

“I AM AIDS”-BRIDGING THE GAP

A Dissertation
Submitted to the Graduate Faculty
of the
North Dakota State University
of Agriculture and Applied Science

By

Leah Marie Brewster

In Partial Fulfillment of the Requirements
for the Degree of
DOCTOR OF NURSING PRACTICE

Major Department:
Nursing

March 2013

Fargo, North Dakota

North Dakota State University
Graduate School

Title

“I am AIDS”- Bridging the Gap

BY

Leah Marie Brewster

The Supervisory Committee certifies that this *disquisition* complies with North Dakota State University’s regulations and meets the accepted standards for the degree of

DOCTOR OF NURSING PRACTICE

SUPERVISORY COMMITTEE:

Dr Molly Secor-Turner

Chair

Dr Dean Gross

Dr Tina Lundeen

Dr Mary Larson

Anne Grande

Approved by Department Chair:

April 4, 2013

Date

Dr Carla Gross

Signature

ABSTRACT

It is estimated that between 252,000 and 312,000 people in the United States are unaware that they are infected with HIV/AIDS and are unaware of their risk for HIV/AIDS transmission to other people (Morbidity and Mortality Weekly, 2003). Placed near the bottom in incidence for HIV/AIDS prevalence rates in the United States, North Dakota has 227 HIV/AIDS (North Dakota Department of Health, 2011). With low prevalence rates, a lack of cohesive healthcare provider groups is a challenge due to low demands for care. The purpose of this project was to identify the needs of persons newly diagnosed with HIV/AIDS and services available to address their needs in the Fargo, ND region. Bridging the gaps between where patients go from the point of diagnosis to the next step in care is where there are fragmented services that could be addressed by an established coordination of HIV/AIDS-related services in the state of North Dakota. Six individuals living with HIV/AIDS within the Fargo community were interviewed for stage one of this project. For stage two of this project, three key informants who specialize in the care of HIV/AIDS patients were identified within the Fargo community and interviewed. Data results from the HIV/AIDS-positive patients as well as the key informants supported the literature that there are gaps within the healthcare system, such as a lack of HIV/AIDS case managers to help patients coordinate and facilitate their care. An HIV/AIDS care quick reference guide was developed to identify the services available and those recommended to bridge the care gap in Fargo, ND. This practice improvement project has the potential to improve healthcare practice by providing practitioners with a resource guide on managing care for individuals living with HIV/AIDS.

ACKNOWLEDGEMENTS

I would like to thank the members of my committee who have freely volunteered their time to helping me complete this project: Dr. Dean Gross, Dr. Tina Lundeen, Dr. Mary Larson, and Anne Grande. I especially wish to thank Dr. Molly Secor-Turner for her dedication and her extra efforts in contributing to my success by being the chair of my committee. Her encouragement, extraordinary expertise, and experience in the field of research helped to greatly inspire me along the way. She put in a lot of extra hours to help make this project a success, and for that, I owe her immensely.

I dedicate this dissertation to the two loves of my life: my son, Will, and my daughter, Brooklyn. They have greeted me cheerfully every morning after I have spent many late nights burdened with the strains of returning to school to further my education. They have provided light when there was darkness and humor when there was stress. They truly are the light that guides me. To my parents, thank you for your strength and for your unending support. I could not have done this dissertation project without you.

TABLE OF CONTENTS

ABSTRACT	iii
ACKNOWLEDGEMENTS	iv
LIST OF TABLES	vii
LIST OF FIGURES	viii
CHAPTER ONE. INTRODUCTION	1
Problem Statement	2
Purpose of the Study	4
Significance of the Study for Advanced Practice Nursing	5
Intended Improvement Project	6
Study Questions	6
CHAPTER TWO. REVIEW OF LITERATURE AND STUDY FRAMEWORK	7
Review of Literature	7
Theoretical Framework	16
CHAPTER THREE. METHODOLOGY	20
Design	20
Setting	20
Recruitment and Data Collection	21
Protection of Human Subjects/Institutional Review Board	23
CHAPTER FOUR. RESULTS	24
Sample	24
Main Themes	25
HIV/AIDS Services Available in Fargo, North Dakota Region	32

CHAPTER FIVE. DISCUSSION AND RECOMMENDATIONS	36
Overview of Results	36
Interpretation of Results	38
Limitations	38
Application of Theory	39
Recommendations for Further Research	40
Implications for Advanced Nursing Practice	40
Dissemination	41
Conclusion	42
REFERENCES	44
APPENDIX A. EXECUTIVE SUMMARY	48
APPENDIX B. PERMISSION TO USE PRECEDE-PROCEED MODEL	53
APPENDIX C. HIV/AIDS PATIENT CONSENT	54
APPENDIX D. HIV/AIDS PATIENT QUESTIONNAIRE	56
APPENDIX E. HIV/AIDS KEY INFORMANT CONSENT	57
APPENDIX F. HIV/AIDS KEY INFORMANT QUESTIONNAIRE	59

LIST OF TABLES

<u>Table</u>	<u>Page</u>
1. Demographics. Sample Characteristics of the HIV/AIDS Population	26
2. HIV/AIDS-Positive Patient Interviews	29
3. Key Informant Interviews	32

LIST OF FIGURES

<u>Figure</u>	<u>Page</u>
1. Precede-Proceed Model	17
2. Quick Guide to HIV Care and Services in Fargo, ND	33

CHAPTER ONE. INTRODUCTION

Human Immunodeficiency Virus (HIV) threatens the lives of men, women, and children all around the world. Left untreated, the virus attacks the individuals' immune systems leaving them immunocompromised, susceptible to immunodeficiency diseases and the development of Acquired Immunodeficiency Syndrome (AIDS). Since first identified in the 1980s, HIV/AIDS has infected over 65 million people and killed approximately 25 million people (Beduk, Ulnu, & Duyan, 2011). When first identified, initial care of persons with HIV/AIDS involved comfort measures for acute infections and provided provisions for palliative care due to the fact that this disease is still incurable. Today, in developed countries, HIV/AIDS infection is considered a chronic medical condition versus a death sentence (Shindel, Horberg, Smith, & Breyer, 2011).

