Statement of the Problem

According to the United Nations Joint Programme on HIV/AIDS (UNAIDS), limited progress made across the globe in preventing and treating Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Disease (AIDS) has resulted in a decrease, albeit small, in both annual rates of new HIV infections and AIDS-related deaths (UNAIDS, 2008). Concurrently, however, annual HIV/AIDS prevalence rates have risen, and HIV-related illnesses are expected to continue to result in premature disability and remain among the leading causes of premature death (UNAIDS) worldwide. In no population are these effects more evident than in women of color of all races and nationalities, including those in the United States.

In the U.S., HIV/AIDS is seen in all sectors of society, though men who have sex with men are the demographic most affected by HIV/AIDS (Centers for Disease Control and Prevention [CDC], 2009a), yet the burden of an HIV/AIDS diagnosis is disproportionately felt by African Americans and Latinos of both sexes. In 2007, 49 percent of all AIDS diagnoses were in African Americans (CDC, 2009a), who nevertheless represented only 12.8 percent of the total U.S. population (U.S. Census Bureau, Quick Facts, 2008). In the same year, 19% of diagnoses were in Latinos (CDC, 2009b), who also represented 15.4 percent of the U.S. population (U.S. Census Bureau, Quick Facts, 2008). The disparities in the effects of HIV/AIDS in the U.S. are even more striking among African American and Latino women, who in 2007 comprised 80 percent of all full-blown AIDS diagnoses yet represented only one-fourth of all women in the country (Avert.org, 2010).

In 2007, Latino women comprised 6.5 percent of the total U.S. population (Pew Hispanic Research Center, 2007), yet Latino women represented 15 percent of all U.S. women living with HIV/AIDS. In the same year, the disease was the fourth leading cause of death for Latino women aged 35 to 44 (CDC, 2008). Nevertheless, research efforts have not kept pace with the dramatic increase in the number of Latino women infected with HIV/AIDS, nor have existing efforts
reflected an adequate understanding of the non-neutral, politicized nature of scientific inquiry particularly around this topic. Furthermore, while previous studies have been largely concerned with preventing infection, no studies were found that employed an emic perspective to focus on Latino women living with HIV/AIDS in the U.S. This evinces a lack of appreciation for the factors critical to preventing and treating HIV/AIDS in Latino women. Indeed, what could be more important--or more enlightening--in this endeavor than eliciting Latino women’s voices regarding their experience of grappling with the disease?

Epidemiological surveillance data indicate that Latino women experience HIV/AIDS differently from women in other ethnic groups and from Latino males (CDC, 2006a). Such differences place Latino women at a disadvantage as compared to both groups in terms of current prevention and treatment initiatives. The Latino experience of HIV/AIDS is rooted not only in gender, but also in the socioeconomic, sociocultural, and political contexts of the women’s lives.

Some studies have sought to examine the relationship between individual factors and Latino women’s experience of HIV/AIDS. Undertaking the research in this manner, however, ignored the fact that the variables (generally one or two only) being considered do not occur in isolation, but rather within the full context of the women’s lives. Moreover, researchers drew on their own definitions and understandings of cultural factors. Thus, treatment and prevention initiatives based upon these studies inevitably lack an awareness of the culturally-mediated, individually-generated meaning of illness, reflecting instead limited understanding and stereotypical definitions of the sociocultural factors pertinent to Latino women.

What remains unexplored is whether Latino women experience HIV/AIDS as occurring against a background of factors distinguished individually or as a confluence of factors that are inseparable from one another. Moreover, the women’s experience-- that is, the emic perspective- -of factors impacting the treatment and prevention of HIV/AIDS remains fundamentally unexplored and unknown.

**Research Questions**

The purpose of this study was to explore Latino women’s narratives of living with HIV/AIDS. The central questions guiding this study were: (a) what issues contribute to Latino women becoming infected with HIV? (b) What factors, or confluence of factors, play a role in Latino women living with HIV/AIDS? (c) What does being infected with HIV/AIDS mean to Latino women? and (d) How do Latino women make sense of being infected with HIV/AIDS within the broader context of their lives?

