

# Quality of Life Issues Among a Small Sample of Persons Living with HIV Disease in a Rural Area

Richard E. Cain, Ph.D., CHES

Assistant Professor of Health Education, Rhode Island College, Department of Health and Physical Education, Room 129 HPEA Complex, Providence, RI 02908; Phone: 401.456.9692; Fax: 401.456.8875; email: [rcain@ric.edu](mailto:rcain@ric.edu) Submitted February 21, 2001; Revised and accepted May 20, 2001

---

## Abstract

*Health-related quality of life was evaluated among a small sample of persons living with HIV disease in a rural area, primarily African Americans. Survey results were supplemented with semi-structured interviews with some of the respondents. Interviews suggest that poor perceptions of quality of life may be enhanced by stigma originating from within the medical community. Many respondents were non-compliant to medical treatment.*

---

## Introduction

Quality of life has been described as the range of capabilities, limitations, and psychosocial characteristics that describe one's ability to function and derive satisfaction from life, and can include concerns about the future (Bergsma & Engle, 1988). As HIV disease has become recognized as a chronic disease, evaluation of one's quality of life has become important because the uncertainty of future health status and the psychosocial distress of living with the infection can have a significant negative impact on the quality of life among those who are HIV positive (Cleary, Wilson, & Fowler, 1995; Renwick & Friedland, 1996).

In the United States, as an increasing number of people become infected with HIV, there is strong evidence that rural America is representing the "second wave" in the geographical spread of infection. From 1993 to the end of 1996, the number of cases of AIDS reported for non-metropolitan areas in the United States increased 42.8% (Centers for Disease Control and Prevention [CDC], 1993, 1996). By the end of 1999, this number had increased 57.6% since the 1993 estimate (CDC, 1993; CDC, 1999).

There are a variety of reasons why there is a spread of HIV into rural areas and, equally, a number of important reasons why more research is needed. Current estimates are that 18% to 50% of people who become infected in cities return to rural areas; whereas only 8% of those diagnosed in rural areas out-migrate (Davis, Cameron, & Stapleton, 1992; Sowell, 1996). These individuals are generally in the advanced stages of the disease, and are returning home to their families for supportive care (Berry, McKinney, & McClain, 1996; Sowell, 1996). Other researchers have suggested that an increase in the number of local infections is a result of injecting drug use (Steel & Haverkos, 1992)

and high risk sexual activity (Berry, 1993; Karon & Berkelman, 1991; Hospers & Kok, 1995).

There are many psychosocial and structural barriers that can affect the health and quality of life of those living with HIV disease who live in rural areas. Members of rural communities tend to be more "tightly knit" and to know one another which makes maintaining privacy, anonymity, and confidentiality more difficult (Martinez & Blundall, 1989). The stigma associated with HIV disease may be more obvious than it is in urban areas because of the characteristics of rural areas which make them less open to diversity (Rounds, 1988). For example, stronger religious beliefs may breed a lack of tolerance for diversity, enforce strong homophobic reactions and discrimination, may discourage persons living with HIV disease to seek treatment, and possibly hinder the development of AIDS clinics (Bell, 1991; Frierson, Lippman, & Johnson, 1987; Heath, 1992). Developing and maintaining support with others living with HIV disease may be difficult because of the fear of being deemed as "not deserving" of care and support from those who could provide support (Frierson, Lippman, & Johnson, 1987; Helms, 1991). Health care services have also been found to be more limited in rural areas. In some rural settings, experimental drugs and protocols, access to speciality care, referral networks for social services, outreach programs, coordination of services and support groups are minimal or nonexistent for those living with HIV disease (Carwein, Sabo, & Berry, 1993).

A limitation for health educators working to improve aspects of health and quality of life for populations living with HIV disease who live in rural areas is the paucity of information. Most studies that have evaluated health-related quality of life have focused on persons living with HIV disease who live in urban areas and, then, most have focused on clinical

care provided to HIV positive individuals to determine needs for short-term outcomes of drug treatments, integrating treatment and disease, or assessing the clinical needs of HIV positive individuals (Wu & Rubin, 1992). Other health-related quality of life studies have focused on instrument development, validity, and reliability (Burgess, Dayer, Catalan, Hawkins, & Gazzard, 1993; De Boer, Sprangers, Aaronson, Lange, & Van Dam, 1994; Holmes & Shea, 1998; Lubeck & Fries, 1993; Wu, et al., 1991).

