

## Culturally Relevant Social Work Services for Latinas Infected or Affected with HIV/AIDS

Yolanda Rodriguez-Escobar<sup>1</sup>,  
Elizabeth C. Pomeroy  
Lori K. Holleran, LaTonya Noel

### Resumen

Al iniciar la tercera década de la pandemia provocada por el VIH/SIDA, las preocupaciones acerca de los aspectos sociales, psicológicos y conductuales de las personas que viven con la enfermedad siguen vigentes. Este padecimiento que en el pasado fue atribuido predominantemente a homosexuales anglosajones se ha extendido en la población heterosexual más allá de las líneas raciales y de clase social. Usuarios de drogas inyectadas han mostrado siempre un riesgo de infección elevado, sin embargo, algunos estudios demuestran que el VIH/SIDA afecta a diferentes poblaciones de forma temerosamente desproporcional. En los Estados Unidos, la pandemia del VIH/SIDA se encuentra representada de manera desproporcionada y crece a tasas más elevadas en las comunidades de minorías étnicas que en el resto de la población (Centers for Disease Control and Prevention [CDC], 2002). Este artículo busca explorar los elementos específicos asociados al VIH/SIDA en minorías raciales y étnicas y se enfoca en particular a la forma como los nuevos casos de SIDA afectan a la población latina. En este contexto se tematizan la falta de acceso a servicios médicos y los factores socioculturales específicos en este grupo y se discuten las implicaciones para el trabajo social práctico, la investigación en el ámbito de las políticas sociales y la educación

### Abstract

As we begin the third decade of the HIV/AIDS pandemic, concerns continue about social, psychological, and behavioral aspects of the living with the illness. What was once thought to be predominately a gay, Anglo disease has now become prominent in the heterosexual population crossing all racial and class lines. Presumed injection drug users have always been highly infected. However, studies show that HIV/AIDS is affecting different populations at shockingly disproportionate rates. The HIV/AIDS pandemic in the United States is disproportionately represented and is growing at a faster rate in ethnic minority communities as compared to majority populations (Centers for Disease Control and Prevention [CDC], 2002). The purpose of

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<sup>1</sup> Yolanda Rodriguez-Escobar is a Ph.D. Candidate at the University of Texas at Austin School of Social Work ([TinyYoli@aol.com](mailto:TinyYoli@aol.com)).

Elizabeth C. Pomeroy is Associate Professor and Director of the BSW Program, The University of Texas at Austin School of Social Work ([bpomeroy@mail.utexas.edu](mailto:bpomeroy@mail.utexas.edu)).

Lori K. Holleran is assistant professor at the The University of Texas at Austin School of Social Work School of Social Work ([lorikay@mail.utexas.edu](mailto:lorikay@mail.utexas.edu)); LaTonya Noel is a Doctoral Student at University of Texas at Austin School of Social Work ([lanoel@mail.utexas.edu](mailto:lanoel@mail.utexas.edu)).

this article is to explore the specific issues associated with HIV/AIDS in racial and ethnic minorities, with a specific focus on how the increase of new AIDS cases is affecting Latinas. Disparities such as lack of access to medical care and unique socio-cultural issues are discussed, followed by implications for social work practice, policy, research, and education.

## **HIV/AIDS and Racial and Ethnic Minorities**

### *Demographic Information*

HIV/AIDS is increasingly an epidemic for lower socioeconomic groups and transcends race, ethnicity, and gender. The growth in number of AIDS cases in the gay community has decreased while African Americans and Latinos remain disproportionately affected. Currently, racial and ethnic minorities comprise approximately 31 percent of the U. S. population, but accounted for more than 68 percent of the nation's new AIDS cases reported (Kaiser Family Foundation [KFF], 2003; Center for Disease Control and Prevention [CDC], 2002). At the beginning of the AIDS epidemic in the United States, Anglo, gay men were most likely to be diagnosed with AIDS and to reflect the public's perception of the stereotype of the illness (Shilts, 1987). This image has been replaced by the new millennium's portrait of AIDS cases, primarily being that of underprivileged urban minority women (Institute of Medicine, 2001).