**Research Method and Analysis**

Latino women are disproportionately diagnosed with HIV/AIDS infection in relationship to their representation in the U.S. population (CDC, 2008). Nevertheless, no quantitative and very few qualitative, studies have focused solely on Latino women living with HIV/AIDS or
specifically addressed their needs. Furthermore, there is little evidence that existing study results were translated into effective prevention and treatment initiatives. Attesting to this lack of significant success is the continuing rise in incidence and death rates for Latino women due to HIV/AIDS (CDC).

The paucity of studies and lack of efficacious prevention and treatment interventions for Latino women are due largely to three factors. One is the frequent use of reductive definitions of cultural variables. A second factor is insufficient acknowledgement of the contextual nature of disease. The third and most important factor is a lack of recognition and understanding of the critical role played by the intersection of gender, culture, and socio-political-economic factors in the lives of Latino women, particularly as they grapple with preventing or living with HIV/AIDS (Amaro, 1995; Campbell, 1999).

Qualitative research studies focusing on HIV/AIDS do exist, though not across all populations being affected. In a metasynthesis of qualitative studies, Barroso and Powell-Cope (2000) found that while the research appeared to be adequate in terms of studying the broad experience of adults living with HIV, existing studies were not sufficiently representative of subpopulations, including Latino women (Barroso & Powell-Cope). Later studies (Ailinger, Gonzalez, & Zamora, 2007; Shedlin & Deren, 2002) confirmed Barroso and Powell-Cope’s findings, concluding that few of the studies they considered attempted to go beyond understanding specific, narrowly-focused aspects of subpopulations’ experiences of living with HIV/AIDS.

The choice of a qualitative research methodology for this study was driven primarily by my recognition that qualitative inquiry best serves the research questions being addressed, the subject matter at hand, and the Latino women who are the focus of the study. Oral and written narratives often reveal what people think is generally important in life, display the factors that individuals consider particularly significant when grappling with the question of life’s meaning, and offer a window into people’s subjective lives and experiences of the world (Chase, 2005; Denzin & Lincoln, 2005a; Lee, Rosenfeld, Mendenhall, & Tynes, 2004). Of equal importance is the way in which narratives provide a reflection of the culture, history, and political context that helped shape those lives.

More specifically, narratives allow us to see how conditions such as poverty, domestic violence, and inadequate access to education, impact women’s lives. These factors, coupled with sociologist Diego Armus’s (2003) view that “diseases cannot be examined outside their societal frame” (p. 2), led to the choice of narrative inquiry as ideally suited for studying and giving voice to Latino women’s unique expressions, perceptions, and experiences of living with HIV/AIDS.

Using purposeful sampling, I recruited nine Latino women, ages 27 to 48, all of whom were first-generation U.S. immigrants. I elicited the narratives from each of the women in Spanish (their choice). The participants were diverse in country of origin and differed somewhat in current faith identification. The overarching analytic methodology employed in this study was
Polkinghorne’s (1995) narrative configuration approach (both narrative and paradigmatic types), complemented by Denzin’s (1989) interpretive biography method of analysis. In addition, Chase’s (2005) analytic schema provided the rationale for analyzing individual narratives first and conducting a comparative analysis second. The result was the presentation of participant profiles in three parts, followed by a comparative analysis of data across individual transcripts.

Starting with participants’ demographic information, the profiles set the stage for the participant’s story, providing contextual information and other clues that allowed for a more in-depth, more comprehensive understanding of the participants and their experiences of living with HIV/AIDS. Subsequently, adapting Polkinghorne’s (1995) narrative-type analytic model, I created the narrative summaries which represent the first major level of data analysis, and highlighted influential and pertinent aspects of the participants’ lives with respect to their experiences of living with HIV/AIDS. Then, using Polkinghorne’s paradigmatic-type model, I generated the analytic commentaries that explored the biographical particulars thought to have contributed to the participant’s infection with HIV; the commentaries represent the second level of data analysis, and comprised the first part of Chase’s (2005) two-part narrative strategy.