Few researchers have studied, specifically, the concept of health-related quality of life among persons who live with HIV disease who live in rural areas. Heckman, Somlai, Otto-Salaj, and Davantes (1998) evaluated health-related quality of life among a sample of 78 people living with HIV disease who lived in small communities and rural areas throughout the state of Wisconsin. Many participants provided responses that were indicative of poor quality of life, such as living with physical pain, experiencing a lack of energy, and feeling that they received little or no support from family and friends. Some researchers have experimented with ways to improve quality of life for HIV positive individuals living in rural areas. Two approaches, such as the development of telephone-linked support groups (Rounds, Galinsky, & Stevens, 1991) or ways to improve services by coordinating comprehensive service programs with appropriate involvement of local, regional, and state units (Cleveland & Davenport, 1989) have been suggested.

An important aspect of quality of life, yet challenging, is that it tends to be subjective. Because of this, using only traditional quantitative instruments to measure health-related quality of life may not always reflect the ways in which people living with HIV disease in rural areas monitor and evaluate their health. Combining both quantitative and qualitative methods in quality of life evaluations may yield the most satisfactory results (Aaronson, 1988). The purpose of this study was to use a quantitative survey instrument supplemented with semi-structured interviews to describe self-perceived health-related quality of life among individuals living with HIV disease who resided in a selected rural area of Pennsylvania.

## Methods

### *Research Design and Measurement*

The research design used in this study is descriptive. A previously validated questionnaire was used to elicit quality of life facts (Wu et al., 1991). Demographic questions were added to the

questionnaire. Answers to all questions were provided directly on the questionnaire, which took no more than 30 minutes to complete. To put the survey data into context, and to assess attitudes, context and interactions among the survey respondents, semi-structured interviews were used to allow respondents the opportunity to describe, in their own words, themes surrounding perceptions about quality of life. This technique is useful when the researcher knows the questions to ask but cannot predict the answers and it ensures that the researcher will obtain the information required while at the same time allowing participants to respond freely and to illustrate concepts (Morse & Field, 1995). During the interviews, probes that elicited certain facts were asked of each participant. Secondary probes were developed as needed during the interview to encourage the participant to elaborate. Otherwise, the participant was allowed to speak freely.

### *Population, Sample Selection & Procedure*

The population for this study was 150 persons living with HIV disease (24 with an AIDS diagnosis), aged 18 years or older, who were clients of AIDS service organizations (ASO) during the winter and early spring of 1997. An ASO is an organization that provides services, referrals and education to those infected and affected by HIV disease.

A sensitive research topic is one that potentially poses a threat to the subject or renders problematic for the researchers in terms of data collection, holding, and dissemination of the research data (Lee & Renzetti, 1993). To encourage participation, all questionnaires were distributed, collected, and returned to the investigator by the ASOs who agreed ahead of time to distribute the questionnaires. When a client presented in person to the ASO, he or she was provided a copy of the survey, an informed consent, and a self-addressed, stamped envelop. Participants were verbally instructed to read the informed consent form and that completion of the survey was voluntary. If the client decided to complete the survey, he or she was instructed to seal it in the self-addressed envelope and to return it to the ASO. If the client decided not to complete the survey, the unused materials were to be returned to the ASO. If a client did not present him/herself in person to the ASO by the end of the data collection period, or if it was suspected that the client would not present, the ASO mailed (to the client's home address) a copy of the survey materials with instructions about how to return the survey.

All survey participants remained anonymous to the investigator. On each survey, the participant was asked if he or she would agree to be contacted for a follow-up interview in order to discuss the results of the survey, and if so, to place his or her name and telephone number and a time to be contacted directly on the questionnaire. The participant then remained confidential. A respondent's indication of willingness to be interviewed was voluntary and a respondent could withdraw his or her name from the interview list at any time. To ensure anonymity of the respondent from the individual hired to perform data coding and entry, the section of the survey that contained the respondent's name and telephone number was removed and retained by the investigator. Fourteen respondents returning a questionnaire provided follow-up contact information for the interview.

