

Psychosocial Variables that Relate to Blood HIV Virus Load Levels

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Abstract

Challenges for health care professionals, resulting from recent advances in drug therapy in persons with HIV, are issues of adherence to prescribed medications and treatment regimes and decisions about the use of expensive and life prolonging medications. The purpose of this study was to examine psychosocial adjustment to illness variables and health locus of control in HIV positive persons and identify any possible associations that existed in this sample. A non-experimental two-group comparison was utilized in this study. Statistical analysis of the data revealed no difference in the domains of the Psychological Adjustment to Illness Scale-Self Report (PAIS-SR) except for the domain of Extended Family Relations. Persons with low levels HIV viral loads perceive themselves as having a more internal locus of control, and believe that doctors have a great deal of influence on their health status. Implications for nurses in advanced nursing practice are discussed.

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INTRODUCTION

New and more complex issues and challenges for health care professionals are currently evolving and influencing treatment strategies and intervention for individuals with HIV. These issues and challenges are the result of recent advances in drug therapy that significantly prolongs the life span of these individuals. Issues include adherence to prescribed medications and treatment regimes, adjustment to illness and decision about the use of expensive and life prolonging medications. Literature documents that numerous factors influence adherence to medication and treatment regimes in populations with chronic illnesses. The purpose of this study was to identify psychosocial adjustment to illness variables and health locus of control in HIV positive persons that identify trends that exist in persons with low or high levels of HIV virus in blood viral load testing.

LITERATURE REVIEW

Review of relevant literature encompassed specific aspects of dealing with HIV and the literature on adherence/non-adherence in relation to chronic illness. The sections on significance and theoretical/conceptual framework and rationale present a representation of the literature reviewed for this study.

SIGNIFICANCE

Literature documented that numerous factors influence adherence to medication and treatment regimes in populations with chronic illnesses. Factors that hindered adherence and non-adherence were numerous and complex. Factors that inhibit adherence included (to name a few): adverse medication effects, medication complexity (e.g. frequency of dosing, number of medications to be taken), need to eat or not eat within a timeframe of taking medications, lack of disease symptomology, lack of social support, beliefs about health/wellness, concurrent alcohol or illicit drug use, knowledge of the treatment regime, negative provider-patient relationships, and cultural beliefs. Factors that promote adherence included: increased knowledge of the illness and medications, positive attitude toward health/wellness promotion, positive provider-patient relationship, external cues or reminders (e.g. alarms, calendars, pillboxes), established routine for taking medications, family/social support, and sensitivity of care

providers to cultural beliefs. ^{1, 2, 3, 4, 5}

THEORETICAL FRAMEWORKS AND RATIONALE

The rationale and theoretical base for this research came from three areas, blame, harm reduction, and the health belief model. Since adherence is viewed as complex, with numerous factors affecting promoting or inhibiting adherence, it seemed reasonable that no one theory/framework or rationale was applicable.

Blame. Poor adherence has been evident in health promotion regimes and in the management of acute and chronic disease. The impact of poor adherence has been significant and issues have centered on the person as the one to blame. Literature on blame suggested that the person may not solely be responsible for the problem. Characteristics of the primary care provider may contribute to the person's ability or willingness to adhere to treatment regimes. ^{6, 7, 8} This supported the rationale for measuring locus of control with the Multidimensional Health Locus of Control (MHLC) tool. ^{9, 10} This tool extracts information about a person's belief about control of health and chance.

Harm reduction. Harm reduction has been described as an approach with persons with HIV that consist of primary, secondary and tertiary prevention strategies ¹¹ applicable in intervention in a variety of settings that include primary care, the community at large, and in drug abuse programs and systems. Strategies focused on prevention that reduces HIV transmission, access to and retention in drug treatment programs, and HIV education and counseling. Harm reduction additionally utilized the concept of therapeutic communities as a unique modality for impacting HIV. ¹² Use of this model supported the utilization of the Psychological Adjustment to Illness Self-Report (PAIS-SR) ¹³ tool in the areas of (1) health care orientation, (2) domestic environment, (3) sexual relationships, (4) social environment, and (5) psychological distress.