The data analysis described up to this point focused on individual narratives, for the purpose of making the whole of each respondent’s HIV/AIDS story known to the reader. The third, and final, level of the analytic schema extended individual analyses by identifying themes found within narratives and comparing them across transcripts. To do so, I used Polkinghorne’s (1995) paradigmatic analytic procedures, i.e., the analysis of narratives method, to “produce taxonomies and categories out of the common elements across the database” (p. 5). The research questions guiding the study were then used to compile and organize the findings.

Results

Several themes addressing each of the four research questions emerged from data analysis. First, themes reflecting issues that contributed to an HIV diagnosis included: lack of education (referring either to formal schooling, HIV/AIDS education, or both); domestic violence; culturally-prescribed norms, especially those related to gender; and religious tenets. The first two issues were noted by all participants and exerted a strong, direct influence both on their lives and in becoming HIV infected. The remaining two issues were equally influential, though their effect was greater as they intersected with and potentiated a lack of education and the pervasiveness of domestic violence.

Second, themes associated with factors in living with HIV/AIDS included pervasive poverty, HIV/AIDS-related stigma, and immigrant status; data supporting these themes suggested that these factors acted on participants’ lives with both singular and combined effects. Furthermore, many of these factors are either extensions or modifications of the biographical particulars that led to their becoming HIV positive or developing AIDS.
Third, when exploring what it meant to them to be HIV positive or infected with AIDS, participants generally responded in concrete rather than abstract terms. They talked about how HIV/AIDS impacted their day-to-day lives and their ability to meet daily challenges, rather than waxing philosophical or reflecting on their internal thought processes about the disease. For example, when asked what it meant to be infected with HIV, one participant responded, “What do you mean?” When I explained, she answered, “It means I have this virus and it could make me sick . . . and to not get sick I have to just take my medicine.”

The fourth and final question, regarding how participants made sense of being HIV-positive or having AIDS, elicited responses not unlike those about the meaning of HIV infection; namely, participants responded in concrete rather than abstract terms. Their narratives emphasized action taken in response to family or personal needs, either because or in spite of their diagnoses. Their responses can be categorized by three themes: treating it as “just one more thing” in their lives, experiencing a deepened relationship to God, and resolving to prevent infection in others.

Conclusions

Three general conclusions can be drawn from the analyses:

(a) Making a distinction between factors that contribute to HIV infection and those involved in living with HIV/AIDS creates a false dichotomy. In reality, the relationship between the contributing issues to HIV infection and the factors involved in living with HIV/AIDS is sufficiently fluid and dynamic to render a distinction between the two moot. This is congruent with the assertion of many researchers (Armus, 2003; Bowden et al., 2006; Campbell, 1999; CDC, 2007b; Dutta-Bergman, 2004; Frasca, 2005; Land, 1994; Marshall et al., 2005; Moreno, 2007; UNAIDS, 2008) that there is a multi-layered, mutually influential relationship between structural factors (i.e., poverty, lack of education, poor or no access to ongoing health care), and domestic violence, culturally-prescribed gender norms, and religious tenets when it comes to HIV infection. Because issues contributing to HIV infection do not disappear once someone is diagnosed with HIV or AIDS--and may in fact be exacerbated by this diagnosis--it is therefore reasonable to suggest that the relationship between these issues and the factors involved in living with HIV/AIDS is, as I have concluded here, dynamic and mutually influential. At times, it is impossible to identify which fact was present in the women’s lives first, particularly if one goes back, as Denzin (1989) suggested, to participants’ biographical origins.