After analysis of the quantitative data was completed, the researcher contacted respondents agreeing to be interviewed. Each respondent was provided with an update about the study (i.e., its purpose and the phase of the data collection process), and was asked if he or she still agreed to be interviewed. If the respondent was in agreement, the time, date, and location for the interview were then determined. Of those 14 who indicated interest in an interview, nine respondents were interviewed (seven African Americans and two whites). One white respondent who had initially agreed to an interview had expired prior to the interview. Four survey respondents were unable to be contacted because they had moved or had their telephone disconnected. All interviews took no more than 45 minutes each and were conducted in a room, away from others, that would assure the respondent's privacy.

#### **Analysis**

Descriptive statistics were calculated for all of the variables. The Student's t-test was used to compare the means of the dependent variables of overall quality of life and subscales against the ordinal independent demographic variables. Pearson correlation coefficients were used to examine the linear relationship between the dependent variables of overall quality of life and subscales against the independent interval demographic variables and the strength of the relationship that existed between the quality of life subscales and overall quality of life.

## **Results**

### ***Quantitative Analysis and Findings***

Of the 43 questionnaires that were returned to the investigator, 39 were useable. Seven respondents self-identified as White and 32 as African American or Black. Twenty-four females (22 African American or Black and two white) and 15 males (10 African American or Black and five white) responded. The average age of the respondents was 34 years ( $SD = 5.4$ ,  $R\ 23 - 43$ ). Only 21 of the respondents had a high school education or higher. Twenty-six respondents were unemployed. Of those, 24 indicated that they were unemployed due to medical reasons. Personal monthly income was less than \$500 per month for 20 (57.1%) of the respondents. Eleven (31.4%) respondents reported a personal monthly income between \$500 and \$999, and four (11.4%) respondents reported a personal monthly income of greater than \$1000. Nineteen respondents reported living alone. Twenty respondents reported living with at least one other person.

Nineteen respondents identified their sexual orientation as heterosexual, 11 as homosexual and five respondents were bisexual. A total of 12 reported that they had been diagnosed with AIDS. Of those males with HIV disease, exposure was from having sex with a male, injecting drug use, and heterosexual contact, respectively. Of those females with HIV disease, 11 were exposed to HIV from having sex with a male, six reported having contracted HIV through sex with a male who was an injecting drug user, three contracted HIV either by sex with a man or injecting drug use but were not sure.

### ***Quality of Life Findings***

Greater than 86% of the respondents reported difficulty in their cognitive abilities ( $r = .70$ ,  $\% = .00$ ,  $n = 30$ ). That is, they had difficulty making plans, were forgetful, and had trouble keeping attention, concentrating or thinking. Respondents who were not employed were more likely to be unemployed due to their cognitive limitations ( $t(34) = -2.22$ ,  $p = .03$ ). Seventy-eight percent of the respondents reported moderate to high degrees of health distress, or feeling weighted down and hopeless about their health problems ( $r = .72$ ,  $\% = .00$ ,  $n = 30$ ). Seventy-five percent of the respondents reported low to moderate limitations in their physical functioning abilities, like

lifting heavy objects, carrying groceries, or bending, lifting or stooping ( $r = .77$ ,  $\% = .00$ ,  $n = 30$ ). All respondents reported some limitations in their role functioning abilities, like doing school work, job duties, or being able to perform roles at work or at home ( $r = .67$ ,  $\% = .00$ ,  $n = 30$ ). Two-thirds of the respondents reported mild to very severe pain ( $r = .64$ ,  $\% = .00$ ,  $n = 30$ ). Ninety-two percent reported moderate to high limitations in social functioning abilities like visiting with friends or close relatives ( $r = .65$ ,  $\% = .00$ ,  $n = 30$ ). Female respondents reported lower levels of social functioning than did males ( $t(37) = 2.14$ ,  $p = .04$ ). Also, those respondents who lived alone had lower social functioning scores than did those respondents who lived with at least one other person ( $t(37) = -2.72$ ,  $p = .01$ ). Almost 90% of the respondents reported moderate to poor mental health functioning in that they felt feelings of being nervous, down, or unhappy ( $r = .53$ ,  $\% = .00$ ,  $n = 30$ ). Almost 80% of the respondents reported moderate to low perceptions of their overall health status ( $r = .47$ ,  $\% = .00$ ,  $n = 30$ ). Self-perceptions of quality of life were moderate (78.9%) to high (10.5%), but the strength of the relationship was low ( $r = .33$ ,  $\% = .04$ ,  $n = 30$ ). When comparing those who identified their sexual orientation, homosexual respondents reported greater mental health than did those who identified as heterosexual ( $t(25) = -2.42$ ,  $p = .02$ ) and had better perceptions of their overall health ( $t(28) = -2.18$ ,  $p = .04$ ).

