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ABSTRACT

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Emerging Needs For Persons Living With HIV or AIDS

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The purpose of this study is to describe the emerging needs that exist for persons living with HIV or AIDS in the 34 county Northern and Western Public Health Regions of Wisconsin. Much time has passed since the early 1980's emergence of the HIV/AIDS epidemic into the biopyschosocial constructs of professional interventions and services. With the passing of time has come significant changes in the understanding and treatment of HIV/AIDS.

With each new bit of information regarding the disease and with each new available treatment comes an interesting series of indicators and markers for both progress and regression. The majority of outcomes derived from progress have been intended and positive. However, it is important to note that some outcomes have been unexpected and adverse. This action and reaction type approach to viewing this epidemic results in a myriad of emerging needs for persons living with HIV or AIDS.

The demographics of the individuals infected with HIV and AIDS have changed significantly in terms of both exposure categories and gender. The effects that HIV and AIDS have on individuals infected has also significantly changed. The resulting needs are continuously

emerging and increasingly diverse as individuals begin to experience better health for a longer period of time.

It is the intent of this study to explore the trends and changes both in progress and regression to outline the emerging needs of persons living with HIV or AIDS. This exploration will consist of an extensive review of current literature as well as analysis of questionnaires anonymously completed by persons living with HIV or AID in the Northern and Western Public Health Regions of Wisconsin.

EMERGING NEEDS FOR PERSONS LIVING WITH HIV OR AIDS

by

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A Research Paper

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Requirements for the Master of Science Degree
With a Major in

Vocational Rehabilitation

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CHAPTER ONE
INTRODUCTION

STATEMENT OF THE PROBLEM

The purpose of this study is to describe the emerging needs that exist for persons living with HIV or AIDS in the thirty-four county Northern and Western Public Health Regions of Wisconsin. Much time has passed since the early 1980's emergence of the HIV and AIDS pandemic. The state of the multiple health, psychological and support needs of this population has been in constant flux and change throughout the progression of this pandemic. With the passing of time has come significant changes in the understanding and treatment of HIV and AIDS, however many of the questions regarding the existing and emerging needs of this population are unanswered.

With each new bit of information regarding the disease and with each new available treatment comes an interesting series of indicators and markers for both progress and regression. The majority of outcomes derived from progress have been intended and positive. However, it is important to note that some outcomes have been unexpected and adverse. This action and reaction type approach to viewing this epidemic results in a myriad of emerging needs for persons living with HIV or AIDS.

The demographics of the individuals infected with HIV and AIDS have changed significantly in terms of both exposure categories and gender. The effects that HIV and AIDS has on individuals infected has also significantly changed. The resulting needs are continuously emerging and increasingly diverse as individuals begin to experience better health for a longer period of time.

It has been over fifteen years since HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome) were first identified and introduced to us through the media. Over this fifteen year span of time, HIV and AIDS have managed to plant a strong foothold in all biopsychosocial aspects of our existence. The Centers for Disease Control and Prevention has determined that the total number of HIV-infected persons in the US is estimated to be between 650,000 and 900,000 and approximately 40,000 individuals are infected each year. These estimates can be further dissected to project that approximately 1 in 300 Americans is HIV-positive or 1 in 160 males and 1 in 1,000 females. Over 410,000 Americans have died of AIDS which makes the disease the second leading cause of death among adults ages 25-44.

The massiveness, seriousness and disbursement of the incidence of HIV and AIDS results in this phenomenon being termed as pandemic. It is important to note that HIV and AIDS is also a social crisis marked by isolation and discrimination stemming from society's perceptions and attitudes regarding the stigma and stereotypes associated with the infection such as affectionate preference, substance use and abuse, poverty, race, gender, disability and sexual activity (Piette, Fleishman, Mor & Thompson, 1992).

Much of the information and attention surrounding HIV and AIDS is focused toward the impact that the disease has had on coastal and urban populations of the United States. The Midwest and Wisconsin are rarely explored or highlighted in media, studies or publications. It is critical that we closely examine HIV and AIDS in rural Wisconsin to determine the level of impact that this disease has on infected individuals within smaller communities.

The State of Wisconsin Department of Health and Family Services has divided the State into five Public Health Regions. Each Public Health Region is assigned a number of counties within the State for which public health issues, statistics and funding can be managed and monitored.

The geographic area of the thirty-four county Northern and Western Public Health Regions will be the focus of this study. The Northern Public Health Region includes the fifteen Wisconsin counties of Ashland, Bayfield, Clark, Florence, Forest, Iron, Langlade, Lincoln, Marathon, Oneida, Portage, Price, Sawyer, Taylor, Vilas and Wood. The Western Public Health Region includes the nineteen Wisconsin counties of Barron, Buffalo, Burnett, Chippewa, Clark, Douglas, Dunn, Eau Claire, Jackson, La Crosse, Monroe, Pepin, Pierce, Polk, Rusk, St. Croix, Trempealeau, Vernon and Washburn.

The Wisconsin AIDS/HIV Program Quarterly Surveillance Summary reports 612 documented cases of HIV and 375 documented cases of AIDS from 1982 through September 30, 1999 within the Northern and Western Public Health Regions (Hoxie, 1999). The technical notes for the surveillance summary indicate that "the documented cases of HIV and AIDS represents only part of the total number of diagnosed cases. Because cases remain undiagnosed, reported HIV infection underestimates total HIV infection morbidity" (p. 7).

The AIDS Resource Center of Wisconsin, Inc. (ARCW) is the State Designated AIDS Service Organization (ASO) providing health and social services to persons living with HIV or AIDS in both the Northern and Western Public Health Regions. ARCW's Health and Social Services Department manages an ongoing caseload of approximately 160 infected clients at any given time within this designated service area. The discrepancy between the documented cases of HIV and the number of infected clients served by ARCW can be attributed to a number of variables such as; death, relocation out of the service area, confidentiality, infected individuals unaware of ARCW's services or infected individuals not in need of services. ARCW will facilitate the distribution and collection of anonymous questionnaires utilized in this study with their established Health and Social Services client base.