The Health Belief Model. The Health Belief Model (HBM) has been an attempt to explain health behaviors that influence prevention and promotion of personal health. ¹⁴ Also the HBM assumed that good health is a goal of most persons and that an person's perception of susceptibility, seriousness, benefits, barriers, and self-efficiency impact the likelihood of a person taking an action that is health related. ^{15, 16, 17, 18, 19, 20} This model supported the use of both measurement instruments, specifically the PAIS-SR domains of health care orientation, social environment and

psychological distress. Use of the MHLC is supported in this model by the degree the respondent believes that his/her health is controlled by self, powerful others, or by fate or luck.

PURPOSE

The purpose of this study was to identify psychosocial adjustment to illness variables and health locus of control in HIV positive persons that might identify trends that exist in persons with low or high levels of HIV virus in blood viral load testing. Specific aims were to (1) identify psychosocial adjustment to illness and health locus of control in a sample of HIV positive individuals, (2) compare patients with high and low viral loads on these variables, and (3) determine whether there are differences in HIV viral load that could be explained by the psychosocial variables.

Identification of trends in variables and group membership can be utilized in designing future intervention studies. The purpose of these intervention studies was to increase adherence to medical treatment regimes in persons who are HIV positive. These intervention studies should be applicable to other populations of persons who experience issues of adherence to treatment regimes.

RESEARCH METHODS

Goals and purposes of any specific research project differ but basic elements are common to all studies. The following sections present the research questions, the design, the setting and sample, procedures, data analysis, and study limitations.

RESEARCH QUESTIONS

The problem of the lack of specific information regarding selected variables created research questions of interest to this research team. Variables of interest to the researchers in persons who are HIV positive were (1) the effect of psychosocial adjustment to illness, (2) locus of control, and (3) person demographic information. Questions of interest were created by the researchers' interest in any trends that might exist between the variables and adherence to medical treatment regimes in persons who are HIV positive.

RQ1: What psychosocial adjustment variables are associated with low HIV blood viral loads?

RQ2: What psychosocial adjustment variables are associated with high HIV blood viral loads?

RQ3: What are the differences in the psychosocial adjustment variables between the groups with low and high HIV blood viral load levels?

RQ4: What is the locus of control of persons with low and high HIV blood viral load levels?

DESIGN

A non-experimental two-group comparison was used. Advantages of this type of comparison were: (1) it is useful for studying problems in social sciences; (2) it permits the analysis of relationships among a large number of variables in a single study; (3) it allows researchers to analyze how the variables, either singly or in combination, affect the pattern of behavior; (4) it provides information concerning the degree of relationship between the variables that are being studied; and (5) comparisons can be made between two groups on selected dependent variables. ²¹ Limitations of this design included: 1) a positive association between variables and group membership could result in an assumption that this association is the cause of adherence or non-adherence to medical treatment regimes, and 2) it is just as plausible that the variables have no effect on issues of adherence/non-adherence and that something that has not been measured in this study is effecting adherence/non-adherence. ²¹

SETTING AND SAMPLE

Researchers recruited study participants from the Ryan White Title III project Early Intervention Services (EIS) Clinic located at a large university health sciences center in Oklahoma. The population of this clinic, at the time of this investigation, was: (1) predominately male; (2) age range of 18 to 65 years; (3) exposure categories of homosexual exposure, injection drug use, heterosexual contact, and blood transfusion, with a large number of persons not disclosing their exposure category; (4) varied ethnicity, and (5) HIV status corresponding to AIDS surveillance case definition for adolescents and adults.

After obtaining Human Assurance Board approval, patients of this clinic, who were currently actively participating in highly aggressive antiretroviral therapy (HAART), were listed as potential participants. Subjects were then stratified into two groups based on documentation on the most recent viral load numbers available as reported on their medical records. One group consisted of patients with HIV blood viral loads less than or equal to 400 copies per ml. The second group consisted of patients with HIV blood viral loads equal to or greater than 20,000 per ml. A convenience sample of 60 consenting participants from the systematically stratified randomized groups was used.

PROCEDURES

First, the staff of the EIS clinic generated a list of subjects from the EIS roster that were currently and actively being treated at the clinic and who are participating in HAART medication regimes. Secondly, subjects from this list were stratified into two groups based on their most recent viral load level. Subjects were then systematically selected by using every n^{th} person until 30 subjects were in each group. These systematically randomly selected subjects from the list were sent a letter in a sealed envelope that provided the purpose and description of the study.