Over the past decade, the fastest growth rates have been among African American and Latina women. African American and Latina women represent less than 25 percent of total U. S. women; yet, they comprise 90 percent of female AIDS cases reported between 1999 to 2002 (KFF, 2003). African American women and Latinas are currently facing a health crisis in the United States. Latinas and African Americans' risk of acquiring HIV/AIDS is 10 to 15 times greater than that of Caucasian women. In 2000, HIV/AIDS was the third leading cause of death among African American women age 25-44 and the fourth leading cause of death among Latina women in the same age group (CDC, 2002). The Kaiser Family Foundation reports that in 2002, of the number of new AIDS cases per 100,000 population, 13% were Latina and 2% were Anglo, making the AIDS rate of Latinas 6 times higher compared to Anglo women (KFF, 2003).

### *Treatment Disparities*

Many racial disparities are evident in the fight to prevent new AIDS cases among women of color. Infected minority women tend to be poor, young residents of urban areas, particularly in the Northeast and the South. Trends show HIV/AIDS infection is often diagnosed at a later stage in women than in men. This may be due, in part, to poor access to health care by women, especially those in minority populations. Reduced access to health care is associated with disadvantaged socioeconomic status and cultural and language barriers that limit access to prevention information and other services (U. S. Public Health Service's Office on Women's Health, 1998).

Even though great strides have been made involving drug therapy, racial and ethnic minorities are less likely to have access to drugs such as the protease inhibitors. Results of an HIV/AIDS Cost Utilization Study showed disproportionate patterns of care for HIV/AIDS among African Americans (Steinbrook, 1998). Minorities with AIDS are less likely than Anglos to know their viral load and their need for medical treatment, and are more likely to make treatment decisions based on little or poor information. For people living with HIV/AIDS, such a lack of information is devastating. Minorities are less likely to have health coverage than Anglos. At every income level, Latinos/as are less likely to be insured than other racial/ethnic groups (HRSA, 2001). According to Congresswoman, Lillian Roybal-Allard, Chair of the Congressional Hispanic Caucus, "Across all income levels, Latinos consistently have the highest rate of being uninsured. In fact, 33 percent of the forty-two million uninsured people in 1999 were Latinos" (HRSA, 2001). Race and ethnicity are not risk factors, but they are markers for other factors that put people at increased risk, such as lack of health insurance and limited access to care, according to Paul Denning, M. D., epidemiologist from the Centers for Disease Control and Prevention (Greeley, 1995).

### **Literature Review: Research on Latinas and HIV/AIDS**

The dearth of basic and applied research with Latinas/as, in general, is particularly striking given that they constitute the second largest minority group in the United States

and are the fastest growing ethnic minority population (Padilla & Salgado de Snyder, 1985). Latinos comprise 12 percent of the total population of the United States, and account for more than 25 million people. Latinos are also the youngest and fastest growing major population group in the United States. The United States has the fifth largest population of Latinos in the world, following Mexico, Spain, Argentina, and Colombia (Raymond, 2001).

In addition to limited research, another problem related to the research on Latinos lies in the use of terms like “Hispanic” and “Latino” as umbrella terms that are applied across the board to groups with distinct historical, political, economic, and racial differences. Unfortunately, most health data, including the data on HIV/AIDS cases, use the term “Hispanic” and do not distinguish between Hispanic subgroups (Amaro, 2000) specifically, Latinos represent a diverse population group comprised of Mexican Americans (63 percent), Puerto Ricans (11 percent), Central and South Americans (14 percent) and Cubans (5 percent). The remaining 7 percent are Spanish-Mexican-Indians who live almost exclusively in the Southwestern U.S. (Maldonado, 1998).