In the beginning of the HIV and AIDS pandemic there were multiple questions existing about the disease and very few answers available. Scientists and the Food and Drug Administration (FDA) have rigorously searched for treatment options and have fast-tracked clinical trails and the availability of life prolonging drugs for individuals infected. The scientific breakthrough and approval of Zidovudine or AZT in March of 1987 provided the first weapon against disease progression (Arno & Feiden 1992). Additionally, the mid 1990's brought the emergence of protease inhibitors and intense combination therapies or highly active antiretroviral therapy (HAART) to further advance quality and duration of life for infected individuals. Markers and indicators for disease progression have also significantly improved to allow medical providers a much more accurate reading of an individual's health status. In addition to the monitoring of CD4 counts is the viral load indicator which reveals the amount of virus in an individual's system (Bartlett). The significance of the improved indicators is that treatment is more accurate than ever before and prognoses has significantly improved.

STATEMENT OF THE PURPOSE

It is the intent of this study to explore the trends and changes both in progress and regression to outline the emerging needs of persons living with HIV or AIDS. This exploration will consist of an extensive review of current literature as well as an analysis of questionnaires anonymously completed by persons living with HIV or AIDS within the Northern and Western Public Health Regions of Wisconsin. This study focuses on the following objectives:

1. To determine the expressed biopsychosocial needs of persons living with HIV or AIDS within the Northern and Western Public Health Regions of Wisconsin.

2. To determine in rank order of most important to least important 20 identified services available to persons living with HIV or AIDS within the Northern and Western Public Health Regions of Wisconsin.
3. To determine if males and females living with HIV or AIDS within the Northern and Western Public Health Regions of Wisconsin express differences in biopsychosocial needs.
4. To determine if individuals living with HIV or AIDS in the age ranges of 18-25, 26-35, 36-45, 46-55 and 56 or older within the Northern and Western Public Health Regions of Wisconsin express differences in biopsychosocial needs.
5. To determine if individuals living with HIV or AIDS that have been positive for less than 1 year, 1-5 years, 5-10 years or over 10 years within the Northern and Western Public Health Regions of Wisconsin express differences in biopsychosocial needs.
6. To determine if individuals living with HIV or AIDS that rate their health very poor, poor, good or great within the Northern and Western Public Health Regions of Wisconsin express differences in biopsychosocial needs.

DEFINITION OF TERMS

Biopsychosocial -

The physical, psychological and social interaction of human systems.

CD4 Count -

CD4 cells are white blood cells which are a very important part of the immune system. A CD4 count can indicate the health of the immune system.

Highly Active Antiretroviral Therapy (HAART) -

The drug combination of protease inhibitors and antiretroviral drugs (AZT, ddI, 3TC, ddC or d4T) used to increase the effectiveness against HIV.

Protease Inhibitors -

The newest class of antiviral drugs. They sot the virus that causes HIV disease from reproducing itself.

Viral Load Indicator -

Detection of the amount of HIV virus in the blood.

LIMITATION

1. This study focuses on the emerging needs of persons living with HIV or AIDS. Inherent in this focus is that needs are constantly changing and emerging. As a result, this study emphasizes issues that will need to be monitored on an ongoing basis and updated as progress is made.

2. Access to individuals with HIV and AIDS can be very challenging due to confidentiality issues. There are 612 documented case of HIV infection in the Northern and Western Public Health Regions of Wisconsin, however this study is only able to access 128 infected individuals through the regional AIDS Service Organization. A large sample of this population is not accessible for questionnaire procedures.

CHAPTER TWO
REVIEW OF THE LITERATURE

The existing literature on the biopsychosocial needs of persons living with HIV or AIDS in rural Wisconsin is minimal. The majority of literature related to persons living with HIV or AIDS has primarily been obtained through studies and research conducted in urban coastal cities or AIDS epicenters. There is transferability regarding medical and pharmaceutical needs from urban centers to rural Wisconsin, however caution must be taken to avoid over generalization and over simplification of the issues. Additionally, there are very unique needs only applicable to rural Wisconsin because of local societal norms and the individualized context of community resources.

There has been a significant growth in the understanding of HIV and AIDS and the treatment of the infection since its initial introduction in the early 1980's. It is critical that researchers and providers approach this pandemic from a historical perspective and reflect upon the acute crisis situation with which it all started. Doctors first identified in 1979 an immunologic disease in gay men from New York and San Francisco. The cause, mode of transmission and treatment of the disease were all unknown and the epidemic became known as the Gay-Related Immune Deficiency Syndrome. Injection drug users, infants and hemophiliacs also began to show signs of immunolgic dysfunctions which resulted in the disease being named Acquired ImmunoDeficiency Syndrome (AIDS). The virus had been more clearly identified by 1983 which provided insights into the cause and mode of transmission (Sherman, et al., 1999). Additionally, screening tools had been developed to indirectly detect the virus and by 1985 the US blood supply was effectively being screened for the virus and considered safe. The primary

medical intervention for those infected consisted of treatment of opportunistic infections and chemotherapy for malignancies.

At the same time, the fear of contagion regarding HIV and AIDS was being further exacerbated by the stigmas associated with gay men and injection drug users. The perceived personal characteristics of the individuals infected resulted in anger from many providers and society as they viewed those infected to be in part responsible for this disease because of who they were. Additionally, individuals who became infected through the transmission modes of sex and injection drug use were not provided pity. This dynamic is significant in that emotional feelings of pity trigger a help-giving response. The judgments placed on the populations infected with HIV and the blame attributed to the mode of transmission resulted in anger and avoidance rather that pity and help (Steins, et al.1999). The attitudes and resulting discrimination against infected individuals rapidly turned the AIDS pandemic into a social crisis as well as a public health issue.

The scientific breakthrough and approval of Zidovudine or AZT in March of 1987 provided the first weapon against disease progression (Arno & Feiden 1992). It was one of many drugs that would emerge in this pandemic to fight disease progression and provide hope to those infected. Some individuals benefited from the drug and some simply could not take it as the side effects were too adverse.

The early 1990's had emerged with AIDS being recognized as one of the ten leading causes of death among 15 to 24-year olds in the United States. AIDS had become a reportable disease in all 50 states and 235,000 US AIDS cases had been reported (Sherman, et al., 1999).

Additionally, the mid 1990's brought the emergence of protease inhibitors and intense combination therapies to further advance quality and duration of life for infected individuals.

Markers and indicators for disease progression had also significantly improved to allow medical providers a much more accurate reading of an individual's health status and immune system. In addition to the monitoring of CD4 counts, the viral load indicator which reveals the amount of virus in an individual's system also became an ongoing monitoring tool utilized by providers (Bartlett). The significance of the improved indicators was that treatment was more accurate than ever and prognoses had significantly improved.

