as homosexual, especially since homosexual behaviors are still thought to be strongly linked to HIV/AIDS. Thus, the drug user living with HIV/AIDS and his family struggle to keep his/her illness secret for fear of being thought of as homosexual. In the Puerto Rican community, being perceived as homosexual is far more shameful than having HIV/AIDS. "*Sharing needles, that's how I got it. I'm not a fag. God, people talk.*" Another participant stated, "*Families worry about what others will say. Before you know it, the whole 'barrio' has judged you, diagnosed you and buried you.*"

The religious and spiritual beliefs which are central to the Puerto Rican individual's reality strongly influence the Puerto Rican's attitude towards prostitution, homosexual activity, and HIV/AIDS. These religious and spiritual beliefs often stimulate PWHA's fantasies about retribution. It is as if HIV/AIDS represents the guilt and shame of all past sins. The fear is that *bochinche* will seal their damnation because this time they have gone too far. HIV/AIDS is the stamp on "the ticket to hell". They are beyond redemption. An uninfected participant who cared for her mother living with AIDS described this painful and conflicting experience, "*My grandmother would be angry with my mom for being infected and call it the Demon's disease. She's very Catholic. Maybe that's where that demon stuff came from. But it would break my mother's heart to hear that.*" Rejection is

understood in terms of retribution. Another participant stated, "*They reject us because the Bible says this or that. It's a sin.*"

It is also believed that an imbalance of body humors can cause illness. This imbalance can occur when impurities enter the body. These impurities can be transmitted through body excretions, saliva, and coughing. In the case of HIV/AIDS, what seems to be coughed or expelled is not a germ. It is instead something impure which seems to be equated with bad or evil. Therefore, if PWHA are viewed as evil, full of impurities, and culpable, one can begin to understand the intense fear this community has of HIV/AIDS. One can also understand why families continue to deny a member has been afflicted with HIV/AIDS. More significantly, we can appreciate the tremendous psychological stress experienced by the infected person as he/she faces the fear of being rejected and abandoned by others.

As PWHA reflect on their future and the prospect of facing death, they experience a combination of resignation, anger and fear. Sadness also emerges as they look back at the people they have lost. Loss of potential, poor choices, shameful acts, and death before fulfillment give rise to much regret for PWHA. "*It hurts me when I think about all the people I've hurt.*" They also live with a sense of impending doom. "*For us [Puerto Ricans] if you have HIV/AIDS you're going to die. It's a matter of time.*" Consequently, there is a wish to avoid talking about the future; yet intrusive thoughts about death and dying are a daily psychic battle. Death means not knowing until Judgment Day if one's sins will be forgiven or if one will be condemned to hell. Therefore, suffering does not end with death. Living in fear of dying a horrific death only to be also punished after death triggers angry and helpless feelings which often result in fantasies about suicide as a way of ending this life's suffering. One participant despaired, "*Before it gets me I will take an overdose.*" Another participant stated, "*My brother gets upset when I tell him that when the time comes I'll take my life.*" It is important to note that what is underlying the anger is the fear of dying alone without family support and comfort. Added to that is the shame associated with the wish to have others take care of them.

Turning to religion appears to free some PWHA from the despair of not knowing what will happen in the end. While not necessarily religious, the belief in a higher power and life after death are strongly held beliefs by most of the PWHA in my study (Roldán, 2003). For many participants, drugs were a way to escape the painful realities of their lives. Although some PWHA did turn

back to drugs as way of coping with fear and anxiety, some turned to their faith to ask for forgiveness in the hope they will be redeemed as they face the painful realities of their illness.

Also, fear of *bochinche* has had a profound impact on the way Puerto Rican families are responding to HIV/AIDS. Fear and *bochinche* are inextricably connected. Beliefs about the causes of HIV/AIDS fuel the fear of *bochinche* which drives the family and PWHAs away from each other. Fear of *bochinche* is a cultural phenomenon which functions as a metaphor for the HIV/AIDS illness in the Puerto Rican community. The greater fear is of becoming infected with *bochinche* which will destroy PWHAs and his family should his/her diagnosis be disclosed. Fear of *bochinche* also serves another function. It pushes the HIV/AIDS illness into the supernatural world that is malevolent and helps to explain the contradictions among cultural standards (Harwood, 1977). *Bochinche* allows family members and the community to distance themselves from the problem. As one participant said, “*They are in the dark – ignorant.*”

In summary, a central assumption in this article is that a compelling cultural phenomenon exists in the Puerto Rican community underlying the stigmatization of HIV/AIDS. It is strongly linked to the culture’s deep religious and spiritual roots that seem to take hold within the context of the meaning Puerto Ricans give to the HIV/AIDS illness. These roots have pushed the HIV and AIDS illness into the realm of sin and evil. This culture’s inability to condone the shameful and sinful behaviors associated with HIV/AIDS, the fear of casual transmission, and the fear of *bochinche* have driven many PWHAs to keep their diagnosis secret.

Most still believe that HIV/AIDS is easily transmitted, that it is contracted when one engages in sinful behaviors such as homosexuality or prostitution, and that it is a death sentence. Because there is enormous shame and dishonor associated with the HIV/AIDS illness, families tend to respond uncharacteristically toward their infected member. Families who ordinarily value family ties, unity and intense relationships break down. They reject their infected member because now this member has crossed the threshold of what is acceptable and tolerated in this culture.

If HIV/AIDS is viewed as a punishment from God for sexual transgressions, the devastating effects of the stigma attached to HIV/AIDS in this community put PWHAs and his family at high risk of being ostracized, rejected and humiliated should their illness be disclosed to the broader community (*bochinche*). Given that the

Puerto Rican community serves as an extended family to most Puerto Rican immigrants and that many rarely come in social contact with communities outside of their own, feeling accepted and respected in one’s community is a matter of survival.

Lastly, I assert that HIV/AIDS prevention programs have failed the Puerto Rican community because they have not tailored interventions that are consistent with the Puerto Rican culture’s values and beliefs. Programs must validate Puerto Rican PWHAs’s cultural experience and encourage behavioral and attitudinal changes within that context. That is, families cannot pull together and respond in a typical way if they are afraid for their own physical and emotional well being. Recognizing and addressing this community’s strong anti-homosexual attitudes, beliefs about health and illness and the roots to the stigma attached to HIV/AIDS is critical to any effective HIV/AIDS prevention program in the Puerto Rican community.

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