Most of the literature focused on Latinas and other women of color who are living with HIV/AIDS, address issues related to modes of transmission and demographics rather than on the psychological issues related to Latinas who are living with HIV/AIDS and/or HIV/AIDS-affected. However, in a recent study, Pulerwitz *et al.* (2002) found that Latinas with higher levels of relationship power were five times as likely as women with low levels of relationship power to consistently use condoms. In addition, Dixon, Antoni, Peters, and Saul (2002) found that heightened negative mood (i.e. depression) in Latinas was associated with unprotected vaginal sex. Research also suggests that Latinas are more likely to become infected due to their male partners HIV risk behaviors rather than personal risk behaviors. For example, researchers found that Latinas who had experienced intimate partner violence (IPV) in the past three months were more likely to report HIV/STD risks based on unprotected sex with a male injection drug using partner and/or a male partner infidelity than women who had not experienced IPV (Raj, Silverman, & Amaro, 2004). Despite these studies that reviewed very limited

psychosocial factors related to HIV/AIDS infection in Latinas, research in this area is still lacking with regard to the specific cultural aspects that may interact with psychological functioning and at-risk-behaviors within this population. For instance, statistics from the Center for Disease Control and Prevention [CDC] (2000) site two primary modes of transmission for HIV/AIDS infection in women as injecting drug use and heterosexual contact. However, unlike other female subgroups, Latinas and Asian American women have reported heterosexual contact as their primary mode of transmission (48 % and 46 %, respectively) rather than injection drug use (33% and 17%, respectively). These statistics suggest that there may be unique cultural factors related to Latina and Asian and Pacific Islander women rates of transmission (CDC, 2000).

Currently there is also a dearth of studies addressing the Mexican American women who are living with HIV/AIDS or uninfected and who have made the decision to stay with their HIV/AIDS positive sexual partner. May want to use term serodiscordant in here it is estimated that these numbers are high, particularly in certain geographic regions of the Southwestern United States where the HIV/AIDS prevalence rates are high among this population. While women of color constitute a large proportion of most social work caseloads, the unique needs of women of color are rarely presented in the social work literature (Gutierrez, 1990).

While the number of women diagnosed with AIDS is doubling every one to two years, little is known about the psychological and behavioral factors influencing the transmission of HIV/AIDS in women, the majority of whom are impoverished and socially disadvantaged (Ickovics, Beren, Grigorenko, Morrill, Druley, & Rudin, 2002). It has proved difficult to identify many of the women at risk for HIV/AIDS and to provide appropriate education, counseling, and HIV/AIDS testing services at the many sites where women traditionally receive medical and social services (O'Leary & Jemmott, 1996). The lack of research on Latinas who are living with HIV/AIDS and affected parallels the lack of research on women in general.

## **Issues Unique to HIV/AIDS Infected and Affected Latinas**

### *Gender Issues*

In order to effectively serve Latinas who are, social workers must understand unique factors related to this population. Central to such understanding is the issue of how gender has played a role since the beginning of the AIDS epidemic. The first issue is that women are generally sicker than men at diagnosis, which leads to earlier death rates for women compared to their male counterparts. A contributing factor can be that women tend to exhibit different symptoms related to HIV/AIDS. Another distinction is that the disease seems to take on different patterns of manifestation for women. For example, gynecologic infections are the most commonly reported condition of women living with HIV/AIDS disease and AIDS (Project Inform, 1998). However, despite the fact that this is a commonly reported condition experienced by many women living with HIV/AIDS, it is often overlooked or misdiagnosed by physicians who do not suspect that the patient is “at risk” for HIV infection. Another factor is that there are fewer clinical trials for women. Early in the epidemic, women were not enrolled in HIV/AIDS-related clinical trials, resulting in limited knowledge of the action, safety, and efficacy of drug therapy for women living with HIV/AIDS- (HRSA, 1998). Thus, exclusion from research and clinical drug trials has negatively impacted women’s health and perhaps hastened progression of the disease for individual women (Gallego, 1998).