The Centers for Disease Control and Prevention determined at the end of 1998 that the total number of HIV-infected persons in the US was estimated to be between 650,000 and 900,000 and approximately 40,000 individuals were being infected each year. These estimates can be further dissected to project that approximately 1 in 300 Americans was HIV-positive or 1 in 160 males and 1 in 1,000 females. Over 410,000 Americans have died of AIDS which makes the disease the second leading cause of death among adults ages 25-44.

The pandemic has continued to grow in rural Wisconsin throughout the 1980's and 1990's. The Wisconsin AIDS/HIV Program Department Quarterly Surveillance Summary reports 612 documented cases of HIV and 375 documented cases of AIDS from 1982 through September 30, 1999 for the Northern and Western Public Health Regions of Wisconsin (Hoxie, 1999). The technical notes for the surveillance summary indicate that "the documented cases of HIV and AIDS represents only part of the total number of diagnosed cases. Because cases remain undiagnosed, reported HIV infection underestimates total HIV infection morbidity" (p.7). Dr. Timothy Heckman (1998) reports that "rural AIDS cases are increasing at approximately three times the rate of urban cases" and that "continued high rates of sexual behavior among at-risk groups in smaller communities portend that even more rural residents will become infected with HIV" (p. 138).

Throughout this nearly two decades of scientific progress in the areas of disease monitoring and medical intervention for HIV and AIDS much has changed regarding the needs of this population. The morbidity and mortality of HIV and AIDS has changed dramatically since the emergence of protease inhibitor based combination therapies in the mid and late 1990's (Kirton, et al., 1999). Individuals with HIV and AIDS are experiencing improved health and a longer life. The reality of individuals living longer and healthier has brought a decline in hospital admissions and an increase in long term care services. A pandemic that primarily utilized acute care for serious physical deterioration is now requiring chronic and sustaining care that are much more diverse and comprehensive. It is also important to note that new individuals continue to become infected with HIV. As individuals with AIDS continue to live longer and as a result do not exit support systems combined with the new infections coming into the system, there exists a greater demand on the services and resources provided by agencies. The emerging chronicity of the disease has also significantly impacted the public's financial support for programs, resources and services. This occurs at a time when public support is more important than ever to meet the growing needs and demands of this population.

It is important to examine closely the needs of persons living with HIV and AIDS as they have emerged and evolved in tandem with each new medical and pharmaceutical intervention. The emerging needs may be the result of progress, however they may also be iatrogenic or physician induced. The outcomes from well intended interventions are sometimes negative results or often something different from what was intended. Evaluation of comprehensive needs within the context of an individual's community and environment must be thorough and ongoing if programs and resources are to be applicable and effective.

The multi-drug therapies and aggressive antiretroviral treatments available require individuals living with HIV and AIDS to manage the administration of multiple pills per day. Additionally, the management of intermittent physician and lab visits to monitor blood and the effectiveness of various protocols further makes the disease management process very complicated (Kirton, et al., 1999). Compliance and integrated health care services are the result of scientific and medical progress for individuals living with HIV and AIDS.

Society continues to demonstrate intolerance and is remiss in recognizing the suffering and loss experienced by a person living with HIV or AIDS. "The fear of contagion is less important than the public's hostility against the mode of transmission, which generates such anxiety that compassion and empathy are prevented" (Groomes, 1998, p. 39). This intolerance may be intensified in rural communities of Wisconsin due to strict morale values and unfamiliarity with issues related to HIV and AIDS. These issues can create significant barriers for infected individuals as they attempt to access the natural support systems within rural communities such as family, friends and church. Additionally, societal perceptions can inhibit an individual's access to medical care and social supports in rural areas of Wisconsin for fear of interfacing with someone he/she knows. It seems that while science and medical intervention has advanced within this epidemic, societal stigmas and attitudes have not made significant progress.

Many of the individuals diagnosed with AIDS are between the ages of 20-39 and are at the prime of their working careers. There can exist significant vocational impacts with HIV and AIDS. At a time when individuals are experiencing better health for a longer period of time, it is critical that their vocational needs are examined. Discrimination and the fear of discrimination appear to be alive and well within the workplace. The rehabilitation implication for individuals living with HIV or AIDS is that they may need emotional and financial support in addition to

what is typically provided in the rehabilitation process (Groomes, 1998). Additional considerations for this population as they return to the work force is continuity in health care coverage. Historically, the focus has been on securing public entitlement benefits for individuals as they would become sick and unable to work. It is now appropriate to address the disincentives to work and provide a safety net of resources for access to medical care and pharmaceuticals while the individual reenters the work force. The uniqueness of HIV is described through the stigma attached to the disease and the blame projected onto individuals infected, especially if they are perceived to have brought the illness on themselves. It is significant that the Rehabilitation Counselor be aware of this issue as she/he may be one of the few individuals that knows about the client's HIV status and may need to provide support and networking to other infected individuals. The client living with HIV not only has to cope with experiencing a disability but also the shame and blame projected onto them by society and systems. These clients must be assessed to determine how they cope and how their disability has affected their self esteem. Counselors must be trained to help the client obtain skills to not personalize societal stigmas and judgments. The client must be nurtured as to not experience feelings of threat and loss throughout the process. Counselors must also emphasize throughout the process the client's right to confidentiality and assure them that information is not shared without a release of information. Considerations must also be given to how the client is contacted, where mail is sent and if it can have a return address to ensure that a client's status is not revealed to someone in the home. Additionally, significant consideration must be given to the financial impact that treatment and drugs have on an individual. It may be that an individual receiving SSI or SSDI may not be a good candidate for rehabilitation as they would not be able to afford the co-pays for

drugs and treatment if they were employed. The extreme cost of pharmaceutical intervention for this population must be a consideration in the rehabilitation process (Groomes, 1998).