This letter asked them to call the clinic and report their willingness or unwillingness to participate in the study. Subjects who indicated willingness to participate were given the names of the principal investigator and co-investigator to set up a convenient time for assessment of meeting the study's eligibility criteria, enrollment into the study, and completion of the study's instruments. Subjects who did not respond to the first mailed letter were mailed a second letter. In the case of subjects who did not respond to the second mailed letter or indicated unwillingness to participate in the study the next n^{th} subject on the list was sent the letter describing the study and asked to call the clinic and indicate willingness or unwillingness to participate in the study. This procedure was done to ensure the most representative sample and the best possible response rate to the mailing. No names of individuals were released to the investigators by the EIS clinic until their willingness to participate and consent for their name to be given to the investigators had been obtained. The principal investigator, co-principal investigator, or collaborators asked all participants to sign the consent form, approved by the Human Assurance Board at the university health sciences center, before any instruments were completed. All research team members received training in administering the instruments. Although all team members received training, the primary investigator collected data on 95% of the participants.

Demographic information sheets and study instruments were coded with identical numbers and a group membership identifier for the purpose of matching scores. Matching on the instruments with the demographic information and group membership was used only for purposes of statistical analysis. No other identifying information was present on any of the forms. Participants were assured of the confidentiality of their identity, HIV status, and scores on the instruments. Data was reported only as group data. No matching of the participants to any demographic data or

laboratory values was available to anyone but the principle investigators. All data was entered into a computer program by participant number. Once this was done all identifying information was destroyed. All raw data was kept locked in a file cabinet by the principal investigator.

SAMPLING MEASURES/INSTRUMENTS

Two measuring instruments were used in addition to the demographic information sheet. The demographic information sheet also contained several questions that participants were asked about support systems, ways they managed their drug therapy, what they considered barriers, and how the therapy affected their day-to-day activities.

INSTRUMENT: PSYCHOSOCIAL ADJUSTMENT TO ILLNESS SCALE SELF-REPORT (PAIS-SR).

During the past several years there has been increased interest in the concept of adjustment to illness as the number of persons living with one or more chronic illnesses has increased. These chronic illnesses have made demands on persons to develop or enhance their coping skills, psychological integrity, and social support systems. About two dozen-measurement instruments exist to measure psychosocial function of persons experiencing psychiatric diagnoses, but few are available for persons with medical diagnoses.

Psychosocial adjustment tends to be defined differently from one situation to another. This adjustment is more than an intrapsychic process and it includes interactions between the person and other persons and the institutions that represent his or her sociocultural environment. A person's behaviors tend to be highly correlated with judgments concerning his or her levels of psychosocial adjustment. This adjustment to illness can be just as important as the status of his/her physical disease state. Psychosocial adjustment is multidimensional and domain relevant, measurability, time constraints, and cost-efficiency determine the choices of domains that are represented in a measurement scale. The PAIS-SR reflects psychosocial adjustment to illness via seven primary domains of adjustment. These domains are (1) Health Care Orientation, (2) Vocational Environment, (3) Domestic Environment, (4) Sexual Relationships, (5) Extended Family Relationships, (6) Social Environment, and (7) Psychological Distress. The PAIS-SR reliability coefficients for the domains are reported to range from .47 to .93 in samples of renal dialysis, lung cancer, and cardiac patients. The total PAIS-SR coefficients in three studies are reported to be: (1) 0.94 (n=260 burns); (2) 0.81 (n=222,

pain); and 0.91 (n=96, cardiac). Interrater reliabilities for the PAIS-SR domains are reported to range from 0.33 to 0.68. Total PAIS-SR reliability coefficients are reported to be 0.86(n=17, breast cancer); 0.83 (n=37, Hodgkin's disease); and 0.86 (n=222, pain).¹³

INSTRUMENT: MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL (MHLC) SCALE-FORM C.