The second issue is that injection drug use is now the second most frequently reported risk behavior for HIV/AIDS infection among women. About 61 percent of all reported cases of AIDS among women were associated with injection drug use or sex with a drug-injecting partner (HRSA, 1998). Although this is a known mode of transmission, there are few drug treatment programs that are sensitive to the needs of women, especially when children are involved. Early in the HIV/AIDS crisis, women were described by the CDC as “vessels of infection and vectors of perinatal transmission”; thus, they were viewed not as individuals needing medical attention, but as sources of infection to others, i.e., to men and children (Faithfull, 1997). There is a great deal of blame and stigma related to perinatal transmission due to societal pressures and prejudices related to women with drug problems.

Poverty is a third issue to consider when examining differences between men and women whose lives are impacted by HIV/AIDS. HIV/AIDS among women in the United States is, to a large degree, related to an epidemic of poverty and its associated problems. Most women with HIV/AIDS were poor before becoming infected and will become poorer as their disease progresses. Recent studies in developed countries have shown AIDS incidence to be highest among the very poor. If these trends are replicated worldwide, AIDS will become like other infectious diseases, disproportionately affecting those in poverty or in the lowest socio-economic groups (World Bank Organization, 2000).

Finally, many women are also faced with the dual challenge of being both patient and caregiver of a child(ren), a spouse or a partner. As women living with AIDS struggle to continue care-giving responsibilities, they must also wrestle with the grief and loss issues that accompany their own terminal illness (Hackl, Somlai, Kelly and Kalichman, 1997). The issue of permanency planning for their children inevitably arises due to the fact that the majority of female related cases of HIV/AIDS involve women of child-bearing age and this has a great impact on women and their families. Custody planning forces a woman to address complex and emotionally charged issues. Some women find it impossible to go through the planning process. It is not unusual for a woman to wait until end-stage disease or to never be able to make guardianship arrangements (Taylor-Brown, 1998).

### **Cultural Issues specific to Mexican American women**

While Latinas face issues similar to those faced by all women whose lives have been impacted by HIV/AIDS, there are additional factors that are culturally-specific to this population. Some of the issues discussed here are not applicable to all Latinas, since they vary depending on the level of acculturation, life-style, where they were born and where they live. Therefore, the reader cannot make the assumption that these factors

automatically apply to all Latinas. Special emphasis is placed in this section on Mexican American women.

There are several issues related to oppression that many Latinas who are and/or affected have to face. For example, the Mexican woman who is undocumented must attend to the issue of permanency planning and be cautious and aware of immigration issues. An individual's immigration status itself can change with results. This has implications particularly for large numbers of Mexican nationals living in the Southwest. An HIV/AIDS positive Mexican immigrant who does not have permission to be in the United States may have difficulty in accessing medical care and applying for entitlements. Immigrant women often work two jobs to send money to relatives in Mexico. Those who are not properly documented cannot get insurance and are often paid illegal, low wages (Lynch, 2000). Some federally funded programs that assist with medical and drug assistance can no longer extend services to those who do not hold U.S. citizenship. For this reason, some community advocates are forming Task Forces to solve this problem.

Discrimination is a reality that must be considered when discussing access to the health care system for Latinas, as well as other people of color. Research has established that women of color struggle with the double burden of racism and sexism, which exacts a toll on their mental health and restricts their opportunities (Gutierrez, 1990). Latinas are disproportionately uninsured or are often considered to be underinsured when seeking medical care. For non-English speakers, access to health care can be extremely difficult. Yet clinics that serve Latinas often do not have bilingual medical providers and thus non-English speaking patients experience difficulty in understanding explanations about their condition and medications (Murphy *et al.*, 2003). Such discriminatory conditions only pose additional challenges to an already difficult situation in accessing medical care.

It is not often that women of color see themselves reflected in the faces of their health care providers. Questions remain regarding the match between the values and priorities of non-European-American patients and their European-American health care



providers. Concurrently, another question in the mind of Latino/a immigrant patients is whether or not health care providers, pharmaceutical companies and government programs are to be trusted (Lynch, 2000).