Education, training and ongoing support are critical components for social service providers coordinating services for infected individuals. The professionals serving this population experience stress and burnout. Oktay (1992) reports that job characteristics for HIV and AIDS social workers are low pay, long hours, excessive paperwork, little opportunity for advancement, powerlessness, and unresponsive and unappreciative bureaucratic environments. In addition, the social service profession is client centered and often requires emotional involvement which puts stress on the professional providing the services. The client population is primarily homosexual and bisexual men, drug users and minorities who are stigmatized resulting in fewer available resources not only for the clients but also for their families and social workers. The work involves people close to the age of the social worker who become sick and demented, waste away and eventually die. The disease is infectious, and although it is well known that health professionals are at a very low risk, irrational fears of contagion still persist. Oktay (1992) examined four variables in relation to burnout: characteristics of the workers, characteristics of the setting, characteristics of the AIDS work, and social support available to the worker. Among the characteristics of the worker only age was significantly related to burnout. The relationship was negative, meaning that the younger workers were experiencing burnout more. Of the variable measuring characteristics of the setting, direct service work and autonomy were significant. None of the variables measuring the characteristics of the AIDS work were significant. Among the variables measuring social support, belonging to a support group was significant. It is imperative that social workers receive education, support and administrative

guidance to achieve their goals in meeting the needs of individuals living with HIV and AIDS (Itzhaky, et al., 1999).

There are many differences in the psychosocial needs of HIV infected urban and rural people. "Access to health care, availability of social support services, incidents of AIDS-related discrimination and illness related coping strategies" are areas where differences in needs exist (Heckman, et al., 1998, p.139). Heckman (1998) reports that individuals living in rural settings experience more difficult life circumstances than their urban counterparts. Difficulty in accessing quality medical and mental health services is common due to the lack of professionals with experience with HIV and AIDS. Additionally, the lack of personal and public transportation further complicate access to care. Individuals living with HIV and AIDS in rural settings also have a very difficult time in accessing support and have an increased sense of isolation and loneliness. Heckman (1998) also reports that individuals with HIV and AIDS distanced themselves from their disease and develop destructive coping mechanisms for dealing with their illness. This dynamic is not conducive to overall psychological health.

A review of the literature regarding the emerging needs of individuals living with HIV and AIDS in the Northern and Western Public Health Regions of Wisconsin results in three common themes. The first theme seems to be access to and compliance with quality medical and pharmaceutical services. Next, it appears that a disease that used to require acute care has evolved into a chronic disease requiring diverse and comprehensive care. Finally, it is clear that stigma and discrimination remain the trademarks of the HIV and AIDS pandemic.

CHAPTER III
METHODOLOGY

The subjects for this descriptive study are individuals living with HIV or AIDS throughout northern and western Wisconsin who are receiving services from the AIDS Resource Center of Wisconsin, Inc. (ARCW). Northern and western Wisconsin are defined for the purpose of this study as the fifteen county Northern Public Health Region and the nineteen county Western Public Health Region. The Northern Region Public Health area includes the counties of; Ashland, Bayfield, Clark, Florence, Forest, Iron, Langlade, Lincoln, Marathon, Oneida, Portage, Price, Sawyer, Taylor, Vilas and Wood. The Western Region Public Health area includes the counties of; Barron, Buffalo, Burnett, Chippewa, Clark, Douglas, Dunn, Eau Claire, Jackson, La Crosse, Monroe, Pepin, Pierce, Polk, Rusk, St. Croix, Trempealeau, Vernon and Washburn. ARCW is the State designated AIDS Service Organization serving the thirty-four Northern and Western Public Health Regions. ARCW is a comprehensive service agency that works to eliminate the effects of HIV and AIDS and provides direct health and social services to infected individuals.

The questionnaire was compiled from assessment categories outlined in the Wisconsin AIDS/HIV Program Practice Standards and Administrative Guidelines for HIV-Related Case Management (1993). The questionnaire elicits information regarding the following assessment categories: health; medication; finances; employment; education; risk reduction; support; legal; mental health and chemical use. The questionnaire is an anonymous self administered two page questionnaire consisting of twenty three questions.

The Director of Health and Social Services for ARCW's Northern and Western Regions, Cheryl Thiede, agreed to disseminate the questionnaire to 128 clients receiving services from her program. She also agreed to facilitate the return of the questionnaires to her program in a manner that maintains the anonymity of each respondent. The questionnaire was completely voluntary for each subject receiving one. This investigator received no information regarding the subjects' name, address or other potentially identifying information.

The subjects involvement in the questionnaire was completely voluntary and anonymous. A packet of 128 consent forms, questionnaires, envelopes with stamps and self addressed return envelopes with stamps were provided to Cheryl Thiede, ARCW Director of Health and Social Services. Ms. Thiede placed the client name and address labels on the mailings and disseminated them. Upon the subjects voluntary completion of the questionnaire, it was returned to Ms. Thiede in the enclosed return envelope. Ms. Thiede discarded the return envelopes and reviewed the questionnaires to ensure that there was no identifying information provided by the subjects.

This study involves no false or misleading information to subjects. Additionally, it does not withhold information such that the subjects informed consent might be questioned. Finally, the research procedure is not designed to modify the thinking, attitude or other aspects of the behavior of the subjects.

There exist no potential or actual physical risk of discomfort, harassment, invasion of privacy, risk of physical activity, risk to dignity and self-respect or psychological, emotional or behavioral risk. The questionnaires were gathered anonymously. There is no name association with the proposed questionnaire. As a result, the questionnaire responses can not be affiliated with a participating subject. Additionally, the questionnaires were voluntary.

CHAPTER IV
RESULTS

The purpose of this study is to describe the emerging needs that exist for persons living with HIV or AIDS in the thirty-four county Northern and Western Public Health Regions of Wisconsin. The subjects for this descriptive study are individuals living with HIV or AIDS throughout northern and western Wisconsin who are receiving services from the AIDS Resource Center of Wisconsin, Inc. (ARCW). Northern and western Wisconsin are defined for the purpose of this study as the fifteen county Northern Public Health Region and the nineteen county Western Public Health Region.

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Fifty-five completed questionnaires were provided to this investigator on Friday, November 19, 1999. The completed anonymous questionnaires were provided to UW-Stout Research and Statistical Consultant, Christine Ness , at the Computer Education and User Services Department on Friday, November 19, 1999 for analysis.

The response rate for this anonymous questionnaire was 43% which is considered acceptable when compared to other similar questionnaire procedures. Timothy Heckman (1998) reported that a self administered survey to individuals living with HIV or AIDS in Wisconsin yielded a response rate of 40% to 47%. It was determined that variables impacting the response rate ranged from some of the subjects surveyed were ill and some were reluctant to disclose personal information even on an anonymous questionnaire.