Now entering its fourth decade in existence, extraordinary advances in healthcare, research, and medicine have contributed to the understanding, prevention, and treatment of HIV/AIDS (Diffenbach & Fauci, 2011). Through advancements in technology, researchers better understand the process and the pathogenesis behind HIV/AIDS. It is now possible to diagnose the rapidly replicating HIV infection cells and then to suppress the cell replication with highly effective antiretroviral therapy (ART). Despite these advances, approximately 2.5 million persons are still being infected with HIV/AIDS each year (Diffenbach & Fauci, 2011). Research and municipal involvement continue to be dynamic to diminish the spread of HIV/AIDS and to find a cure for this disease.

Community involvement has been vital in identifying the key components to address since the HIV/AIDS epidemic began. Forming partnerships with community members and organizational representatives to improve the health and well-being of

communities and to reduce society's burdens associated with HIV/AIDS have been community-based goals throughout the history of HIV/AIDS (Rhodes, Malow, & Jolly, 2010). Many HIV/AIDS programs have struggled to create positive outcomes due to a lack of effective community mobilization. It is clear that community involvement enriches the effectiveness for a range of biomedical and behavioral HIV/AIDS interventions.

HIV/AIDS-affected communities need to take control of the growing epidemic occurring within their populations (Campbell & Cornish, 2010). Community empowerment helps to increase the likelihood that community members will engage in health-enhancing behavioral changes such as health prevention, health promotion, healthcare, and appropriate health treatments. Despite all the current efforts to coordinate medical care for infected individuals, a significant number of HIV/AIDS-infected people delay care initiation after diagnosis (Garland et al., 2011). Why is there a delay in treatment? Are the services not accessible to the populations in need, or are the services simply not utilized by the individuals who need them the most?

Problem Statement

It is estimated that between 252,000 and 312,000 people in the United States are unaware that they are infected with HIV/AIDS and are unaware of their risk for HIV/AIDS transmission to other people (Center for Disease Control and Prevention [CDC], 2006). These statistics means one in five persons in the United States is unaware of their infection status and is spreading the virus to others without knowing they are infected (CDC, 2011). The most recent poll from the Centers for Disease Control and Prevention states that, in the United States alone, there are 1.2 million people living with HIV/AIDS infections (CDC, 2011). Placed near the bottom in incidence, North Dakota has 227 reported cases of

HIV/AIDS (North Dakota Department of Health [NDDoH], 2011). Having a low occurrence rate in the hierarchy of prevalence rates for HIV/AIDS cases in the United States, a lack of cohesive healthcare provider groups becomes the problem for the patients as well as the providers to access consistent, organized healthcare.

Advancements in pharmacologic therapy have dramatically altered the course and the progression of HIV/AIDS and have transformed the disease into a chronic illness. The availability of highly active antiretroviral therapy has enabled infected individuals to live with the once-terminal illness for years (Eldred & Malitz, 2007). Once treatment has begun the medications must be continued indefinitely and be strictly adhered to in order to keep resistant strains from developing.

Billions of dollars have been spent on the prevention, treatment, and further advancements for HIV/AIDS research. The most recent guidelines for treatment state that, in order to qualify for antiretroviral pharmacologic therapy, the patient must have a CD4 count of less than 450 (Mountain Plains AIDS Education [M PAEC], 2011). Unfortunately, only about one-third of patients who qualify for treatment under the relatively conservative World Health Organization (WHO) guidelines actually receive therapeutic treatment (WHO, 2011).

Delays in treatment may be related to a lack of knowledge about HIV/AIDS status or available treatment options as well as inaccessible care. Patients infected with HIV/AIDS frequently suffer from other co-morbidities that make engagement in healthcare difficult to manage. For example, they may be socioeconomically disadvantaged and unable to afford healthcare (Garland et al., 2011). Personal struggles are further compounded by the challenges of accessing care in the patchy U.S. healthcare system

(Eldred & Malitz, 2007). Challenges to access HIV/AIDS-related care in North Dakota are further compounded by the lack of services available due to the relatively low regional prevalence rates of HIV/AIDS. A lack of services and specialty providers may lead to fragmented care for patients in this region.

Purpose of the Study

Ranking low in the overall HIV/AIDS incidence and prevalence rates in the United States, North Dakota services available to HIV/AIDS-infected patients are minimal due to a lack of demand. Patients in North Dakota who are diagnosed with HIV/AIDS face a shortage of HIV/AIDS-related care and resources as compared to other states and are often faced with confusion about how to proceed. The lack of services and the fragmentation of care result in significant gaps in HIV/AIDS-related care for patients. North Dakota is a rural state with considerable geographic distance between larger cities. There are only four major cities, with smaller towns spread across the state, leading to difficulty accessing care for certain individuals depending on their geographical location within the state.

The CDC provides leadership in addressing the HIV/AIDS epidemic by working with local community programs, as well as having state, national, and international partnerships. As part of its overall public health mission, the CDC partners with others for surveillance, research and prevention, and evaluation activities (CDC, 2011). North Dakota currently lacks the infrastructure to support HIV/AIDS-related care statewide. Current efforts focus on providing HIV testing and scattered medically related healthcare services. There is an obvious lack of support services and coordination related to HIV/AIDS in North Dakota.

The purpose of this project was to identify the needs of persons newly diagnosed with HIV/AIDS and services available to address their needs in the Fargo, ND region. This study is based in the largest community in North Dakota and consists of individuals living in the eastern part of the state, mainly Fargo.

Significance of the Study for Advanced Practice Nursing

A key factor in decreasing the transmission of HIV/AIDS involves timely linkages to care, including early diagnosis, connection to HIV/AIDS-related care, services, and further education (Garland et al., 2011). HIV/AIDS diagnosis alone has been shown to reduce risky behaviors because patients are aware of their HIV status (Thomas, Aggleton, & Anderson, 2010). People who have not been tested, or are not receiving HIV/AIDS-related care, do not have the benefit of antiretroviral therapy, continuity of care, or linkages to further services.