#### **Interview Analysis and Findings**

The interviews were recorded by handwritten notes and tape recordings. Before the interview, the participant was reminded of informed consent. After the interview, tape recordings were transcribed immediately. To try to put quality of life into context, during transcription of the interviews, notes about certain themes that were developing were recorded in order to develop tentative ideas about categories and relationships among the data. As suggested by Morse and Field (1995), this fracturing of the data and to rearrange it into categories would, in turn, allow for the comparison of data within and between categories and that would aid in the development of theoretical concepts. Four primary themes developed as a result of the interview data: 1) experiences of stigma from the medical community, 2) perceptions of physician knowledge, 3) noncompliance to HIV treatment, and 4) experiences with family and friends.

#### **Experiences of Stigma from the Medical Community**

Of the African American respondents interviewed, all felt that the medical community had negative attitudes toward them because of their race/ethnicity, sexual orientation, HIV status, or history of injecting drug use, although not all injected drugs. Many respondents felt that, on one hand, their overall quality of life was improved by not living in urban areas where there was a greater temptation of drug use, but that on the other hand, felt plagued by stigma and discrimination from within the medical community regarding their race/ethnicity, sexual orientation, or mode of HIV infection. The interview findings suggest that these perceptions may have had a negative impact on health-related quality of life.

*"When I first came here, I was told not to go to the local hospital because they were extremely prejudice against Blacks and persons with HIV."* - African American Female

*"When you go the doctor for the first time you have to fill out the forms. I hate put'n down HIV positive and I know I am put'n Black. I wonder if they is [sic] going to see me or not because I am Black and HIV."* - African American Female

*"... and they say they ain't prejudice... but come on. There are a lot of Black people in this town and they don't like that... shit... because this is a white peoples' town. They don't want us up here."* - African American Female

*"The hospital treats you bad. There are attitudes and gestures toward me being black, HIV positive, gay and a recovering drug user."* - African American Male

African American and Black respondents who received medical care from a larger, regional medical center reported being more satisfied than those who received medical care from the local community hospital. The drive, however, was long - more than one hour, and many did not have the transportation to drive the longer distance to the regional medical center or to urban areas where they felt more comfortable receiving care. Public transportation was not always available. If they could ride the bus, they had little resources to purchase the fare. If they had personal transportation, they had little resources for gasoline.



**Perceptions of Physician Knowledge**

Many African American or Black respondents had poor perceptions of the care they were receiving, especially as it related to the physician's knowledge and experience in working with persons living with HIV disease. When asked to compare their perception of their local physician's knowledge to the knowledge and level of care they received from other places, such as the regional medical center or from their urban home, respondents were generally more satisfied with care from other places.

*"With all of the treatments available in the big cities, the doctors here in this area are totally clueless to those treatments. I think they are naive about the treatments that are beneficial to people. They are not making an effort to find out new information and to treat the person to the best of their abilities."* - African American Woman

*"The doctors here are conservative in terms of their treating me. They don't give me treatment. Or, they tell you that you are still HIV positive when you have full-blown AIDS. When it was time for a friend of mine to receive medication, it wasn't doing anything for her, and she died. They waited too late."* - African American Male

*"Here, they don't have enough doctors and enough knowledge."* - African American Male

Respondents were asked to describe what, if anything, made them feel comfortable with the treatment they were receiving from their local physicians. Most indicated that it is helpful when the physicians took the time to understand.

