

# La Desesperacion: Migrant and Seasonal Farm Workers Living With HIV/AIDS

Barbara Aranda-Naranjo, PhD, MSN  
Susan Gaskins, MPH, DSN, ACRN  
Lucia Bustamante, BA, SWA, LCDC  
Linda C. Lopez, RN, MSHP, MSN  
Josefa Rodriquiz, LVN

*Migrant seasonal farm workers (MSFWs) in south Texas are predominantly Mexican American and represent one of the most impoverished and medically underserved populations in the United States. La Frontera is a collaborative partnership between the University of Texas Health Science Center at San Antonio, migrant organizations, and HIV service delivery organizations to study and address special needs of MSFWs in Hidalgo and Maverick counties of south Texas. The purpose of this qualitative study is to explore the health-seeking experiences of HIV-positive MSFWs living in the La Frontera service area. Denzin's interpretive interactionism methodology guided the study. Thirteen participants were interviewed and audiotaped as they described their experiences. Findings from content analysis of the interviews revealed a description of the life of an HIV-positive MSFW as la desesperacion (a separate way of life). After their diagnosis of HIV/AIDS, the major themes in their lives were living in secrecy (a silent cry), finding and receiving health care, and accepting the disease (may it be the will of God).*

**Key words:** HIV/AIDS, migrant seasonal farm workers, La Frontera

There are estimated to be as many as 4.1 million migrant and seasonal farm workers (MSFWs) in the United States (Organistra & Organistra, 1997). States with the largest populations of MSFWs are California, Texas, Florida, North Carolina, and Washington (Go & Baker, 1995). The majority of MSFWs live in poverty,

have limited education, and are young and male. Typical environmental factors for MSFWs include poor housing, limited sanitation facilities, inadequate diet, and limited access to health care (Betchel, Shepard, & Rogers, 1995). More than 90% of MSFWs are minorities, with Latinos making up about 70% of the population (Go & Baker, 1995; Organistra & Organistra, 1997). Many of the characteristics of MSFWs (e.g., living in poverty, being a member of a minority population) correlate with the presence and increased rate of HIV disease. Tuberculosis, sexually transmitted diseases, and substance abuse, which are strongly associated with HIV, have been found to occur more

*Barbara Aranda-Naranjo, PhD, MSN, is co-principal investigator, Frontera Project, University of Texas Health Science Center, and Brigadier General Dunlap Professional Chair, School of Nursing, University of The Incarnate Word, San Antonio, Texas. Susan Gaskins, MPH, DSN, ACRN, is associate professor, Capstone College of Nursing, University of Alabama, Tuscaloosa. Lucia Bustamante, BA, SWA, LCDC, is field research specialist, La Frontera Project, University of Texas Health Science Center, San Antonio. Linda C. Lopez, RN, MSHP, MSN, is assistant professor, National Center for Farmworker Health, Austin, Texas. Josefa Rodriquiz, LVN, is project coordinator-Colonia Health Worker Program (CHWP), Migrant Health Promotions, Relanpago, Texas. This study was part of the Special Program of National Significance, La Frontera HIV Service Model for Border Migrant and Seasonal Farm Workers. The program (No. BR970173-01-0) is funded by the Health Resources and Services Administration under the Ryan White Care Act.*

often among MSFWs than among the general population in the United States (Centers for Disease Control and Prevention, 1992; Hopewell, 1992). The dearth of studies investigating the presence of HIV among MSFWs has had mixed results. Although some have found higher rates of HIV among MSFWs, there has been difficulty obtaining accurate figures because the population varies ethnically and culturally by geographical location in the United States (Centers for Disease Control and Prevention, 1988; Salgado de Snyder, Perez, & Maldonado, 1996\* ).

In south Texas, the predominantly Mexican American MSFWs are among the most impoverished and medically undeserved populations in the country. They are predominantly Spanish speaking, and their culture is a mixture of Mexico and the United States. A unique difference of this border population is that it often lives in *colonias*. The housing is temporary and substandard, with inadequate water, electricity, and sewage. The migrant culture and lifestyle, along with the cultural and living conditions, describe a distinct and unique population.