Advanced practice nurses have a professional obligation to facilitate treatment and to provide evidence-based care for patients as well as to work with other disciplines to provide cohesive and coordinated care. Primary prevention efforts may focus on education and individual behaviors to avoid HIV/AIDS exposure. Secondary prevention efforts may focus on testing and early diagnosis. Tertiary prevention efforts, the focus of this project, may help limit the morbidity and mortality associated with the HIV/AIDS diagnosis. A key component of tertiary prevention involves connecting patients who have HIV/AIDS with high-quality medical care, social services, and other professional services to provide exceptional, comprehensive, community-based care.

Intended Improvement Project

The purpose of this project was to identify the needs of persons newly diagnosed with HIV/AIDS and services available to address their needs in the Fargo, ND region. Individuals who are newly diagnosed with HIV/AIDS need to know where to get started in connecting with related healthcare services, and people who have lived with HIV/AIDS for years need a continuation of services for disease management. This practice improvement project will help improve the care given by practitioners by providing a resource guide on managing care for individuals living with HIV/AIDS. Resources and referral information are included in this guide and aid the provider with getting patients initiated into the healthcare system and keeping them involved within the healthcare system once they have begun care.

Study Questions

The following questions guided the practice improvement project:

1. What are the health and social service needs of individuals who have a diagnosis of HIV/AIDS living in Fargo, North Dakota?
2. What health and social services needs are available to individuals who have an HIV/AIDS diagnosis and live in Fargo, North Dakota?
3. What is the gap between the available services and the identified needs for individuals who are diagnosed with HIV/AIDS and live in Fargo, North Dakota?

CHAPTER TWO. REVIEW OF LITERATURE AND STUDY FRAMEWORK

Review of Literature

In June of 1981, the *Morbidity and Mortality Weekly Report (MMWR)*, published by the Centers for Disease Control and Prevention (CDC), described what became known as HIV/AIDS and one of history's worst pandemics (CDC, 2006). An epidemic, as defined by Webster's online dictionary, is when a disease or virus affects many individuals at once by being spread from person to person (Merriam-Webster, 2013). A pandemic then occurs when an epidemic spans across a large geographic location, possibly crossing continents (Merriam-Webster, 2013). Thirty years later, there is still no end in sight. Hiding in the very immune cells that kill it, HIV/AIDS has proven that its intelligence is far greater than that of humankind. It has the ability to rapidly mutate and integrate itself into the human genotyping while persisting and hiding in every organ of the body (Neimark, 2011). This terrible plague has taken the lives of many in our communities, across our country, and around the world. The virus has outsmarted every vaccination scientifically developed, and the moment any medications are discontinued, the virus has the ability to roar back to life and take control (Neimark, 2011).

The Human Immunodeficiency Virus (HIV) can be categorized into two types, HIV-1 and HIV-2. Worldwide, most HIV infections are categorized as HIV-1, whereas HIV-2 has been largely confined to persons in or near West Africa (Torian, 2011). Both types of HIV have the same transmission routes (horizontal and vertical), and both can cause AIDS; however, they should be differentiated because clinical management differs. Horizontal transmission is transferred from person to person through blood or body fluids.

Vertical transmission is transferred from a mother to a fetus during delivery (Cichocki, 2009).

Human Immunodeficiency Virus type 1 infections result after initial transmission has occurred. Whether it has occurred by sexual contact, contact with blood, or by vertical transmission, a progressive state of immune system destruction ultimately leads to the development of Acquired Immunodeficiency Syndrome (AIDS) if the HIV infection is left untreated (Goldman & Schafer, 2011). AIDS is a syndrome characterized by an extreme depletion of CD4+T lymphocytes (CD4 count \leq 200) and the inability to control infections by opportunistic pathogens that typically do not cause disease in an otherwise healthy individual (Goldman & Schafer, 2011).

HIV/AIDS targets the lymphoid organs, including the thymus, spleen, and lymph nodes (Goldman & Schafer, 2011). The virus is shielded from the immune system in the acute, initial phase, and at this time, an infected person may remain symptom free for several years. Seventy percent of HIV-infected patients experience flu-like symptoms during this initial phase of infection (Neimark, 2011). Even though symptoms may not be present, the virus continues to replicate in the lymphoid organs, the initial site of infection. The virus then lays in a dormant phase until receiving a cue for activation in response to weakening of the body's immune response, such as stress at work, stress of daily living, illnesses, lack of sleep, and poor nutrition (Neimark, 2011).

When the body's immune defenses become weakened, the CD4+T cells drop to dangerously low levels while the HIV viral load in the blood continues to increase dramatically (Neimark, 2011). Individuals at this stage begin to experience the complications of the disease progression due to opportunistic infections, such as

pneumonia or tuberculosis, associated with fewer than 200 CD4+T cells per cubic millimeter of blood (HIV/AIDS, 2009). This point is where the HIV infection is diagnosed as AIDS.

Human Immunodeficiency Virus type 2 (HIV-2) infections were initially identified with AIDS-like symptoms in West African patients whose serum antibodies reacted not with those of HIV-1, but with a distant, related lentivirus. The lentivirus was isolated from captive rhesus macaques in U. S. primate centers and from wild sooty mangabey monkeys in West Africa (Goldman & Schafer, 2011). Initially identified in West Africa, HIV-2 has now been identified in patients from the United States, South America, India, and Europe (Torian, 2011). HIV-2 selectively infects the CD4+T cells. Evidence has suggested that it is less virulent, causing disease in fewer individuals and requiring a longer infection period. HIV-2 is less easily transmitted than HIV-1; therefore, incidence rates for this strain are declining (Torian, 2011).