*"My doctor is pretty good. He is a local doctor. He is kind, courteous, but I have to tell him what I want done. I have to say to him this is what is bothering me and I have to tell him how I am feeling and then he will do it."* - African American Female

*"My doctor is real good. He doesn't tell you a lot, but if you ask questions he will give you the answers."* - White Male

The negative attitudes described above regarding knowledge and treatment was not held by all of the African American and Black respondents, and neither of the two white respondents. A complaint, however, is echoed about the viability of culturally appropriate models that are used to treat an increasing number of

minorities becoming infected with HIV who may live in rural areas, especially African Americans and Blacks.

**Non-Compliance to HIV Treatment**

In this sample, all respondents reported not taking advantage of the new drug therapies available to persons living with HIV disease. The animosity about not to use treatment centered around perceived side-effects of drug therapy and a lack of knowledge about HIV treatment benefits. Also, many interview respondents reported, vicariously, the experiences about how HIV treatment affected others and explained that these were reasons influencing a personal decision about why not to use medications.

*"I am not on medications. Everyone I know who was ever on those prohibiters [sic] is dying. I don't know one person who is on that medication who is doing okay. It was suggested that I try prohibiters [sic] to decrease my viral load. But I am not going to take a risk, not until I have investigated more. I have to have at least a 75% chance that the drugs will improve my health."* - African American Male

*"I am getting no treatment and taking no medications. The side effects of taking medication for Hepatitis B were too toxic and I decided then that I was not going to do that again."* - White Male

*"I will take AZT, because I am planning on having a baby. I would not take the drugs if I was not going to have a baby. The drugs are too toxic. I have seen other people taking them. The effects, reactions to the medicine are too bad."* - African American Female

*"I cannot be on such a rigorous schedule. I would not stick to it. ...and the odds of taking the medication are not that great."* - White Male

**Experiences with Family and Friends**

During the interviews, when respondents were asked to speak about living with HIV disease, two women mentioned that living with this disease was mentally and emotionally painful, and verbalized their fears of rejection and isolation. It is clear that feelings of psychosocial rejection because of being HIV positive took away from their self-esteem.

*"I am afraid of not being able to find another man who would love me."* - African American Female

*"Being HIV positive labels me as being dirty, unfit, contagious, threatening."* - African American Female

Most respondents indicated that their family's reaction was generally positive, but also indicated that the family's greatest concern was worrying about the loss of their loved one. A problem for one respondent was that she and her family lived apart. This participant indicated that education could help her family, but stated that she cannot educate her family because of the geographic distance between her and her family. Some respondents experienced rejection from family and friends. For others, acceptance from family and friends came only after understanding and education. The majority of the respondents who were interviewed had family members who knew of the participant's positive HIV status.

*"My father kept wanting me to get tested because my partner was HIV positive and had been diagnosed with AIDS. My father was very supportive."* White Male

*"First the abandonment came from people I dealt with. My family understood, but were afraid that I would leave them."* - African American Male

*"I have a 22 year old daughter. She was upset at first. She was afraid of me dying. She has come to accept it now. Now she comes to groups with me."* - African American Female

*"At first my family rejected me. At one point I also had hepatitis and then they really rejected me. They thought I was going to die right away."* - African American Female

*"My mother has more problems with my being gay than being HIV positive."* - White Male

## Discussion

The response rate for this study was low and there was an unexpected higher response from African Americans and Blacks. All respondents reported migrating to the area after being diagnosed with HIV disease and no African American or Black was indigenous to the area, but had migrated for drug rehabilitation services or to be with a partner who was undergoing rehabilitation. Many of the respondents reported experiencing pain, having difficulty concentrating, feeling distressed and hopeless about their health problems, experiencing difficulty performing tasks at work or at home, feeling down and unhappy. Rural areas are not homogeneous, and although it is difficult to generalize, the results of

this study are consistent with those of other researchers who reported that persons who are living with HIV disease who live in rural areas suffer quality of life concerns (Heckman, Somlai, Otto-Salaj, & Davantes, 1998). The interviews with some of the survey respondents provided a deeper contextual understanding into the factors which may have influenced the perceptions of quality of life among the participants.