Items 1 through 4 of the questionnaire were designed to learn demographical information on the respondents regarding sex, age, number of years being HIV positive and self rating of current health status. Each of the 55 respondents answered each of the first four items on the questionnaire which is displayed on Table-1. As reported in Table-2, of the 55 respondents 44 *(80%)* were male and 11 *(20%)* were female. This is not a surprising ratio as the Wisconsin HIV/AIDS Quarterly Surveillance Summary reports that 86% of the States documented HIV cases are men and 14% are women (Hoxie, 1999).

The largest age group represented by 29 *(49%)* of the respondents are those individuals between 36 and 45 years of age. The populations of respondents between 26 and 35 years of age and those between 46 and 45 years of age are both represented at 11 *(20%)* each. The age group of respondents at 56 years of age and older are represented at 5 *(9%)* and the smallest group represented is the age group of 18 to 25 year olds at 1 *(2%)*. These age group responses are represented in Table 2. The Wisconsin HIV/AIDS Quarterly Surveillance Summary reports that over 96% of the documented HIV cases in the State are in the 19 years and above age group. There were no individuals under the age of 18 involved in the study.

The third questionnaire item seen in Table-2 requested respondents to indicate how long they have been infected with HIV. Of the 55 respondents, 20 *(36%)* had been HIV positive between 1 and 5 years. This group was followed closely at 18 *(32%)* by the group that had been positive for over 10 years. The third category of individuals at 17 *(30%)* had reported being positive between 5 and 10 years.

Question item four asked respondents to self rate their health status as indicated in Table 2. Thirty-nine *(71%)* of the respondents rated their health as "good" and another 7 *(13%)* of the respondents rated their health as "great". This means that 46 *(84%)* of the respondents rate their health as good or better. Another portion of the respondents at 9 *(16%)* rated their health as "poor". This is an interesting result given that 35 *(62 %)* of the respondents have been living with the disease for over 5 years.

Questionnaire Items 5 through 22 require the respondents to choose between yes and no regarding their need for specific service areas. As seen in Table-1 each of the 55 respondents answered most of the questions with fewer respondents answering questions relating to medication schedules, transportation, child care needs, return to work, weight and exercise.

Eleven of the questions were answered by 55 respondents, another 5 questions were answered by 54 respondents and 1 question was answered by 53 respondents. Question number 14 asked respondents "if not employed, do you want to return to work?" Only 32 respondents answered this question because for many of the respondents it was not applicable as they were currently employed.

TABLE 1. Number of respondents per item from a total of 55 returned questionnaires.

Item Number	Number Of Subjects Responding T Number
1. Gender Of Respondent	55
2. Age Of Respondent	55
3. How Long Have You Been Positive	55
4. How Would You Rate Your Health	55
5. Adequate Access To Dental Care	55
6. Adequate Access To HIV Knowledgeable Physician	55
7. Access To Medications	55
8. Medications On Time And At The Right Dose	54
9. Do You Have Adequate Housing	55
10. Do You Have Legal Needs	55
11. Do You Have Accessible And Affordable Transportation	54
12. Do You Have Child Care Needs	54
13. Are You Currently Employed	55
14. If Not Employed, Do You Want To Return To Work	32
15. Access To Information On HIV And AIDS	55
16. Access To Information On The Transmission Of HIV	55
17. Do You Have Emotional Support	55
18. Do You Have Access To An HIV-AIDS Support Group	55
19. Are You Above Your Desired Weight	54
20. Are You Below Your Desired Weight	53
21. Do You Have A Desire To Exercise	54
22. Do You Have Access To Information On Nutrition	55
23. Rank Order Prioritizing Service Categories	45

TABLE 2. Gender, Age, Years Positive, Health of Respondents

Gender of Respondents	**Percent**
Men	44 (80%)
Women	11 (20%)
Age of Respondents	
18-25 years	1 (2%)
26-35 years	11 (20%)
36-45 years	27 (49%)
46-55 years	11 (20%)
56 or older	5 (9%)
Number of Years Being HIV Positive	
1-5 years	20 (36%)
5-10 years	17 (31%)
10 years or more	18 (33%)
Self Report of Health Status	
Poor	9 (16%)
Good	39 (71%)
Great	7 (13%)

As highlighted in Table-3 adequate access to dental care services appears to be problematic for 30 *(55%)* of the respondents and 31 *(56%)* of the respondents have needs regarding legal services. Of the 55 respondents, 23 *(42%)* are currently employed and do not require services to become employed. However, 32 *(58%)* of the respondents are not employed while 16 *(50%)* of the 32 respondents on question item 14 desire return to work services. Another 30 *(56%)* of the respondents report that they are above their desired weight and 13 *(25%)* are below their desired weight. There exists 37 *(69%)* of the respondents who express a desire to exercise.

Service areas that appear in Table-3 that are somewhat accessible or are an expressed need by fewer of the respondents include transportation which 46 *(85%)* of the respondents report they can obtain. Additionally, child care needs remain a concern for 6 *(11%)* of the respondents which may be reflective of the respondent pool being 80% male. Fifty-four *(98%)* of the

respondents report that they have adequate access to information on HIV and AIDS and 48 *(87%)* report that they have emotional support in their disease process. Forty-four *(80%)* of the respondents have access to HIV-AIDS support group services and 48 *(87%)* have access to nutrition information. All of the respondents report that they have access to information on the transmission of HIV and do not express a need for additional services.

TABLE 3. Frequency of Responses.