Impact of HIV

The HIV epidemic has continued to grow in the United States ever since being identified (CDC, 2006). Rapidly increasing in the 1980s, HIV/AIDS incidence rates peaked in 1992 before stabilizing in 1998. Approximately 40,000 cases of HIV/AIDS were diagnosed annually in recent years (CDC, 2011). Between 1981 and 2004, 522,723 deaths related to HIV/AIDS were reported to the CDC (CDC, 2011). Since 1996 and the discovery of antiretroviral treatments, substantial increases in survival rates were reported (CDC, 2006). By the end of 2003, approximately 1,039,000-1,185,000 people living in the United States were living with HIV/AIDS (CDC, 2006). It was estimated that 24-27% of infected persons were unaware of their viral infection (CDC, 2006).

The majority of HIV/AIDS cases continue to occur among males in the men having sex with men category, however, the overall number of all HIV/AIDS cases has increased from 15% (1981-1995) to 27% (2001-2004) for females (CDC, 2006). The proportion of all HIV/AIDS cases decreased in the pediatric population, from 1.4% (1981-1995) to 0.2% (2001-2004, CDC, 2011) with the help of better testing for blood supplies and better testing when a woman becomes pregnant.

Racial and ethnic minorities are still the groups most affected by the HIV/AIDS epidemic. From 1981 to 1995, 47% of persons diagnosed with HIV/AIDS were non-Hispanic whites (CDC, 2006). From 2001 to 2004, the majority of new cases shifted to non-Hispanic blacks (50%), followed by Hispanics (20%) (CDC, 2006). Variations in transmission rates also occurred. Case rates were 131.6 per 100,000 among blacks males and were 67.0 per 100,000 among black females (CDC, 2006). Rates were 18.7 per 100,000 for white males and were 3.2 per 100,000 for white females (CDC, 2006). Men having sex with men had the highest transmission rates at 44% followed by heterosexual contacts at 34%, injection drug use at 17%, the combination of men having sex with men and injection drug use at 4%, and perinatal transmission at 0.6%. The greatest decrease (9.1%) occurred in the injection drug-user category between 2001 and 2004 (CDC, 2006).

Since first being recorded in North Dakota in 1984, HIV/AIDS ranked near the bottom in incidence (47th overall) of HIV/AIDS in the United States (CDC, 2011). The most recent poll taken in 2010 showed that a total of 25 HIV/AIDS cases were reported to the North Dakota Department of Health (NDDoH, 2011). This total included newly diagnosed cases and people who were previously diagnosed in other states and had moved to North Dakota during 2010. Thirteen new cases were diagnosed in North Dakota

residents and reported to the NDDoH in 2010, with three of those cases meeting the case definition for AIDS at the time of diagnosis (NDDoH, 2011).

Between 1984 and 2010, 500 cases of HIV/AIDS were reported to the North Dakota Department of Health, 265 cases of which were newly diagnosed in North Dakota (NDDoH, 2011). Within this same time frame, 142 people with HIV/AIDS died while living in North Dakota (NDDoH, 2011). The latest report, completed on December 31, 2010, showed that there were 227 people known to be living with HIV/AIDS in North Dakota (NDDoH, 2011).

Sixty-eight percent of all HIV/AIDS cases diagnosed in North Dakota between 1984 and 2009 were individuals between the ages of 25 and 49 (NDDoH, 2011). Men having sex with men remained the most frequently reported risk factor for HIV/AIDS transmission at 45 % occurrence rates (NDDoH, 2011). However, there was an increase in the reports of heterosexual-relationship transmissions, being 33 % of the cases diagnosed in North Dakota between 2004 and 2010. The intravenous drug-use category was at 8% (NDDoH, 2011).

During 2008, of the 2,370 HIV/AIDS tests completed in North Dakota, two were reported to be positive. The North Dakota Cares Program served 73 (39%) of the 227 people living with HIV/AIDS in North Dakota. Of these 73 individuals, 69% were male (NDDoH, 2011).

Modes of Transmission

The primary mode of viral transmission throughout the world is by horizontal transmission, which is usually sexual contact with another individual. Most commonly, transmission occurs when an individual with an unknown HIV/AIDS status is not aware of

their viral status because they have never been tested. HIV/AIDS is like other sexually transmitted infections (STIs) in that it is spread from body fluid to body fluid. The virus can be transmitted by unprotected oral-genital sex, vaginal intercourse, and anal intercourse (CDC, 2011). Other types of horizontal transmission include the sharing of infected needles as well as exposure to the blood, vaginal secretions, semen, and breast milk of an HIV/AIDS-infected person. A form of vertical transmission would be that of a fetus being exposed from an infected mother in utero or during childbirth (CDC, 2011). HIV/AIDS cannot be transmitted by kissing or holding hands; mosquitos; sharing bathrooms; sneezing or coughing; and partaking in normal workplace, day-care or school interaction (CDC, 2011).

High-Risk Populations

Early in the presentation of HIV, high-risk groups contracting and spreading HIV/AIDS were primarily men who had sex with other men and injection drug users. Eventually, other modes of transmission became more prevalent, including transmission through heterosexual relationships as well as transmission from a mother to a fetus in utero or during delivery. In the early 1980s or before, HIV/AIDS was also spread to individuals requiring a blood transfusion before it was recognized that blood contained this virus. Also in the 1980s, individuals requiring organ and tissue transplantations as well as those with blood disorders were also considered to be in the high-risk categories. Healthcare workers were also placed at an increased risk of becoming infected if they by cross-contamination via a needle stick from a positive patient to a provider were to occur (Namakhoma et al., 2010).

Testing for HIV/AIDS

Early diagnosis and initiation of antiretroviral therapy (ART) requires testing and diagnosis. The earlier in the disease process that the virus is identified, the more likely the person is to control and manage his/her HIV/AIDS progression. The Center for Disease Control and Prevention (CDC) estimates that individuals diagnosed late in the course of the disease do not do as well fighting the opportunistic infections that can develop as a result of the low immune status (CDC, 2006). Late HIV/AIDS diagnosis presents missed opportunities for the patient, including, missed linkages to care and delays in treatment. Current efforts in the United States to help decrease the spread of HIV/AIDS focus on increased HIV testing. The testing is a policy initiative that has been a central theme in the prevention and spread of HIV/AIDS.