Researchers have demonstrated that to improve survival time, people living with HIV disease should have an accurate positive perception of their health status (Linn, Anema, & Sandra, 1996) and that physicians with more experience in treating those living with HIV disease tend to experience lower mortality rates among their patients (Kitahata, et al, 1996). In general, most patients living with HIV disease tend to feel that their physician has some control over their illness (Kalichman, 1995). These constructs appear to have particular bearing on the quality of life among this study's sample, especially for those interviewed. It is possible that in this rural area, there is the absence of a culturally viable medical and treatment model for improving health-related quality of life among those living with HIV in this rural area, especially for African Americans and Blacks. Planning for health promotion should assess the quality of life concerns of minorities and include cross-cultural continuing medical education for medical staff that addresses the concerns of minorities. One key to cross-cultural health promotion is an understanding of value systems in other cultures and their influence on health. Continuing cross-cultural professional education for medical staff could be helpful, especially about what it is like to live with HIV disease, to be a recovering drug user, or to be the partner of a recovering drug user, or to be a minority living in traditionally non-white rural areas.

The problem of non-adherence to HIV treatment is still being acknowledged and poses problems for health educators (Demmer, 2001). So many of the therapies for HIV are still experimental as they were when they were first being discovered and non-adherence to treatment has been described since treatment regimens first began (Freeman, Rodriquez, & French, 1996; Wu, et al, 1991). Many of this sample's interview respondents described having little information about the benefits of treatment. The information they did relate to the investigator was negative, primarily about the toxic side effects of the drugs, and many of the respondents reported their experiences vicariously.

Health promotion efforts that include clarification of all available treatment options, provided in a culturally sensitive manner and with respect to management of treatment side-effects, may increase a sense of adherence and efficacy that is integral to overall quality of life. There is also the possibility that some persons undergoing treatment will at some point discontinue treatment or choose alternative methods of treatment. Further, treatment that is carried out is dependent upon the attitude toward the disease, treatment options, and the trust supported by the physician's perception of the patient's quality of life. If health educators realize this, they may at least be able to help the patient maintain the patient/physician relationship, rather than abandoning medical care altogether.

#### ***Limitations of the Present Study and Recommendations for Further Research***

While the present study presents some valuable insight into the quality of life for the sample living with HIV disease in the rural setting, the small response rate in both quantitative and qualitative data collection, the subsequent small cell sizes used in the data analysis, and the over sampling of African Americans and Blacks may affect the degree to which these findings can be generalized to rural populations living with HIV disease in other geographical areas. The population selected for this study was one of convenience. Only persons living with HIV disease who were on record as clients of the ASOs were invited to participate in the study. No attempt was made to include all possible persons living with HIV/AIDS (e.g., those working with physicians, and other private and public agencies providing services and needs to persons living with HIV disease). As such, perhaps these results only express the views of the participants who were clients of the ASOs. For a broader perspective, future studies should be conducted utilizing a larger sample from the population being studied. The population base should be broadened to include all possible persons living with HIV disease. This includes working with both physicians, and private and public agencies providing services and needs to persons living with HIV disease.

There are several factors that may explain the over sampling of African Americans and Blacks in both the survey and the interview data. All of were clients of the same ASO. Further, the ASO had assigned an HIV positive African American to act as a gatekeeper and to monitor the distribution of the questionnaires. In the other ASOs, front-line staff managed the distribution and collection of the questionnaires. While this was not

planned in the present study, the gatekeeper who was demographically close to the subjects and HIV positive might have had the impact in recruiting participants. Future attempts should employ intensive work with the data collection representatives from each agency and is suggested so that staff are knowledgeable and feel closely attached to the study.

Perhaps due to the psychosocial and cultural differences of living with HIV disease in rural areas, and of problems of anonymity and confidentiality, some persons who received services from the participating ASOs may have decided not to participate in this study. Future researchers may want to consider studying the effect of rural characteristics and stigma on rural populations living with HIV. Future quality of life studies should enhance the quality of life questionnaire to include information about stigma originating from within the medical community.