Item Number	% Of Yes Responses	% Of No Responses
5. Adequate Access To Dental Care	25 (45%)	30 (55%)
6. Access To HIV Knowledgeable Physician	50 (91%)	5 (9%)
7. Access To Medications	52 (95%)	3 (5%)
8. Medications On Time / At Right Dose	48 (89%)	6 (11%)
9. Adequate Housing	51 (93%)	4 (7%)
10. Do You Have Legal Needs	31 (56%)	24 (44%)
11. Accessible / Affordable Transportation	46 (85%)	8 (15%)
12. Do You Have Child Care Needs	6 (11%)	48 (89%)
13. Are You Currently Employed	23 (42%)	32 (58%)
14. Do You Want To Return To Work	16 (50%)	16 (50%)
15. Access To Information On HIV And AIDS	54 (98%)	1 (2%)
16. Access To HIV Transmission Information	55 (100%)	0 (0%)
17. Do You Have Emotional Support	48 (87%)	7 (13%)
18. Access To An HIV And AIDS Support Group	44 (80%)	11 (20%)
19. Are You Above Your Desired Weight	30 (56%)	24 (44%)
20. Are You Below Your Desired Weight	13 (25%)	40 (75%)
21. Do You Have a Desire To Exercise	37 (68%)	17 (32%)
22. Access To Information On Nutrition	48 (87%)	7 (13%)

Question item 23 was formatted as a rank order of twenty service areas requiring the respondents to prioritize the services as most important (#1) to least important (#20). Of the 55 respondents, 45 of them followed the instructions correctly and ranked services in order of

priority from 1 to 20. As seen in Table-1 the remaining 10 respondents either did not complete the rank order or completed it incorrectly.

Friedmans one-way analysis of variance of ranks was performed on the twenty services and a priority list of service categories was obtained from the 45 completed questionnaires. The results of this tabulation can be seen in Table-4.

Dental care and medical care services were most frequently ranked as the highest priorities. Financial assistance services were ranked as the third service area as a most frequently occurring priority. Alternative therapies such as massage and acupuncture were the fourth service area ranked as a priority most frequently occurring. Following Alternative therapies were the categories of support groups and benefits counseling. Housing assistance and legal services were the seventh and eighth ranked service areas most frequently identified by respondents. Next were the service areas of exercise programs and emotional support buddies rated as the ninth and tenth most frequently ranked service priorities. Medication schedules and nutrition counseling were the eleventh and twelfth most frequently ranked service priorities with mental health services and SSI-SSDI-Medical Assistance-entitlement application assistance scoring as the next most frequently prioritized service areas. Transportation assistance, home health care and vocational or return to work services were ranked fifteenth, sixteenth and seventeenth in terms of most frequently prioritized service areas. Hospice care was ranked as the eighteenth most frequently prioritized service area with the categories of education on HIV transmission and chemical dependency counseling being reported as the least frequently prioritized service area.

TABLE 4. Service Priorities - Friedmans One-Way Analysis Of Variance Of Ranks.

Rank Order	Service Area	Mean Rank
1	Dental Care	5.22
2	Medical Care	5.89
3	Financial Assistance	6.13
4	Alternative Therapies-Massage-Acupuncture	8.31
5	Support Groups	8.82
6	Benefits Counseling	9.13
7	Housing Assistance	9.38
8	Legal Services	9.49
9	Exercise Programs	9.56
10	Emotional Support Buddies	10.24
11	Medication Schedules	10.56
12	Nutrition Counseling	11.07
13	Mental Health Counseling	11.62
14	SSI-SSDI-Medical Assistance-Entitlement	11.67
15	Transportation Assistance	11.98
16	Home Health Care	12.53
17	Vocational Or Return To Work Services	12.78
18	Hospice Care	14.58
19	Education On HIV Transmission	14.6
20	Chemical Dependency Counseling	16.44

The results of the questionnaire must be viewed within the context of two environmental circumstances. The first being that there are ongoing emerging needs demonstrated and expressed by individuals living with HIV or AIDS. The other factor to consider is that demonstrated and expressed emerging needs may presently be addressed by service programs existing within the Northern and Western Wisconsin Public Health Regions. Both of these factors may be issues to consider when determining existing needs of individuals living with HIV or AIDS in the thirty-four county Northern and Western Public Health Regions of Wisconsin. This issue can perhaps be seen most evidently in variations from respondent answers represented in Table-3 and the prioritization of service needs rank ordered and presented in Table-4.

CHAPTER V
CONCLUSIONS AND RECOMMENDATIONS

The purpose of this study is to describe the emerging needs that exist for persons living with HIV or AIDS in the thirty-four county Northern and Western Public Health Regions of Wisconsin. The subjects for this descriptive study are individuals living with HIV or AIDS throughout northern and western Wisconsin who are receiving services from the AIDS Resource Center of Wisconsin, Inc. (ARCW). Northern and western Wisconsin are defined for the purpose of this study as the fifteen county Northern Public Health Region and the nineteen county Western Public Health Region.

The questionnaire was compiled from assessment categories outlined in the Wisconsin AIDS/HIV Program Practice Standards and Administrative Guidelines for HIV-Related Case Management (1993). The questionnaire elicits information regarding the following assessment categories: health; medication; finances; employment; education; risk reduction; support; legal; mental health and chemical use. The questionnaire is an anonymous self administered two page questionnaire consisting of twenty three questions.

The Director of Health and Social Services for ARCW's Northern and Western Regions, Cheryl Thiede, agreed to disseminate the questionnaire to 128 clients receiving services from her program. She also agreed to facilitate the return of the questionnaires to her program in a manner that maintains the anonymity of each respondent. The questionnaire was completely voluntary for each subject receiving one. This investigator received no information regarding the subjects' name, address or other potentially identifying information.

The subjects involvement in the questionnaire was completely voluntary and anonymous. A packet of 128 consent forms, questionnaires, envelopes with stamps and self addressed return envelopes with stamps were provided to Cheryl Thiede, ARCW Director of Health and Social Services. Ms. Thiede placed the client name and address labels on the mailings and disseminated

them. Upon the subjects voluntary completion of the questionnaire, it was returned to Ms. Thiede in the enclosed return envelope. Ms. Thiede discarded the return envelopes and reviewed the questionnaires to ensure that there was no identifying information provided by the subjects.

Fifty-five completed questionnaires were provided to this investigator on Friday, November 19, 1999. The completed anonymous questionnaires were provided to UW-Stout Research and Statistical Consultant, Christine Ness , at the Computer Education and User Services Department on Friday, November 19, 1999 for analysis.

The response rate for this anonymous questionnaire was 43% which is considered acceptable when compared to other similar questionnaire procedures. Timothy Heckman (1998) reported that a self administered survey to individuals living with HIV or AIDS in Wisconsin yielded a response rate of 40% to 47%. It was determined that variables impacting the response rate ranged from some of the subjects surveyed were ill and some were reluctant to disclose personal information even on an anonymous questionnaire.