Technology advances have made it easier and quicker to test for the virus. Approved by the Food and Drug Administration in 2002, the OraQuick HIV rapid test is a simple, rapid test that provides HIV results within 20 minutes. This rapid test can be stored at room temperature, can be performed outside a clinic/hospital setting, and requires no specialized equipment. With the receipt of a positive result from the OraQuick test, HIV-positive patients then require complete confirmation by the Western Blot or immunofluorescence assays (“Advancing,” 2003).

North Dakota is an opt-out state, which allows for testing to be completed without the use of a separate consent form. The law also requires that providers report HIV/AIDS-positive patients to the North Dakota Department of Health. Testing is free and confidential and reporting a positive test is required by law (ND HIV/AIDS Resources, 2009).

Treatment Options

Decades of scientific research have led to the development of lifesaving and life-prolonging treatment for HIV/AIDS (De Cock, Jaffe, & Curran, 2011). Although a cure is nowhere in sight, individuals diagnosed with HIV/AIDS are living for years with the chronic disease without it being an immediate death sentence. In 1987, the approval of Azidothymidine or Zidovudine (AZT), the advancement of antiretroviral drugs, and the enterprise of modest and standardized therapy approaches in the developing worlds constituted a public health conquest. The International AIDS Society is also working independently with a group of experts in an attempt to spearhead this global epidemic in hopes of finding a cure.

Clinical knowledge and skill are essential to ensure that care is being provided to individuals with HIV/AIDS according to the current recommendations and that recommendations are driven based on the most recent evidence-based guidelines (Bashook et al., 2010). Adherence to prescribed drug therapy is essential in order to control HIV/AIDS. Sometimes, however, the overwhelming side effects, as well as the inconvenience of the strict drug regimen serve as deterrence for patients to take their medication. Patients who are partially adherent to treatment are facilitating the emergence of new drug-resistant strains and mutations. All current medication regimens are geared at fighting current strains causing the disease.

Current medication regimens using antiretroviral therapy can control the disease, prolong survival rates, and slow the progression of developing AIDS. When using pharmaceutical medications, side-effects are always the unwanted issues. Adverse reactions include nausea and vomiting, diarrhea, fatigue, skin rashes, fat redistribution, and

soreness. These and other side-effects play a large role in patients skipping doses or discontinuing to take their antiretroviral medications, thus falling through the cracks of the healthcare system (Chiou et al., 2006).

Needs of HIV/AIDS Affected Individuals

Unlike other chronic diseases, HIV/AIDS affects more than just a pretentious individual's overall health status. Diagnosis with HIV/AIDS is a social, political, cultural, economic, and personal issue (Rowan & Honeycutt, 2010). People living with HIV/AIDS face social stigmas, discrimination, health concerns, and psychological issues, which have an impact on their ability to deal with life and life satisfaction. It is estimated that one million people die each year because of suicide, and research studies show that people living with HIV/AIDS have higher rates of suicide attempts compared to those not living with HIV/AIDS (Davis & Niebes-Davis, 2010).

Since the earliest cases of HIV/AIDS were first identified, discrimination and stigmatization have been closely related to the infection. Affected individuals have been stigmatized as being immoral, unworthy, and responsible for their disease. People living with the disease are often forced to keep their disease a secret to avoid the social consequences as well as the negative psychosocial outcomes of the disease.

Case-management services are a standard practice in the United States for the effective care of people living with HIV and AIDS. Case management provides coordination and easier access to services than positive individuals could expect to obtain on their own (Thurman, Haas, Dushimimana, Lavin, & Mock, 2010). Studies have shown that there are higher patient retention rates and better compliance with medical regimens among HIV/AIDS clients who have a case manager (Thurman et al., 2010). It is possible

that case managers are the fundamental connection to facilitating the process of accessing services for this specific patient population.

The financial burdens of living with HIV/AIDS and being able to afford medications are often the reason why people do not seek treatment. Low-income earning individuals may qualify for a particular government program known as the Ryan White Program. The Ryan White Program is the largest federally funded program designed specifically for people with HIV/AIDS in the United States, and it is estimated to reach more than half a million people with HIV/AIDS each year. It functions as the “payer of last resort” by filling the gaps for individuals who have no other source of coverage or face coverage limits (Kaiser Family Foundation, 2009).

Theoretical Framework

Created for its use in public health, the Precede-Proceed model (Figure 1) deals with community issues (Green & Rabinowitz, 2012). The focus of this model is not towards treating the diseases but towards preventing the diseases from occurring in the first place. The fundamental foundation is based on the individual wanting a change and is, therefore, strictly voluntary. Changing a person’s health beliefs and attitudes as well as focusing on health promotion can greatly improve the quality and duration of one’s life span. The model can be organized as a community effort and, by involving the community, allows for more ideas and community ownership over the resolution of those ideas (Green & Rabinowitz, 2012).

If aimed at the prevention of HIV, this model can be put into place to prevent HIV transmission before it actually occurs. Making people aware of their HIV status by having them tested is one way of getting people aware of their status. If they were HIV negative,

then interventions would focus on practicing safe sex, such as using condoms and decreasing the risk for IV drug users by encouraging the use of clean needles. If a person has a positive HIV/AIDS status, then focusing on health promotion is vital. Health-promotion interventions that include guaranteeing antiretroviral treatments, encouraging rest, reducing stress, eating healthy, and exercising are crucial for making this model work.