Latinas who live near the *frontera* (border) experience a multitude of problems. Lack of access to care or poor health care is a big problem that affects Latinas and their children who have to rely on rural health care services. Often, there is no specialized medical services for Latinas who are HIV/AIDS. Since extreme poverty is an issue affecting many Latina-headed households in rural areas, HIV/AIDS is not always the most important stressor. Thus, they are likely to devote their energies to addressing immediate needs of food and housing for their family over medical care for themselves, particularly if they are asymptomatic (HRSA, 1998).

Gender inequality in interventions is another form of oppression experienced by Latinas. For example, Latinas involved with a Latino male partner are often encouraged by HIV/AIDS educators to practice condom negotiation. This can pose a potential risk for domestic violence if their partners suspect infidelity as a result. If a woman insists that her partner use a condom, the implication may be construed to mean that he, or even she, has been 'unfaithful'. For women who are already victims of domestic violence or who fear becoming such victims, negotiation of safer sex practices is even more difficult, thus magnifying the risks of becoming infected with HIV/AIDS (Suarez-Al-Adam, Raffaelli, and O'Leary, 2000).

Another type of oppression that is grounded in gender inequality is related to the social role Latinas play in their culture. For example, they are taught not to ask questions regarding their partner's indiscretions, which could ultimately put them at risk for acquiring HIV/AIDS. Married and single women are likely to face somewhat different situations in regard to the participation of their partners in behavioral risk reduction and thus educational and behavioral change strategies may need to be tailored accordingly (Raj, Silverman, and Amaro, 2004).

Though there is little research about Latino males engaging in ‘at risk’ behavior and the implications this has for their partners, it should be noted that there are some behaviors that are practiced by this group which, in turn, can be a mode of transmission for HIV/AIDS. Men who are incarcerated, for example, pose a serious risk to their female partners due to engaging in unprotected sex with men as well as sharing infected syringes with other inmates. The fact that Latinos are over-represented in the prison system (Greenberg, 2003) suggests a potential risk to their female sexual partners.

Another risk common to Mexican American women, is to be the partner of a migrant farm worker. This group suffers a high incidence of HIV/AIDS. One contributing factor is that some migrant laborers leave their spouses at home and engage in sex with secondary partners and use prostitutes. Another factor is that, in order to stay healthy, farm workers and their families inject medicine and vitamins (such as vitamin B12) they have brought to the U. S. from their home country (Holleran, in press). Needle-sharing associated with this activity places them at risk for HIV/AIDS and complicates the care of those already living with the disease (HRSA, 1999).

One subject that is not generally discussed in Latino households is the fact that men are having sex with other men. In some instances this involves married men who consider themselves to be heterosexual. This phenomena, also referred to as the “Down Low,” is occurring in a number of cultures. Thus, another risk of transmission for Latinas is that their sexual partners may be engaging in sex with men and keeping it a secret. For Latinos, in particular, the disclosure that they may have bisexual or homosexual tendencies may never come. An early study of thirty-three women who were married to men who were having affairs with other men, found that women in these relationships are at serious risk (Gochros, 1989). The authors state;

What we don’t know is how many infected wives, former wives, or other female partners of gay/bisexual men are waiting in the wings about to become sick. We only assume that there are many. We do not have a completely reliable estimate of the degree of risk from either a ‘category’ or a specific sexual behavior (p. 200).

In summary, Lee and Covington, public health specialists in the Food and Drug Administration's Office of AIDS and Special Health Issues, argue that there are a number of common factors, many economic ones, affecting many minority groups that contribute to the increase in AIDS (Greeley, 1995). They certainly apply to Latinas:

- \* Lack of medical insurance, which results in a lack of access to health care;
- \* A higher incidence of diseases or maladies in general;
- \* Fear of medical care, particularly among illegal aliens;
- \* Limited or no means of transportation to get to a health clinic; and
- \* Too few doctors, particularly in rural areas.

In addition to the above list, Latinas experience unique factors related to their particular cultural circumstances, some of which have been described in this section.