### La Frontera

La Frontera is a collaborative partnership of organizations in south Texas whose primary purpose is to describe HIV risk factors and characteristics of MSFWs and facilitate early identification of HIV in that population. The University of Texas Health Science Center at San Antonio, MSFW organizations, and HIV service delivery organizations in Hidalgo and Maverick counties are working together to establish an integrated HIV service delivery model for individuals in that area. Existing systems and providers of care are being linked and coordinated to provide culturally appropriate HIV education, counseling, testing, treatment, and prevention. Lay health care workers (*promotoras* and *consojeras*) from the migrant communities are extensively trained in health issues and participate in all aspects of the project including instrument development, counseling, education, and testing.

This 5-year project began in October 1996. It is a Special Program of National Significance project funded by a grant from the Health Services Resources Administration. Major project activities that have

begun include (a) outreach interventions in the colonias, (b) identification of HIV-positive MSFWs through a seroprevalence study, (c) development of a coordinated system of care and the necessary infrastructure, (d) involvement and training of providers, and (e) qualitative interviews with HIV-positive MSFWs. The purpose of this study was to explore the health-seeking experiences of MSFWs living with HIV/AIDS in this area.

### Method

Denzin's (1989) methodology, interpretive interactionism, was used as the sensitizing framework for the study. Denzin was influenced by the writing of C. Wright Mills, who in 1959 challenged researchers in the human disciplines to link human beings' troubles to public responses and policy. Interpretive interactionism aims to bring out the lived experience through "thick descriptions" of the everyday lives of people. In describing their experience's, clients may relate "epiphanies," which Denzin described as major turning points in the life of a person. The clients' experiences, as they report them, make their world directly accessible to the investigator.

The interpretive process of inquiry includes six steps: (a) framing the research question, (b) deconstruction of prior conceptions of the phenomena, (c) capturing the phenomena and locating them in the natural world, (d) bracketing the phenomena and examining their essential features, (e) construction of the essential structures, and (f) contextualization of relocating the phenomena back in the natural world.

Three research questions guided data production: How do MSFW individuals/families who are HIV infected experience living with this disease? How do MSFW individuals/families who are HIV infected seek health care? Which factors do MSFW individuals/families with HIV/AIDS identify that facilitate and/or hinder their care? Open-ended, in-depth interviews were conducted from October 1997 to February 1998. Interviews were conducted at the clinic and in the participants' homes. Many chose to be interviewed away from their homes for fear of disclosure to a family member who was unaware of the diagnosis. The interviews began with open-ended questions that became more specific as the researcher attempted to

clarify the responses to the questions. Once the initial questions were asked, the participant's response helped to guide further questioning. The researcher worked with an interpretive team to analyze each interview. The interpretive team consisted of two nurses experienced in working with the target population, a field researcher who had been a migrant when she was growing up, and an LVN who works at a community-based migrant agency and who also had been a migrant. The final team member is an MSFW who is HIV infected but not part of the study.

## Findings

### Sample

A purposive sample of 13 MSFWs who were HIV positive or had been diagnosed with AIDS were recruited for this study. Participants were identified by the community-based agencies that serve HIV-infected individuals in the community. Eight of the participants were from Maverick County, and 5 were from Hidalgo County. Eight were male, and 5 were female. Ages ranged from 23 to 47. Disease status was HIV positive for 7 participants, and 6 were diagnosed with AIDS. All were experiencing some form of financial difficulty. Many of the participants answered the questions in English and Spanish, whereas some preferred only Spanish. Five participants were still migrating (2 males and 3 females), and 8 had stopped migrating.

During the time of the interviews, the local community happenings included political-economic issues related to building a bridge, illegal border crossings, and drug seizures, as well as social events. Information was available in newspapers and on flyers distributed in the communities. However, the participants in the study were more concerned with their personal, immediate lives than with others, their communities, or the future. The poverty most of them experienced was a major factor in how they lived and made decisions.