The results must be viewed within various contexts to interpret accurately the data compiled from the questionnaires. Expressed needs may be the result of emerging needs within the population or they may be needs that are not addressed by current regional service providers. Dental care is an expressed need by 30 *(55%)* of the respondents which may be an emerging need or an issue of access to adequate dental care. It is ranked first as a frequent service priority by respondents. Dental care needs and services must be analyzed to determine the specific nature of the existing dental issues and the barriers to accessing quality dental service providers. Fifty *(91%)* of the respondents report that they have an HIV knowledgeable medical provider, however medical care is ranked as the second service priority indicated by frequency of prioritization. While a significant portion of the respondents do report access to quality medical services it

continues to remain a very high priority. The monitoring of medications, CD4 counts and viral loads requires intense and ongoing medical visits. Access to medications seems to be achievable by 52 *(95%)* of the respondents and 48 *(89%)* report the ability to take medications at the correct time and dosage. Medication scheduling ranks eleventh as a frequently rated service priority. It appears that a large portion of the respondents are receiving proper pharmaceutical cares, however this service category remains at about the 50% range of frequently rated priorities. Fifty-one *(93%)* of the respondents indicate that they have adequate housing, however housing assistance is ranked seventh as a frequently identified service priority. It is possible that housing needs are met to an acceptable level, however the prioritization of this service category could indicate a desire on the part of respondents to improve their housing or receive financial assistance for housing needs. A rather large need has been expressed for legal services as 31 *(56%)* of the respondents report that they have legal needs. Legal services are also ranked eighth as a frequently identified priority. It is unknown through this questionnaire the nature of the legal needs expressed by respondents. The needs may be related to the respondents' HIV status or they may be unrelated legal needs. Regardless, this is a service area that continues to present itself as a need for individuals living with HIV and AIDS. Transportation is accessible to 46 *(85%)* of the respondents and is ranked fifteenth as a frequently rated priority service. This is an interesting finding given the large geographical disbursement of programs and service providers in greater rural Wisconsin. Only 6 *(11%)* of the respondents indicate that they have needs regarding child care. This may be contributed in part to 80% of the respondents being male as previously identified. There may be an increased demand for child care services as additional populations become infected with HIV. It is a very significant issue for parents who have no respite or resources for child care. Twenty-three *(42%)* of 55 respondents report that they are

working and 16 *(50%)* of 32 respondents report that they would like access to vocational or return to work services. These services ranked seventeenth as most frequently prioritized services. With 46 *(84%)* of the respondents reporting their health status as good or better this is sure to be an emerging need for this population. Fifty-four *(98%)* of respondents report that they have access to information on HIV and AIDS and that 100% of the respondents have information on HIV transmission. Additional education on HIV transmission was reported as the nineteenth most frequently prioritized service. It appears that the respondents have information on how to keep themselves from being re-infected with HIV and to avoid infecting other individuals. Forty-eight *(87%)* of the respondents report that they receive emotional support in their disease process and 44 *(80%)* report that they have access to a support group. It is important to note that while a large portion of the respondents report that they have emotional support, it is ranked tenth as a frequently prioritized service area. Additionally, 30 *(56%)* of the respondents report that they are above their desired weight and 13 *(25%)* report that they are below their desired weight. It is not known to what degree individuals are over or under weight, however 37 *(68%)* of the respondents report that they have a desire to exercise and it was ranked the ninth most frequently prioritized service . It can be assumed that 12 *(29%)* of the respondents are at their desired weight. Forty-eight *(87%)* of respondents report that they have access to nutrition information and it was ranked twelfth as a frequently reported priority service. Financial assistance was ranked third as a frequently prioritized service, however the type and amount of financial assistance desired is not known from this questionnaire. There may be a gap between the respondents' expressed financial need and which entitlement programs they may actually be eligible for. Income levels and entitlement benefits were not determined in this survey and do not allow for interpretation of specific financial needs. Alternative therapies such as massage

and acupuncture were ranked fourth as a frequently prioritized service area. It is not evident from the survey results what alternative therapies are used for, however it is clear that they are an expressed high priority. Benefits counseling and entitlement application assistance were ranked sixth and fourteenth as frequently prioritized services. The availability of these current services was not explored by this questionnaire. Home health care and hospice services were rated low priority service needs. This is significant in that it indicates that the medical model approach to acute disease management is not applicable to the majority of the respondents. This relates well to respondents indicating that 46 *(84%)* of them self report their health status as good or better. Chemical dependency counseling was the least frequently prioritized service need. This may be due in part to the implication of denial in the chemical dependency process.

It is evident that dental care, medical care, financial assistance, alternative therapies, legal services, housing assistance, exercise programs, benefits counseling, vocational or return to work services and emotional support services present themselves as important needs for the majority of the respondents. Service providers within rural Wisconsin must be able to provide high quality services to meet these need categories. The approach to service programming should be comprehensive and implemented in the communities within which the individuals live.

There also exist needs that have been identified by a small sample of respondents. These needs may not be as wide spread as the previously identified needs, however they can have a significant impact on the person living with HIV or AIDS. Medication management is a critical need for those respondents not able to administer their medications at the right time and dosage. The individuals not able to follow regiments will experience a failure in health requiring more support, resources and services. Medication management must be an available service for individuals demonstrating the need. Additionally, transportation appears to be an issue for a

small number of respondents. Without the availability of public transportation systems in rural Wisconsin it is imperative that service providers secure transportation resources for individuals with HIV and AIDS to enable them to travel to medical appointments and other service providers. Although respondents report that they possess information on HIV and AIDS and the transmission of the disease, access to information on HIV and AIDS is a necessary service program as the information changes on an ongoing basis. This information should be inclusive of nutrition education and risk reduction counseling. Assistance with applications to entitlement programs should be available to those individuals in need. The consequences of poor choices regarding benefits and entitlement programs have life and death consequences for individuals living with HIV and AIDS. Mental health and chemical dependency counseling may be a need expressed by only a few respondents, however for dually diagnosed individuals the issues are critical. Quality services for mental health and chemical dependency must be available and referral resources must be in place. Home health care services and hospice services are designed to address the needs of individuals with significant health problems impacting their activities of daily living and independence. Resources and referrals should be in place as a safety net for individuals who experience a rapid decline in health.