(b) The meanings ascribed to, and sense made of, being HIV/AIDS infected are culturally mediated and congruent with the exigencies of the participants’ lives. This second conclusion reinforces the centrality of culture in this narrative inquiry study. This is the least surprising of the conclusions, given the degree to which individuals’ views, attitudes, and responses to illness are shaped by the culture in which they live. Within the social work profession, this type of interaction is embodied in ecosystems theory (Kirst-Ashman, 2007), which blends the ecological
perspective and general systems theory. The focus of ecosystems theory is on “the interactions between the individual and various systems in the environment” (Kirst-Ashman, p. 24). This locus of attention and action provides fertile ground for generating meaning and making sense of life events. While ecosystems theory offers a framework for understanding this second conclusion, Kleinman’s (1980) theoretical perspective is more to the point in that he posits that illness has culturally-mediated meanings that are particular to individuals.

(c) Researchers exploring the prevention and treatment of HIV/AIDS amongLatinas have an insufficient understanding of the gestalt of the HIV/AIDS experience in the participants’ lives. This third and final conclusion fits well with the three theoretical assumptions on which this study is based. The first is that science is non-neutral and political (Benston, 1989; Foucault, 1994; Harding, 1991; McKenzie, 1991b). According to this assumption, analysis of factors such as gender, race, and ethnicity is essential in understanding the scientific response to diseases such as HIV/AIDS, as well as in gaining insight into people's experiences with HIV/AIDS. Amaro (1995) underscored this essentiality in a theoretical paper that noted the need to address HIV prevention among women in general and among women of color in particular. Amaro suggested that behavioral approaches to HIV prevention thus far have paid insufficient attention to the ways gender, social status, and women’s roles impact sexual behavior and risk taking, as well as the ability to take the actions necessary to protect oneself against risk.

Implications for Social Work Practice

There is a dearth of studies that focus on Latinas’ experiences with HIV/AIDS, particularly from the perspectives of women living with the illness. Those that do are primarily concerned with preventing infection and focus on discrete factors (e.g., culture) related to the experience of living with HIV/AIDS. In doing so, they fail to address the critical issue this study has highlighted: the need for HIV prevention initiatives, as well as efforts to help infected women cope with the illness, that take into account the entirety of these women’s lives, recognizing and honoring the many influences that shape who they are. A review of the literature did not uncover any study that focused on the emic perspectives of Latinas with HIV/AIDS in the U.S., much less one that looked at the confluence of factors and issues facing this population. This narrative study, in exploring the stories of nine Latino women living with HIV/AIDS, provides a richer depiction of their experiences than exists in the literature to date.

While this study has theoretical implications, more importantly, it has import for the profession of social work, particularly in the areas of practice and education. In addition, many of the inferences are relevant for professionals in allied disciplines (e.g., health care), given the study’s emphasis on both the nature of HIV/AIDS and the psychosocial needs of Latino women living with it.

First and foremost, this study may be beneficial for those who work with Latinas who are at risk for HIV infection, Latinas living with HIV/AIDS, or “simply” Latino immigrants. Rothery
(2001) noted that social workers most commonly utilize an ecosystems model in working with clients, in which they are “encouraged to view situations holistically, attending simultaneously to people, their families, and whatever other systems might be important to their needs” (p. 69). To do as Rothery suggested requires having information about the women and their circumstances. Participants’ narrative summaries, the analytic commentaries, and the comparative analyses of the narratives contain a wealth of specific, detailed information about the women and their experiences that is not available elsewhere. While the profiles cannot replace those of a social worker’s own clients, the data nevertheless suggest the kinds of issues that clients may present with in both medical and mental health settings.

Second—and the importance of this point cannot be overstated—effective social work practice with Latinas living with HIV/AIDS requires an understanding of and appreciation for the contexts of their lives. This research study illumimates for practitioners how poverty, education, domestic violence, culturally-prescribed gender roles, and religious tenets, singly and in combination, influence not only how others see Latino women but, more importantly, how they see themselves. Because disease does not occur in a vacuum, these influences impact how Latinas will hear and respond to prevention messages and treatment. The steady increase in HIV/AIDS morbidity and mortality among Latinas suggests that they are either not receiving or not heeding existing messages. This study adds to the knowledge base that will help practitioners understand why this is the case and how it can be changed.