### La Desesperacion

The diagnosis of being infected with HIV was a life-changing experience for the participants. They

described a difficult life as an MSFW prior to the diagnosis. They talked about migrating for work away from their homes. For many, migrant farm work had been a way of life in their families for generations. They described how disruptive migrating was to families and behaviors that increased MSFWs' likelihood to be exposed to HIV. Then they described how they were now living with a chronic, progressive, and terminal disease in the context of that life. The dominant theme used to describe the experience of an MSFW living with HIV disease was *la desesperacion* (a desperate way of life). The major themes related to the dominant one were living in secrecy (a silent cry), finding and receiving health care, and accepting the disease (may it be the will of God).

Participants talked about their struggles in life and the many hardships, such as poverty, long working hours, and an unstable home life. The moving and relocating for work meant family disruption whether the whole family migrated or men migrated alone. They described family hardships, illnesses, and death that had been influential in their lives. Many were working to change their lives and to have a better life for themselves and their families. They wanted to get an education and have a family and a home. One way to achieve their dreams was to work harder and make more money. The work, which was a strategy to improve their lives, is very labor intensive. It is physically difficult, and the hours are long, making health and stamina necessities for success. Becoming infected with HIV made it more difficult if not impossible for participants to achieve their goals. Having HIV was an additional hardship to be endured by MSFWs.

The participants described how the lifestyle of a migrant worker influenced their risk of HIV infection. Typical responses addressed their moving to different places, being away from home, being isolated, and meeting different people as possible risks. Men migrating alone increased their risk of exposure to HIV because of sexual practices whether they were married or not. The biggest concern was the lack of access to information and education about HIV among migrant workers. They talked about not having access to a television or "communications." An issue for some migrants was the language barrier. Information that is available, especially in areas where MSFWs go

for work, is usually in English, which most MSFWs are unable to read. They talked about getting information and learning about HIV "through the grapevine." One possible reason why MSFWs are not informed could be due to Hispanic cultural beliefs (e.g., sex and AIDS are not discussed openly). One participant stated: "It is not like we talk about it. I think Hispanic people are a little more reserved when they talk about sex. . . . We are not very open to talk about it."

A majority of the participants were diagnosed while migrating upstream. Their diagnosis of HIV was a surprise and a shock. A deep sadness was described as the reality of their diagnosis became clear to them. They had not sought testing because of the fear of being exposed; rather, they were tested because they were ill, were receiving prenatal care, or had a partner who was diagnosed with HIV. Although they were surprised and shocked by their diagnosis, most participants were aware of the risky behavior they had engaged in to become exposed. The majority of the participants attributed their exposure to unsafe sexual practices, although several were using drugs also. The unsafe sexual practice was most likely unprotected heterosexual sex with multiple partners. One man remembered learning about his diagnosis and stated: "I felt like it was the end of it, you know. Like I felt like I wanted to commit suicide."

### **Living in Secrecy (a silent cry)**

Disclosure of their HIV status was an issue for all of the participants. Many had shared their diagnosis with their sexual partners and their immediate families. They usually were not open to their entire family, but rather to the family members with whom they were closest or who would understand and be supportive. For the participants with children, telling them was the biggest concern. Most had not told their children because they felt the children were too young to understand. One mother whose husband had died of AIDS told her children that he had had cancer. Neither had she told them about being HIV positive herself. Other participants talked about saying they had more "acceptable" illnesses such as liver disease or cancer. Many worried about rejection, but there was an overwhelming sense of others not understanding. They felt that people were uninformed and, worse, preferred to

remain uninformed. A 43-year-old mother discussed why she did not tell others about her diagnosis:

If I would tell them, if I would be open because they don't know what it is and what to expect. . . . They are not informed and they are not willing to be informed. . . . In our culture I believe that its the macho image which creates the biggest burden as far as identifying people because they don't want to accept it. . . . There are lot of people who want to deny it rather than get information.

### **Finding and Receiving Health Care**

Receiving health care for HIV was difficult for the majority of the participants. Even when they were not migrating, they had trouble receiving care. A big issue was transportation. Many were able to take a bus to the clinic but talked about the long, inconvenient ride and schedule. Some had been refused care because they could not pay and did not have insurance. Others were refused care because of their diagnosis. If they were extremely ill, they were able to obtain care, and many had been hospitalized. It was the ambulatory, follow-up care that was difficult for them to obtain or to maintain. Participants described the inconsistency of their care related to migrating. Some waited to get their medication until they got home or to a certain clinic. Ironically, some had better care when migrating. One woman who migrated to Michigan received all of her medications from a clinic that was financially supported by a grant. Participants spoke about needing to take their records with them from one clinic or physician to another.