The Multidimensional Health Locus of Control (MHLC) is derived from the general scales of Rotter's Internal/External Scale and Wallston, Wallston, Kaplan and Maides' Health Locus of Control Scale, both unidimensional scales are reported to measure a person's belief in the external and internal controlling agents of their physical health. This multidimensional approach is deemed by its developers to be more valid and powerful due to the three scores obtained. These scores indicate the degree to which the respondent believes that his or her health is controlled by self, powerful others (such as health care professionals), or by fate or luck. Scales are reported to be internally consistent with alpha reliabilities ranging from 0.67 to 0.77. Test re-test stability coefficients range from 0.60 to 0.70. Reliability estimates vary depending on many issues (e.g. the population studied and the length of time between administrations).^{9, 10}

Administration of instruments. Although instructions are printed on each instrument, every participant in this study had the instructions and questions read to them by the investigators. The participant was also asked if he/she has any questions about the assessment and if there was anything that was unclear. Should any participants refuse to answer any question, leaving the instrument(s) incomplete, that participant was not used in the final data analysis.

DATA ANALYSIS

Total scores on the PAIS-SR, its domains, and the MHLC were analyzed using inferential statistics. This analysis determined the degree of association that existed between the measured variables within each group. Data was reviewed for any linear or non-linear relationships that existed and influenced statistical analysis. Demographic information was not used as part of the analysis since there were not large enough numbers in any group (e.g. age, socioeconomic level, years of being HIV positive) to warrant analysis.

LIMITATIONS/POTENTIAL DIFFICULTIES

The primary difficulty in this study was the willingness of persons in the EIS clinic to participate in the research study.

These persons faced many challenges in their day-to-day activities and this might have been an additional burden that they were not willing or able to assume. A monetary incentive (\$20.00) was given to each participant to help cover the cost of transportation. Researchers were also willing whenever feasible to schedule appointments conveniently for the participant (e.g. in connection with office visits) All of the data was collected in the EIS clinic in a private examination room. Limitations of the study revolved around the design. These limitations were: (1) positive association of the variables and group membership could result in an assumption of cause of adherence or non-adherence, and (2) an assumption that the variables have no effect on adherence or non-adherence. An additional limitation was the assumption that adherence is actually measured by low HIV blood viral levels. Literature supports that low viral loads maybe related to treatment adherence and other measures (e.g. self report, drug urine testing) are no more valid in assessing adherence. ^{3,6,8}

RESULTS

The total sample size was 54 participants, but group sizes were not equal (n=36, low HIV viral load levels [LVLL]; n=18, high HIV viral load levels [HVLL]. The mean age was 40.4 years of age (N=54) with a mean for LVLL participants of 41 years and a mean of 38 for the HVLL. Sixteen of the participants were female and 38 were male. In terms of ethnicity 37 were self-reported Caucasian (67% LVLL) and nine were Black (55% LVLL) and 78% of the participants (N=54) were unemployed, 19% were employed full-time, and 4% were employed part-time.

Open-ended question (Q1) revealed that 44 % of the participants lived alone, 26 % had one other person in the household, and the remaining 30% had two to eight other members of the household. Responses for the question (Q2) "Who would you say is your famil?" were classified into four categories. These categories were: (1) friends, e.g. non-blood relatives as well as ex-significant others; (2) significant others, e.g. spouses, boy/girl friends [both heterosexual and homosexual], and fiancés; (3) 1st degree relatives, e.g. parents, siblings, children and significant others of these relatives; and (4) 2nd degree relatives, e.g. grandparents, grandchildren, uncles, aunts, nieces, and nephews, as well as significant others of these relatives. All data was able to be categorized for this question but were not exclusive for most subjects. Most subjects had responses that fit into more than one category.

Response to the question (Q3) "What would you say causes problems in following your prescribed treatment regime?" were classified into three categories. These categories were: side effects, lifestyle, and money. Side effects included any negative physical responses due to treatment (65%), lifestyle was very broadly defined and included anything dealing with work, family, leisure, scheduling problems, diet, and forgetting (61%), and money (7%) included responses related to difficulties in paying for any aspects of disease treatment. The next question (Q4) asked for facilitators to following prescribed treatment. This question was very difficult to categorize due to variability of responses, however three main categories emerged. These were: motivation, established routine, and friends/family. Motivation varied from motivated to live, motivated to beat the disease, and motivated because of treatment success. Established routine was anything inanimate that helped them with treatment, e.g. pagers and pill boxes. Friends/family were any responses that stated family or friends aided in following treatment. Motivation was the facilitator for 69% of the participants and was followed by established routine (33%) and friends/family (28%). When asked about the influence of the prescribed treatment on everyday activities (Q 5), 70% reported that their lifestyle was affected, 59% that health issues were affected and 13% did not respond. In conclusion to this data analysis two questions (Q1 & 2) were easily categorized due to consistent responses but three questions (Q 3, 4, & 5) were more difficult to categorize and interpretation needs to be dealt with cautiously.