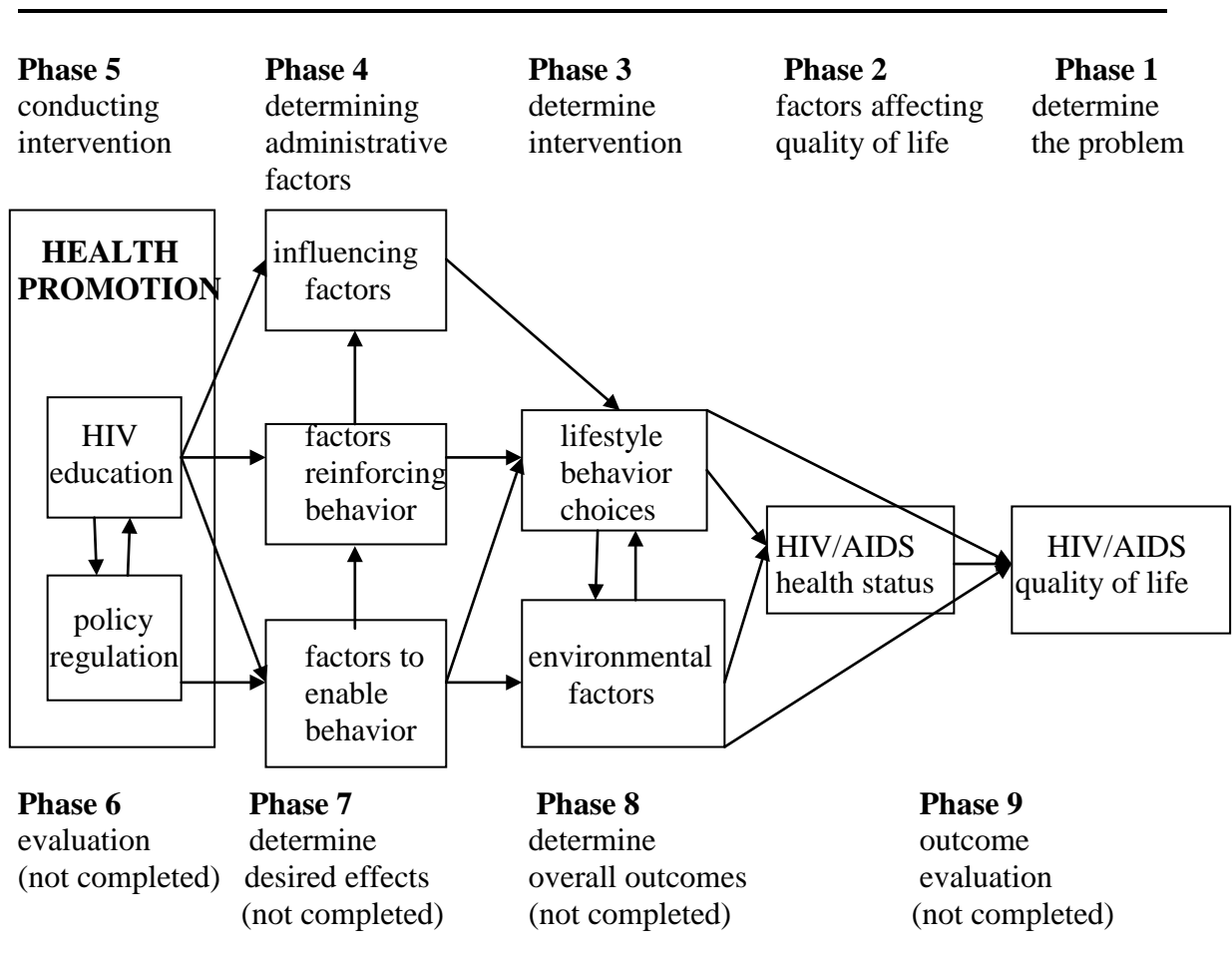


Figure 1. Precede-Proceed Model [Figure 1 is adapted with the author's permission (Appendix B), from the Precede-Proceed model to represent its association with HIV/AIDS. Each phase is represented by its indicated number (Green & Kremer, 1999)].

The precede portion of the model has the focus that a change is warranted and an intervention needs to be formed. It consists of four phases. Phase one involves the community in identifying the problem and motivating community members to improve the problem outcomes by creating a social diagnosis describing the problem. Phase two consists of any other issues that may be affecting the community's quality of life and determines an epidemiological diagnosis by analyzing the problem (Green & Rabinowitz, 2012). Phase three consists of coming up with an action plan and determining what to do in order to change the factors involved in the behavior. The aim of phase four is to determine the internal and external administrative factors for supporting an intervention (Green & Rabinowitz, 2012).

The proceed portion of the model is the treatment portion. This includes carrying out the intervention and evaluating its effectiveness and consists of four phases. Phase five is conducting the intervention that was identified. Phase six is the evaluation phase; it determines whether the actions that need to take place are actually occurring. Phase seven ascertains whether the intervention has the desired effects on situations involved in the unwanted behaviors. Phase eight determines the overall outcomes. This phase is where the community decides if the overall quality of life was improved by changing the behaviors occurring within the environment (Green & Rabinowitz, 2012). Phase nine evaluates the outcome to determine if the desired result is accomplished. Phases six through nine were not actually carried out during this project.

The precede-proceed theoretical model helped guide this practice improvement project because HIV/AIDS is a community issue. For people who are HIV/AIDS negative, the focus included community prevention. Continuing to protect themselves by not

engaging in high-risk activities or coming into contact with infected body fluids are primary prevention tactics to help prevent the virus from spreading.

CHAPTER THREE. METHODOLOGY

Design

The purpose of this project was to identify the needs of persons newly diagnosed with HIV/AIDS and services available to address their needs in the Fargo, ND region. Individuals who are newly diagnosed with HIV/AIDS need to know where to get started in connecting with related healthcare services, and people who have lived with HIV/AIDS for years need a continuation of services for disease management. This qualitative study intended to identify barriers, gaps, and services to accessing comprehensive treatment services for persons living with HIV/AIDS in the Fargo North Dakota region. Findings from this project can be used to inform primary care practitioners about identified barriers and gaps in treatment. In addition, the findings can be used to develop community-based programs to improve the HIV/AIDS care in Fargo and broader North Dakota.