Not all of the participants were on medication for HIV/AIDS, but most had been at one time. Some had discontinued their medication because of side effects. Others chose not to take medication. Most were not knowledgeable about their medication. For example, they did not know the names or understand the actions of the antiretrovirals. A few were on highly active antiretroviral therapy (HAART) and talked about feeling better and healthier since being on it.

All understood the seriousness of HIV disease. However, they were not clear on managing and monitoring the progression of the disease. Although some

talked about their "counts," most did not know them and did not have them checked routinely, especially when migrating.

### Accepting the Disease

Participants talked about learning to accept and live with HIV/AIDS. For many, strength to deal with their diagnosis and to continue to live their lives as fully as possible came from their faith in God. They were Catholic and talked about how their religion influenced their response to their disease. Although their religious belief that what happens in our lives is "God's will," they explained how that belief was not fatalistic. One woman described how her faith helped her deal with her situation: "Real faith gives you the opportunity to say 'Well, I gave it my best shot but God will always have the last word.'"

Children and families were participants' biggest concern and worry. They also were the impetus to stay well and "keep going." Participants talked about taking care of their children, being there for them, and wanting to be sure they would be taken care of when they died.

### Discussion

Participants' accounts of their lives as an MSFW with HIV described the disease as an additional stress in an already difficult, stressful life. Their stressful lives continued with changes mandated by failing health or the knowledge that eventually the disease would take away their ability to continue to work as an MSFW and to take care of their families. HIV was viewed as a terminal disease, and few had hope of living with it as a chronic, manageable disease. There was a overwhelming sense of sadness and lack of control related to their HIV disease.

The sense of stigma and shame attached to their diagnosis was overpowering for the participants. They wanted to protect themselves and their families from the anticipated negative reactions from others and ramifications in their lives. Disclosure has been an issue for many individuals with HIV/AIDS. As the disease extends into different populations and geographical areas, it is not unusual for the newly affected

groups to struggle with disclosing their HIV disease status (Heckman, Somlai, Kalichmam, Franzoi, & Kelly, 1998; Moneyham et al., 1996; Sowell et al., 1991). Women and people in rural populations have described repeatedly the importance of protecting their confidentiality and not sharing their diagnosis. One difference between descriptions of MSFWs and descriptions of other populations of issues surrounding disclosure has to do with the lack of any positive outcomes. Other individuals with HIV/AIDS have described receiving love and support from others, and the importance of disclosing their HIV status to teach prevention and to increase society's understanding of the disease (Gaskins & Brown, 1997). Among MSFWs, neither of these possible positive outcomes had happened or were anticipated.

Health care for HIV/AIDS was a challenge for the participants whether migrating or at home. Their health care had always been problematic, and the addition of HIV disease made it all the more difficult to obtain, and especially to maintain, continuity. Health care issues included where to go for care, paying for the care, transportation, and changing providers when migrating. Changing providers reintroduced the previous issues plus working hours, making it difficult to get to care. None of these problems were new for MSFWs or unique to their HIV disease. HIV/AIDS was an additional obstacle to receiving health care. With the exception of migrating, many of the issues surrounding health care for HIV/AIDS are similar to those encountered by people from rural areas (National Rural Health Association, 1996; Sowell & Christensen, 1996). However, it made the participants more likely to be committed to finding and obtaining health care in spite of the myriad associated obstacles. Montoya, Bell, Richard, Goodpastor, and Carlson (1998) found that HIV-positive individuals who migrated to an urban area were likely to experience eligibility barriers to government-administered social services, and knowledge barriers to both government-administered social services and community-based organization (CBO) services. However, they were not likely to experience significant eligibility barriers to CBO-administered social services.

For some, the lack of understanding related to managing and monitoring the disease made it less likely that they would take the actions necessary to live a

healthy life with HIV. Even the ones who did understand the importance of continuity of care and treatment of HIV found they were often in the wrong place at the wrong time to obtain the needed care. Adherence to HAART is a challenge for many individuals with HIV/AIDS. Therapeutic effectiveness and viral inhibition is dependent on systemic drug concentration that demands adherence to prescribed regimes (Williams, 1999). Among MSFWs, adherence to monotherapy was difficult, and HARRT was most likely not an option. They hoped for a cure one day for others but were not encouraged by treatment available to them.