A concept of quality of life as explained by Renwick and Brown (1996) defines quality of life in terms of being, belonging, and becoming, in which belonging is the individual's feeling of fit or link between the self and the environment (i.e., physical, social, and community). With a feeling of not belonging, or in being displaced from one's more familiar surroundings, such as with the African American and Black respondents, a lower quality of life could be expected. Given the fact that AIDS and HIV infection has been particularly devastating within minority communities, these results suggest that there is a necessity for more research addressing quality of life for those living with HIV in rural areas. Also, given the spread of HIV disease into rural areas, there is no reason to believe that minorities would not also be affected as disproportionately as they have been in urban areas, adding to the importance for additional research. The face-to-face interviews were effective and are encouraged.

#### **Acknowledgment**

The author would like to thank Collins Airhihenbuwa, Ph.D., The Pennsylvania State University, for his many suggestions during earlier revisions of this manuscript

#### **References**

- Aaronson, N. K. (1988). Quantitative issues in health-related quality of life assessment. *Health Policy, 19(3)*, 217-230.
- Bell, N. K. (1991). Social/sexual norms and AIDS in the South. *AIDS Education and Prevention, 3(2)*, 164-180.

- Bergsma, J., & Engel, G. L. (1988). Quality of life: Does measurement help? *Health Policy*, 10(3), 267-279.
- Berry D. E. (1993). The emerging epidemiology of AIDS. *Journal of Rural Health*, 9(4), 293-304.
- Berry, D. E., McKinney, M., & McClain, M. (1996). Rural HIV service networks: Patterns of care and policy issues. *AIDS & Public Policy Journal*, 11(1), 36-46.
- Burgess, A., Dayer, M., Catalan, J., Hawkins, D., & Gazzard, B. (1993). The reliability and validity of two HIV-specific health-related quality of life measures: A preliminary analysis. *AIDS*, 7(7), 1001-1008.
- Carwein, V. L., Sabo, C. E., & Berry, D. E. (1993). HIV infection in traditional rural communities. *Rural Nursing*, 28(1), 231-239.
- Centers for Disease Control and Prevention. (1993). *HIV/AIDS surveillance report: Year-end edition*. Atlanta, GA: Author.
- Centers for Disease Control and Prevention. (1996). *HIV/AIDS surveillance report: Year-end edition*. Atlanta, GA: Author.
- Centers for Disease Control and Prevention. (1999). *HIV/AIDS surveillance report: Year-end edition*. Atlanta, GA: Author.
- Cleary, P. D., Wilson, I. B., & Fowler, F. J., (1995). Health-related quality of life in HIV- infected persons: A conceptual framework. In J. E. Dimsdale, & A. Baum (Eds.), *Quality of Life in Behavioral Medicine Research*, (pp. 191-204). Hillsdale, NJ: Lawrence Erlbaum.
- Cleveland, P. H., & Davenport, J. (1989). AIDS: A growing problem for rural communities. *Human Services in the Rural Environment*, 13(1), 23 - 28.
- Davis, K. A., Cameron, B., & Stapleton, J. L. (1992, October). The impact of HIV patient migration to rural areas. *AIDS/Patient Care*, 225.
- De Boer, J. B., Sprangers, M. A. G., Aaronson, N. K., Lange, J. M. A., & Van Dam, F. (1994). The feasibility, reliability and validity of the EORTC QLQ-C30 in assessing the quality of life in patients with symptomatic HIV infection or AIDS (CDC IV). *Psychology and Health*, 9(1-2), 65-77.
- Demmer, C. (2001). Nonadherence to HIV treatment: Implications for health educators. *Journal of Health Education*, 32(1), 16-23.
- Freeman, R. C., Rodriquez, G. M., & French, J. F. (1996). Compliance with AZT treatment regimen of HIV-seropositive injection drug users: A neglected issue. *AIDS Education and Prevention*, 8, 58-71.
- Frierson, R. L., Lippmann, S. B., & Johnson, J. (1987). AIDS: Psychological stresses on the family. *Psychosomatics*, 28, 65-68.
- Heath, J. (1992). The rural AIDS front. *Health/PAC Bulletin*, 22(2), 20-21.
- Heckman, T. G., Somlai, A. M., Otto-Salaj, L., & Davantes, B. R. (1998). Health-related quality of life among people living with HIV disease in small communities and rural areas. *Psychology and Health*, 13, 859-871.
- Heckman T. G., Somlai, A. M., Kalichman. S. C., Franzoi, S. L., & Kelly, J. A. (1998). Psychosocial differences between urban and rural people living with HIV/AIDS. *Journal of Rural Health*, 14(2), 138-145.
- Helms, C. M., (1993). Rural HIV infection: The window of opportunity is still open. *Journal of General Internal Medicine*, 8(4), 210-212.
- Holmes, W. C., & Shea, J. A. (1998). A new HIV/AIDS-targeted quality of life (HAT- QoL) instrument: development, reliability, and validity. *Medical Care*, 36(2), 138-154.
- Hospers, H. J., & Kok, G. (1995). Determinants of safe and risk-taking sexual behavior among gay men: A review. *AIDS Education and Prevention*, 7, 74-94.
- Kalichman, S. C. (1995). *Understanding AIDS: A guide for mental health professionals*. Washington, DC: American Psychological Association.
- Karon, J. M., & Berkelman, R. L. (1991). The geographic and ethnic trends in homosexual and bisexual men in the United States. *Journal of Acquired Immuno-Deficiency Syndrome*, 4(12), 1179-1189.
- Kitahata, M. M., Koepsell, T. D., Deyo, R. A., Maxwell, C. L., Dodge, M. T., & Wagner, E. H. (1996). Physicians' experience with the acquired immunodeficiency syndrome as a factor in patients' survival. *New England Journal of Medicine*, 334(11), 701-706.
- Lee, R. M., & Renzetti, C. M. (1993). The problems of researching sensitive topics: An overview and introduction. In C. M. Renzetti & R. M. Lee (Eds.), *Researching sensitive topics* (pp. 3-13). Newbury Park, CA: Sage.
- Linn, J. G., Anema, M. G., & Hodess, S. (1996). African American clients of AIDS counseling centers. *Journal of Nurses in AIDS Care*, 7(2), 43.
- Lubeck, D. P., & Fries, J. F. (1993). Health status among persons infected with human immunodeficiency virus. *Medical Care*, 31(3), 269-276.