Setting

Since the HIV/AIDS epidemic began, identifying and addressing the needs of HIV/AIDS- positive communities relied on community involvement. Ineffective HIV/AIDS programs that have not produced positive outcomes often lacked effective community utilization (Campbell & Cornish, 2010). The setting for this community-based project was Fargo, North Dakota, with an approximate population of 149,778 people according to the 2010 report of the United States Census Bureau (U.S. Census Bureau, collected 2011). The number of people living in North Dakota with HIV/AIDS, according to the last report by the CDC, in 2011, was 227 people (CDC, 2011). There were 13 newly diagnosed cases in 2010 (U.S. Census Bureau, 2011).

Recruitment and Data Collection

Two groups of study participants were included for this project. The first group was community HIV/AIDS-related service providers who were identified as key informants because they provide healthcare to individuals and are recognized as experts in this level of care. Potential key informants were identified through referrals from an HIV/AIDS educator and included providers who have patients with HIV/AIDS. The second group of study participants was individuals who are HIV/AIDS positive and live in the Fargo, North Dakota region.

Inclusion criteria for the HIV/AIDS key informant part of the survey were: providers that deliver care to HIV/AIDS patients; those who provide care to patients in Fargo, North Dakota; and those who are able to speak English. Exclusion criteria included: providers who do not care for patients who are HIV/AIDS positive; those who do not provide care in Fargo, North Dakota; and those who do not speak English. Inclusion criteria for the HIV/AIDS participant part of this survey were: individuals who are over the age of 18; those who have been diagnosed with HIV/AIDS; those who live in the state of North Dakota; and those who are able to speak English. Exclusion criteria included: individuals who are under the age of 18; those who do not have an HIV/AIDS diagnosis; those who live outside North Dakota; and those who are strictly non-English speaking.

Participants were recruited via email from two community agencies that serve HIV/AIDS patients, including the American Red Cross in Bismarck, North Dakota and the Minnkota Health Project. The Minnkota Health Project is a government-funded facility, which lost its federal funding but is still run by its volunteers. The American Red Cross in Bismarck was utilized in an attempt to gain a broader variation in participation. Interested

participants were informed about the study purpose and reassured that all information would be kept confidential. They were asked to contact the investigator to arrange a private meeting time. Private meetings were held mainly in the participants' homes, with one held at a hospital in a private meeting room. After explaining the practice improvement project in more depth, informed consent was obtained (Appendix C). Interviews with HIV/AIDS positive participants focused on perceptions of their experiences with accessing HIV/AIDS-related services in Fargo and perceived health-related service needs using a semi-structured interview questionnaire (Appendix D). The average interview lasted 60 minutes, and participants were given a \$10 gift card in appreciation for their time and participation. Interviews were recorded with the participants' consent, and all data was transcribed

Following informed consent (Appendix E) key informant interviews were conducted using telephone (N=1) conducted by the primary investigator and via email (n=2) using a standard set of open-ended questions. Questions were used to understand services and programs available to the HIV/AIDS patients they provide care for (Appendix F).

Phase two of the study evaluated the services available from community agencies in Fargo. Current services were assessed to determine their availability to individuals who are living with HIV/AIDS. This was done by making telephone and email contacts and asking them questions about the services they have available to those living in Fargo with HIV/AIDS.

Protection of Human Subjects/Institutional Review Board

The study proposed was approved by the Institutional Review Board (IRB) of North Dakota State University (NDSU [NDSU IRB approval # PH12182]). Approval date was April 2012 with a review renewed February 2013.

CHAPTER FOUR. RESULTS

Sample

HIV/AIDS-positive patients as well as key informants in the care of HIV/AIDS-positive individuals participated in interviews. Six HIV/AIDS positive participants were recruited to participate in individual interviews. Interviews were conducted by the student researcher in a private location of the participants' choice such as at the participants' homes. Interviews were recorded and notes were taken during the interviews. Recordings were then listened to several times and additional notes were taken as needed.

Three individual interviews were conducted with key informants who provide health care services to patients with HIV/AIDS in nonprofit (n=2) and government (n=1) healthcare facilities. All key informants were male and reported currently providing care to approximately 20-45 HIV/AIDS patients. Interviews were conducted by the student researcher via face to face interaction and electronic emailing. Two providers had worked in other states and one had only practiced in North Dakota. Notes were taken during the interviews and copies of emails were assessed to compile the data.

HIV/AIDS-Participants

Participants included one female and five males who ranged in age from 30 years old to 70 years old. Participants reported living with their HIV/AIDS for 3 to 20 or more years. Four participants were Caucasian, and two participants were African American and immigrants from other countries. Five participants were diagnosed in the United States, and one was diagnosed in Ethiopia. Of the five diagnosed in the United States, two were diagnosed in North Dakota; one was diagnosed in Minnesota; one was diagnosed in Illinois; and one was diagnosed in New Jersey. HIV transmission occurred primarily

through horizontal transmission, including male-to-female transmission, male-to-male transmission, and unknown transmission. Sample data are displayed in Table 1.

Key Informants

Three individual interviews were conducted with key informants who provide health care services to patients with HIV/AIDS at nonprofit and government healthcare facilities. All key informants were male and reported currently providing care to approximately 20-45 HIV/AIDS patients. Two providers had worked in other states, and one had only practiced in North Dakota.

Main Themes

HIV/AIDS Positive Participants

Individual interviews were reviewed to identify main themes in response to the interview questions. The interviews revealed six common themes (Table 2). Each theme is presented here, followed by relevant quotations to exemplify each theme.

Services needed at initial diagnosis. Participants expressed a range of services that they felt would have better served their needs at the time of initial diagnosis. Identified needs included counseling and support, case management, and assistance enrolling in Medicaid and other supportive services such as food stamps or meal programs. Participants' reactions to these needs varied from feeling very ready to receive the services to feeling "put off" by the system and not being interested in engaging in services. For example, one participant described his reaction to the need to engage in services following an HIV diagnosis received over the phone.

"As a matter of fact, I ostracized the healthcare system for a full year and lived in denial due to the fact that I felt I was treated so poorly at the time of my diagnosis and didn't want to go back to that facility."