Third, for practitioners who counsel HIV/AIDS-infected women, understanding contextual influences provides critical information about what the diagnosis means to their Latino clients and how they make sense of having the disease. The information can thus help practitioners understand how the women incorporate the diagnosis into their everyday lives, enabling counselors to better assist their clients with this task. In addition, examining context may uncover areas in which the women need to be empowered to take action that is intimidating to them, such as becoming knowledgeable about HIV and how it affect their bodies, or actively exploring treatment options.

This study contains important information for educators as well. Working with Latinas who are at risk for or living with HIV/AIDS requires more than the standard complement of skills (e.g., evaluation, assessment, treatment planning, etc.) that social workers learn in BSW or MSW programs. A surprisingly small number of social work programs offer specialized courses that cover the kind of information contained in this study; many do not teach a course providing even basic information about HIV/AIDS (Humble, 2009).

Practitioners must learn about the dynamics that impact Latinas if they are to respond effectively. They need to be taught how to empower their clients, but more specifically, they need to learn what the impediments to empowerment might be. They must understand the cultural information contained herein, as well as the ways it impacts Latinas’ ability to advocate for themselves, and those who educate practitioners must therefore make sure their students are exposed to this information. Lastly, it is critical for practitioners to recognize the critical lack of
information about how HIV/AIDS acts on and impacts the health of Latino women, and to be aware of this population’s lack of knowledge about available treatment options and what they entail. While practitioners do not prescribe medication, it is increasingly their responsibility to assist clients in adhering to the medication regimens that prevent HIV from becoming AIDS (Lopez, 2007).

**Recommendations for Future Research**

The purpose of this study was to explore the narratives of Latino women living with HIV/AIDS. Based on this qualitative study, I offer five recommendations for future research.

First, while there were some variations among study participants, they nevertheless do not represent all Latinas or all women who come from the same country, were all from a similar socio-economic status, and only two had attended college. In addition, the study took place over a three-month period and participants were interviewed only twice. To address these limitations, the study should be repeated with a larger sample size, with recruitment geared toward achieving maximum variation, to see if the results hold up across a larger number of women with greater demographic diversity. Additionally, it would be beneficial to repeat the study over a longer period of time, with a series of interviews rather than only two. While all the participants warmed up to me and the information they provided suggests that they trusted me, having more time with them might produce richer data.

The second recommendation may be the most important one. Social science researchers must conduct more community-based, participatory research, or research that engages communities in partnership with researchers. Those affected, in this case Latino women, need to be included in all phases of the research to the extent possible, from the development of the grant proposal through all subsequent phases of the study. There are numerous benefits to engaging in this type of research, including: (a) focusing on issues that are important and relevant to Latinas; (b) targeting interventions to identified needs; (c) developing approaches that incorporate Latino cultural norms and values, and are therefore both valid for the community and based on empirical evidence; (d) improving interpretations of findings so as to be sensitive to genuine (but not stereotypical) cultural meanings; and (e) increasing the participation of Latino women in research.

I have often heard colleagues lament that Latinas are “hard to engage in the research process;” not so in this study. The participants recruited were eager to participate and believed they had something to contribute. What engaged them, first, was that as a Latino woman I was “one of them” and therefore someone they could relate to and trust. Second, the interviews were conducted in Spanish, without the need for an interpreter, and in a place of their choosing (in their homes, and in one case on a private stairwell). Many of the participants commented that the aforementioned circumstances under which the interviews took place were part of the reason they agreed to participate. Third, I provided a “safe space” for them to share what I was
interested in, their personal stories. It was truly surprising how unaccustomed they were to being asked to talk about themselves. I stopped here.