As the needs of individuals with HIV and AIDS become more comprehensive, it will become increasingly difficult in a rural setting for providers to provide highly specialized programming. A model for addressing the varying needs of this population in rural Wisconsin may be the development of specialized service teams representing the diverse service categories. This structure would allow professional teams to develop expertise in HIV and AIDS issues while implementing and coordinating the various service categories. This model would also ease the coordination of multiple service providers on the part of the individuals living with HIV and

AIDS. It may also be beneficial to create varying levels of intensity of case management services and case monitoring for those clients with multiple and complex needs.

Additionally, mechanisms must be in place to monitor the emerging needs of this population as treatment options change. This mechanism would allow circular input into the development of new and comprehensive service programs. A significant component of this process would be to incorporate the input of those individuals living with HIV and AIDS into the program development process. It is critical that the perspective of the individual with HIV and AIDS be represented in service programs.

Additional areas of further research would include the surveying of various service providers representing the diverse service categories expressed by individuals living with HIV and AIDS to determine their willingness and expertise in serving this population. Professional team resources and referral resources could be developed from the survey process. It would also be important for future research to determine the long term side effects of the rigorous medication regiments that individuals with HIV and AIDS must adhere to. This research may provide critical insights into what the new and emerging needs may be for this population. An additional recommendation for further research is exploration of the various income levels that this population represents within rural Wisconsin. The results of this research could give insights to the resources available to this population and their ability to access information and services.

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APPENDIX

DATE:

Dear Consumer of Health and Social Services:

Please accept this correspondence as a request for you to complete and return the enclosed anonymous Needs Survey.

I am currently in the process of completing my Graduate Degree in Rehabilitation Counseling through the Department of Rehabilitation and Counseling at the University of Wisconsin-Stout in Menomonie, Wisconsin. I am conducting a study on the emerging needs of persons living with HIV or AIDS in the Northern and Western Public Health Regions of Wisconsin. It is my hope that data gathered from existing literature and the enclosed anonymous questionnaire will result in the creation of new and improved services for persons living with HIV or AIDS. It is very important that you take advantage of this opportunity to share your perspective and information so that your needs are reflected in programming and services.

Cheryl Thiede, ARCW Director of Health and Social Services has facilitated this mailing to ensure that your confidentiality is maintained in addressing the envelope that this document arrived in. Additionally, the anonymous questionnaire has no place for your name, address or any other identifying information. Upon completion of the anonymous questionnaire, please place it into the postage paid envelope and return it to Cheryl Thiede, P O Box 11, Eau Claire, WI 54702-0011. The return envelope has P O Box 11, Eau Claire, WI 54702-0011 as the return address so that the envelope also maintains the anonymity of the questionnaire. Ms. Thiede will remove your questionnaire from the envelope and place it with the other returned surveys. The completed surveys will be provided to me with no identifying information. The surveys will be completely anonymous.

Thank you very much for your time and input.

Sincerely,

Jamie P. Sorenson

Cheryl Thiede
ARCW Director of Health and Social Services

Participant Consent

I understand that by returning this questionnaire, I am giving my informed consent as a participating volunteer in this research. I understand the basic

nature of the research and agree that any potential risks are exceedingly small. I also understand the potential benefits that might be realized from the successful completion of this research. I am aware that the information is being sought in a specific manner so that no identifiers are needed and so that anonymity is guaranteed. I realize that I have the right to refuse to participate and that my right to withdraw from participation at any time during the research will be respected with no coercion or prejudice.

NOTE:

Questions or concerns about participation in the questionnaire or subsequent complaints should be addressed -

First To:

ARCW Director - **Cheryl Thiede, Director of Health and Social Services, ARCW, P O Box 11, Eau Claire, WI 54702-0011, phone (800) 750 2437**

Researcher - **Jamie Sorenson, 505 Dewey Street South, Suite 107, Eau Claire, WI 54701, phone (715) 836 7710**

Second To:

Advisor - **Robert Peters, Program Director, University of Wisconsin-Stout, Department of Rehabilitation and Counseling, 221 10th Avenue, VR Building, Menomonie WI. 54751, phone (715) 232 1983**

Chair - **Dr. Ted Knous, Chair, UW-Stout Institutional Review Board for the Protection of Human Subjects in Research, 11 HH, UW-Stout, Menomonie, WI 54751, phone (715) 232 1126.**

Anonymous Questionnaire

1. Gender: ___Male ___Female

2. Age: ___18-25 ___26-35 ___36-45 ___46-55 ___56 or older

3. How long have you been positive? ___less than 1 year ___1-5 years
___5-10 years ___over 10 years

4. How would you rate your health? ___poor ___good ___great

5. Do you have adequate access to dental care? ___yes ___no
6. Do you have adequate access to an HIV knowledgeable physician? ___yes ___no

7. Do you have access to the medications that you require? ___yes ___no
8. Do you take medications on time and at the right dose? ___yes ___no

9. Do you have adequate housing? ___yes ___no
10. Do you have legal needs? ___yes ___no
11. Do you have accessible and affordable transportation? ___yes ___no
12. Do you have child care needs? ___yes ___no

13. Are you currently employed? ___yes ___no
14. If not employed, do you want to return to work? ___yes ___no

15. Do you have access to information on HIV and AIDS? ___yes ___no
16. Do you have access to information on the transmission of HIV? ___yes ___no
17. Do you have emotional support? ___yes ___no
18. Do you have access to an HIV/AIDS support group? ___yes ___no

19. Are you above your desired weight? ___yes ___no
20. Are you below your desired weight? ___yes ___no
21. Do you have a desire to exercise? ___yes ___no
22. Do you have access to information on nutrition? ___yes ___no

(Please turn over and complete other side)

23. Please rank in order of most important to least important the following twenty services that you could benefit from, (1 is most important and 20 is least important).

___ Medication schedules
___ Legal services

___ Financial assistance
___ Housing assistance
___ Hospice care
___ Home health care
___ Vocational or “return to work” services
___ Benefits counseling
___ Applications for SSI, SSDI, Medical Assistance, and other entitlement programs
___ Support groups
___ Nutrition counseling
___ Exercise programs
___ Dental care
___ Medical care
___ Emotional support buddies
___ Transportation assistance
___ Alternative therapies such as massage, acupuncture, etc...
___ Mental health counseling
___ Chemical dependency counseling
___ Education on HIV transmission

Please place your survey in the enclosed postage paid envelope and return to: Cheryl Thiede, P.O. Box 11, Eau Claire, WI 54702-0011.