Martinez-Brawley, E. E., & Blundall, J. (1989). Farm families' preferences toward personal social services. *Social Work, 34*(6), 513-522.

Morse, J. M., & Field, P. A. (1995). *Qualitative research methods for health professionals*. Sage: Thousands Oaks, CA.

Renwick, R., & Brown, I. (1996). The centre for health promotion's conceptual approach to quality of life: Being, belonging, and becoming. In R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation* (pp. 75-86). Thousand Oaks, CA: Sage.

Renwick, R., & Friedland, J. (1996). Quality of life experienced by a sample of adults with HIV. In R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation* (pp. 171-189). Thousand Oaks, CA: Sage.

Rounds, K. A. (1988). AIDS in rural areas: Challenges to providing care. *Social Work, 33* (3), 257-261.

Rounds, K. A., Galinsky, M. J., & Stevens, L. S. (1991). Linking people with AIDS in rural communities: The telephone group. *Social Work, 36*(1), 13-18.

Sowell, R. (1996). HIV infection in rural communities. *Nursing Clinics of North America 31*(1), 107.

Steel E., & Haverkos, H. W. (1992). AIDS and drug abuse in rural America. *Journal of Rural Health, 8*, 70-73.

Wu, A. W., & Rubin, H. R., (1992). Measuring health status and quality of life in HIV and AIDS. *Psychology and Health, 6*(4), 251-264.

Wu, A. W., Rubin H. R., Mathews, W. C., Ware, J. E., Bryske, L. T., Hardy, W. D., Bozzette, S. A., Spector, S. A., & Richman, D. D., (1991). A health status questionnaire using 30 items from the medical outcomes study: Preliminary validations in persons with early HIV infection. *Medical Care, 29*(8), 786-798.

Copyright © IEJHE 2001