My third recommendation is that until a cure is found, the advancement of HIV/AIDS prevention research should begin with the recognition that the greatest impact on the epidemic will come from effectively preventing HIV transmission in the first place. While this may seem obvious, this matter is complicated significantly by cultural tenets (Vinh et al., 2003) and gender and social inequalities (Bowden et al., 2006; Bowleg, Belgrave, & Riesen, 2000; Campbell, 1999; Gates Foundation for Global Health, 2007; Land, 1994) both in the U.S. and throughout the world. Existing prevention tools are largely dependent on male behavior, rather than being under Latino women’s control. Prevention researchers, then, would do well to follow Amaro’s (1995) advice and use behavioral approaches that reflect the role of gender and social status in women’s ability to negotiate sexual contact and protect themselves against becoming HIV infected.

My fourth recommendation is that social work researchers should play a larger role in prevention research by incorporating their knowledge of non-stereotypical, psychosocial characteristics of Latino women into existing prevention initiatives while also using this understanding as a basis for creating new initiatives. In addition, social work researchers can make clear the enduring impact of prevention impediments on the women’s lives post-HIV infection. Doing so will advance cultural competence in both prevention (Vinh et al., 2003) and psychosocial treatment interventions for Latino women living with HIV/AIDS (Campbell, 1999).

Fifth and finally, social work researchers must aim to ameliorate the circumstances that hinder HIV prevention and fuel HIV infection, while simultaneously calling attention to the expansion of the epidemic in the Latino community. Specifically, research and action are needed in relation to the following areas and issues: (a) demonstrating the impact on women and girls of promoting gender equality and addressing gender norms and relations, while also highlighting the need to involve men and boys in the effort; (b) promoting the links between HIV prevention and sexual and reproductive health; (c) demonstrating the impact on HIV/AIDS prevention and treatment of mobilizing community-based responses throughout the continuum of prevention, care, and treatment; and (d) demonstrating the need to strengthen financial, human, and institutional capacity across all sectors, particularly in health and education.

Concluding Thoughts

Aside from failing to produce a vaccine that would inoculate against HIV, the sheer volume of research on every other aspect of preventing and treating HIV/AIDS is truly astounding; this paper is based on dissertation research that cited almost 100 disparate types of research on the medical and psychosocial aspects of HIV/AIDS. Yet a recent re-reading of Randy Shilts’ (1987) journalistic account of the beginnings of the HIV/AIDS epidemic, *And the Band Played On*, read like a prophecy. For me it was a *déjà vu* experience, and when I was done,
I realized that it is no mystery, really, why even knowing what we know and possessing the resources we do, there were nevertheless 2.7 million new cases of HIV infection globally (55,000 in the U.S.) and approximately 2 million deaths from AIDS-related illnesses (25,000 in the U.S.)(UNAIDS, 2009). The answer lies at the intersections of gender, race, class, and ethnicity and in the political context into which HIV/AIDS emerged and in which it continues exist. Researchers, practitioners, and service delivery providers need to take this into account in a more comprehensive way.

Shilts (1987) decried the lack of media attention to AIDS until “October 2, 1985, the morning that Rock Hudson died” (p. xxi). By then, however, 12,000 other Americans had died as well (Shilts). The evidence strongly suggested, and continues to suggest in many ways today, that political expediency won out over matters of public health. Recounting the history of HIV/AIDS, Shilts said, “is a tale that bears telling, so that it will never happen again, to any people, anywhere” (p. xxiii). Yet the statistics indicate that it is happening again, particularly in minority communities in the U.S. and across the globe. We need once again to be riveted by and address the HIV/AIDS epidemic, at all level, as if it were in its infancy. Barring that type of attention, the difference made by research and other efforts will be of little consequence in stemming the impact of people behaving as if HIV/ADS were not a disease to be considered possibly of long duration, but deadly nevertheless.
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