Statistical analysis of the data revealed no differences in the domains of the PAIS-SR (theoretical range for each domain is 0 to 18) except for the domain of Extended Family Relations (mean HVLL = 3.22, and mean LVLL = 4.00). This domain must be interpreted very cautiously since there were significant unequal numbers in each group and large variability within the groups. Many of these individuals do not have extended families and may have had difficulty answering the questions (due to force choice answers). It is of interest to the researchers that items in the PAIS-SR with the lowest score and the highest score did vary between the groups. Differences are difficult to state with certainty because domains are not weighted when evaluating total PAIS-SR scores (HVLL X = 59.29, LVLL X = 53.86).

Although there was not a statistical significance in the groups, the difference in the lowest scored item and the highest scored items in the domains merits more detailed evaluation and may provide some ideas for future research

and ideas about intervention studies with this population. Analysis of the Multidimensional Health Locus of Control revealed that individuals with a low HIV viral load reported a more internal locus ($X_{LVLL} = 27.08$, $X_{HVLL} = 24.61$) of control than those participants with high HIV viral loads. Of interest is that both groups believed that health care professionals, specifically in the case of physicians had a great deal of influence on their health and well-being.

IMPLICATIONS FOR ADVANCED NURSING PRACTICE

Advances in technology and increasing complexity of health care services continues daily. This rapidly changing practice environment demands that health care providers be able to investigate and provide innovative as well as expanded health-care options for all clients. These skills and abilities require nurses who are prepared with advanced knowledge and skills. Advanced knowledge and skills in affords clients opportunities for enhanced health options.²² On an international scale reports, research studies and institutional documents support that advanced practice nurses provide feasible, safe, and effective options as primary care givers.^{23, 24} The ability of these advance practice nurses to diagnosis, treat, and prescribe makes them a viable option for individuals with HIV/AIDS as care providers. This practice is extremely important in areas where access to qualified health care professionals is limited.

AIDS and HIV infections were initially identified in intravenous drug users in urban centers. Those initially infected were primarily homosexual men, but recently there has been a growth in the numbers of those effected by HIV living in rural areas, although the highest number continues to be in urban cities. Women are being increasingly affected particularly in rural areas.^{25, 26} According to 1998²⁷ Center for Disease Control [CDC] data, 688,200 cases of AIDS have been reported, but since 1996 there as been a decrease in the deaths of individuals living with AIDS and a decrease in the occurrence of opportunistic infections. This decline can be related to earlier diagnosis, antiretroviral therapies, and lifestyle changes of those living with HIV infection.

Persons living with HIV/AIDS in rural communities face complex health, socioeconomic, and environmental problems that put them at high risk for disease and disability. These individuals over time experience multiple transitions across health settings that include availability of services in rural areas, and barriers such as distance, geography and poor distribution. These things limit access to health care.

Individuals with chronic illnesses who live in rural areas experience more medical conditions, more functional limitations, poorer perceived health status, higher rates of poverty, lower educational levels, and more limited transportation and housing resources.^{28, 29, 30} Barriers to healthcare for individuals residing in rural communities are multiple and varied. Barriers include: (1) poverty, (2) shortages of healthcare workers, (3) under insurance or lack of health insurance, (4) inconvenient health services locations and service hours, (5) prolonged waiting times, (6) lack of transportation, and (7) and lack of specialized care providers.^{27, 31, 32} Nurses at all levels of training and education will continue to assume essential roles in the delivery of health services particularly in rural communities. Evidence-based practice and the training of nurses in planning programs and evaluating outcomes will make a difference in the care of individuals living with HIV in rural communities. Advanced practice nurses are often the primary caregiver in rural areas. Questions that arise from this research will lead to increased research that looks at issues of specifically support from families in the changing demographics of rural America.

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