## **Implications for Social Work Practice and Education**

### *Need for Cultural Competence*

Under-utilization of HIV/AIDS services by ethnically and culturally diverse people is often a function of the cultural inappropriateness of services rendered. In the cross-cultural intervention, the key to successful outcomes lies in the 'goodness of fit' between services and the cultural reality of diverse clients (Ka'poua, L. S., 1998). Thus, organizations and social workers caring for Latinos in general should adopt the following guidelines in order to assure quality care (HRSA, 1999):

- Collaborate with organizations that have already established trust with the community to build a network of services;
- Aggressively educate the community about testing and treatment;
- Implement educational campaigns in the preferred language of the population;
- Assure that all case managers and physicians are bilingual and bicultural;
- Provide translation services;

- Help clients access support services including support groups;
- Integrate social services with AIDS treatment in order to help patients comply with regimens, return for appointment, eat nutritiously, and maintain overall health; and
- Recognize that HIV/AIDS status affects individuals' legal status and/or desire to normalize their legal status.

It is important to consider culture with regard to risk and protective factors when working with Latinos/as at risk for HIV/AIDS. For instance, among Latino males, those with low- acculturation were involved in significantly more risky behaviors than other ethnic groups (Zule, Desmond, Medrano & Hatch, 2001). Even cultural values which may strengthen aspects of the lives of Latinos/as can underlie risks; for example, *fatalismo* can be conducive to solidarity and spiritual reliance and also serve as a reason to ignore safety practices.

#### *Policy Practice Recommendations*

There are a number of ways services for Latinas with HIV/AIDS need to be improved. Gallego (1998) suggests several practices that social workers should advocate for in order to take social work practice beyond the individual level to systems and policy levels:

\* Agencies serving women with HIV/AIDS must incorporate and include women with HIV/AIDS in all levels of programming, planning, education, and decision-making, regardless of their sexual orientation, race, and education.

\* Women with HIV/AIDS need to be provided with education and training about their basic rights, including the right to have all medical procedures explained in a language they understand, the right to refuse treatment, and their rights under the Americans with Disabilities Act (ADA).

\* Childcare and transportation services need to be incorporated into all programs serving women so that they can take part in research, clinical trials, medical care and social services, as well as participate on planning and decision-making levels previously described.

\* “User-friendly/one-stop-shopping” types of services need to be created. Ideally, women with HIV/AIDS should be able to go to one place for their medical care and their child’s medical care (pp. 441-442).

### *Social Work Education and Research Recommendations*

As the number of cases of HIV/AIDS among minorities increases, the need for culturally competent counseling and other mental health services has become apparent. It would therefore be practical for Schools of Social Work to include curriculum that addresses the specific needs of people of various cultures as related to HIV/AIDS. Just as social workers are challenged to consider cultural diversity issues as they relate to child abuse, alcoholism, domestic violence and mental illness, the profession needs to take responsibility for addressing cultural influences in working with ethnic minorities who are living with HIV/AIDS.

Cultural diversity courses should be required and should include the task of increasing knowledge about ethnic minorities living with HIV/AIDS. Although there are some courses offered about culture, there are far fewer courses that adequately address psychosocial issues related to HIV/AIDS, despite the high prevalence rates. Historically, the social work profession has taken the lead in addressing unmet needs of the underprivileged and the disadvantaged and is positioned to take the lead with this new challenge. Education is a key to this effort.

When the HIV/AIDS epidemic first arose, social workers found themselves providing mostly emotional support to families and significant others, specifically in the area of death and dying. Now that HIV/AIDS is beginning to be recognized as a more chronic and manageable disease, social workers are being challenged to expand their knowledge base and move into the area of long-term counseling, as well as HIV/AIDS prevention. Culturally appropriate knowledge and skills are required.

Research is needed to develop best practice interventions with HIV/AIDS-infected and/or affected Latinas. Inquiries related to identifying effective strategies for

helping women living with HIV/AIDS address stressors such as social stigma, infidelity, religiosity, marital obligation, and other culturally related pressures would augment our understanding of social work with this population. In addition, such research could identify more effective coping strategies for Mexican American women living with HIV/AIDS.

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