HIV testing was an issue for the participants. Only the females in prenatal care had had testing offered when they were asymptomatic. Participants had not sought testing even when aware of engaging in risky behaviors. They did not perceive themselves to be at risk for HIV. McBride, Weatherby, Inciardi, and Gillespie's (1999) study of drug-using migrant farm workers and their sex partners found that the majority did not perceive themselves to be at high susceptibility for HIV/AIDS. However, the more frequently high-risk behaviors were engaged in, the higher the perception of AIDS susceptibility. In addition, AIDS susceptibility was significantly related to subsequent reduction in risk behaviors.

Living with HIV/AIDS for most of the participants meant learning to accept it as they had learned to accept their lives in general. They had a profound spiritual belief that whatever they encountered in life was "God's will", and that they had to make the best of it." They felt a responsibility to deal with living with their disease. The majority were overwhelmed with the extra burden of living with HIV/AIDS, and talked about trying to continue their life as an MSFW as long as possible while they were healthy. Other studies have found a more positive attitude as participants with HIV/AIDS talk about the importance of enjoying every day. Among MSFWs, there is more an attitude of surviving and making it through another day the best way one can.

### Implications

There is a critical need for culturally appropriate HIV/AIDS education for MSFWs. The participants

had a basic, general knowledge about HIV/AIDS but had been unable or unwilling to change risky behaviors for transmission. There is a need for outreach to this population to increase their knowledge and understanding of AIDS susceptibility. Ultimately, this knowledge will enhance the likelihood of behavior changes that decrease disease transmission. Media campaigns and information distributed at church, in school, at the work site, and at health care facilities are a few strategies to reach MSFWs. Of course, all strategies need to be culturally and linguistically tailored for MSFWs. Education is also key to decreasing the shame and stigma surrounding HIV/AIDS in this population. To increase their beliefs about susceptibility, it would be helpful for MSFWs with HIV/AIDS to be open about their HIV status and involved in outreach efforts.

The secrecy surrounding the HIV status of MSFWs has implications for prevention efforts, program planning, and care being received. Their reluctance to disclose their HIV status to others encourages the "don't talk about it" attitude for all involved. It results in a lack of support and increased stress for infected individuals. Reports of not even telling health care workers is of utmost importance because of lack of needed care and follow-up.

Care of HIV-infected MSFWs is a paramount challenge for the infected individual as well as health care workers. HIV demands coordination of care in a population that has not been privileged to health care in general. MSFWs need to be encouraged to seek HIV/AIDS and services when migrating from government-administered and CBO-administrated services. The new medications given in combination offer hope for a longer, healthier life for HIV-infected individuals. However, once taking the medications, individuals must have an adequate supply, adhere to prescribed regimens, and have CD<sub>4</sub> counts and viral loads done regularly to ensure effectiveness. Patient-clinician relationships have been found to be a key to adherence to HAART (Williams, 1999). La Frontera has begun coordinating care for HIV-infected MSFWs in its home base of Texas. These efforts must extend beyond the Texas border to make a difference in this population.

HIV testing must be made available and encouraged for MSFWs. Education can increase the participants'

understanding of when they should get tested and what the test means. However, health care workers need to address the need for testing whenever they encounter MSFWs. Testing is a key to early care and treatment for individuals with HIV disease.

The HIV-related stigma described by MSFWs has implications for coping with the disease, testing, and care. It is after all the reason that individuals do not seek testing and delay in seeking care after diagnosis (Chesney & Smith, 1999). Ultimately, these delays result in compromised treatment, hastened disease progression, and, possibly, increased transmission of HIV.

There is a clear need for research related to HIV/AIDS and MSFWs. Prevention of transmission, care, and treatment of infected individuals are areas in need of culturally appropriate interventions. La Frontera is an example of a partnership of university-based researchers with grassroots community organizations that is beginning to answer the questions and meet the needs related to HIV/AIDS in this special population.

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