- Participant # 6

Table 1
Demographics. Sample Characteristics of the HIV/AIDS Population (Sample N=6)

Characteristic	Number
Age (range 30-70)	6
Age at Time of Diagnosis (range 20-70)	6
Race/Ethnicity	
Caucasian	4
African American	2
Gender	
Male	5
Female	1
Place of Diagnosis	
United States	5
North Dakota	2
Minnesota	1
Illinois	1
New Jersey	1
Ethiopia	1
Mode of Transmission	
Male to Male (MSM)	3
Male to Female	1
Unknown	2
Co-Infected with Another Chronic Condition	
No	5
Yes (Hepatitis C)	1

Information most beneficial at initial diagnosis. Participants reported that the information they felt was most beneficial at initial diagnosis was the support groups, someone to help coordinate their care, and information about where to get HIV/AIDS services. Participants described struggling to make sense of how to coordinate their services and understand how to proceed. For example, one participant described how some of these tools could have easily guided his or her care to help facilitate treatment.

“I had to do everything on my own, and I had no idea what I was doing. I had just gotten this diagnosis, and my family was not supportive, and just to of had someone to help me know what services to connect with would have been so much easier.”

- Participant #5

Barrier at time of diagnosis. Barriers to care varied, depending on the type of facility and in which state participants were diagnosed. Barriers to HIV/AIDS care and services at the time of diagnosis included a lack of transportation, knowing where services are located in Fargo, access to programs such as food stamps, and a lack of family support. For example, one participant attempted to be open and honest with the public about the HIV/AIDS status, and family asked that it not be discussed for fear people would figure out their child had this stigmatizing disease. Access to financial services that would help include programs such as food stamps and money for a city bus pass to get to and from a job.

Services needed. To improve patient care outcomes, patients need to be retained in care and connected to services. Participants felt that having access to insurance, such as Medicaid would be very beneficial. Being unable to afford health insurance is further compounded by not meeting the criteria created to qualify for Medicaid. Being uninsured

then creates additional financial burdens and struggles. The following statement made by a participant helps explain ones frustrations with not meeting the criteria.

“It is so hard for me because I came from another country and I can’t meet the criteria to qualify for Medicaid. I have funds for my HIV/AIDS related care, but my eyes are getting so bad that I can’t go see a doctor. I am losing my eyesight and do not have extra money to pay for that appointment so all I can do is continue to get care for my HIV/AIDS and hope someday I can see an eye doctor.”

- Participant #1

Having more services available, such as the food bank, would help with the financial burdens that living with HIV/AIDS presents. Having access to Ryan White funding has helped many people living with this disease, however, it is a payer of last resort when nothing else is available. Also, easily accessible support groups would help encourage individuals living with HIV/AIDS to stay compliant with their current treatment regimens.

Difficult services to access. Participants reported that the services that were the most difficult to access were financial assistance and transportation. The necessities for strong support groups that can meet a greater variety of participants needs were emphasized. As stated by one patient, routinely having a little extra spending money for necessary items was a challenge.

“All I want is a little extra money to be able to buy Boost shakes and vitamins. When I do these simple things, I have learned that it just keeps my immune system healthy and I can live with this disease. Without them, I get sick easier.”

- Participant # 4

Routine dental care for patients with Medicaid insurance is difficult for participants to access because there are not many dental offices that accept Medicaid in the region. As stated by one patient, he/she cannot afford out of pocket expenses.

“I can easily go to a dentist, but I don’t have the money to pay out of pocket for the appointment, so I cannot go. With many dentists not accepting Medicaid anymore, it is really becoming a challenge, and I do not know where to go that will take me.”

- Participant #6

Table 2
HIV/AIDS Positive Patient Interviews

Services	Services to Help Bridge the Gap
Services Needed at Initial Diagnosis	<ul style="list-style-type: none"> • Case Management • Financial Assistance
Information Most Beneficial at Initial Diagnosis	<ul style="list-style-type: none"> • Someone to Help Facilitate Services • Where Support groups are Located • How to get Financial Assistance
Barrier at Time of Diagnosis	<ul style="list-style-type: none"> • Family • Finances • Information About Where to get Services
Services Needed	<ul style="list-style-type: none"> • Case Management • Financial Assistance • Support Groups
Difficult Services to Access	<ul style="list-style-type: none"> • Financial Assistance • Support Groups • Transportation
Services Needed Throughout	<ul style="list-style-type: none"> • Case Management • Financial Assistance • Dental Services • Legal Services • Transportation

Services needed throughout. Additional funding to help patients meet additional needs, such as extra spending money each month for a bus pass, would be beneficial, especially for those who do not have the means to own a vehicle. The Minnkota Health Project offers support services, but participants were discouraged that the same individuals were always present and they had to listen to the same stories each time. Services are under-utilized because participants simply quit going and struggle to manage their emotional state either on their own or through a psychologist. One of the participant's spouses also spoke to this question and stated the following:

“I know you are not asking me the questions, but from a spouse's point of view, support groups are such a challenge. With [him/her] having a positive HIV/AIDS status and me not having the virus, it is hard to find a good support system for us as family as well.”

- Spouse of Participant #6

In addition, participants suggested that more providers who are comfortable managing HIV/AIDS care in rural health would help to increase access in rural areas. In addition, participants also expressed the need for legal representation related to HIV/AIDS.

Key Informants

Main themes were identified in response to each interview questions for the key informants. The interviews revealed five common themes (Table 3). Each theme is presented here, followed by relevant quotations to exemplify the theme.

Services needed. In general, key informants emphasized the need for primary-care services, social services, pharmacy services, nursing services, and mental-health services. In addition, they identified the need for someone, such as a case manager, to help aid HIV/AIDS-positive patients with enrollment in the Ryan White program. Many pharmacies in Fargo offer HIV/AIDS medications, but to have one specific pharmacist who specializes

in HIV/AIDS medications would be helpful for patients. One of the key informants expressed frustrations regarding lack of a pharmacist specializing in HIV/AIDS medications:

“[Most patients know more about their HIV/AIDS medications and the side effects associated with each medication than the pharmacist’s do because there isn’t a pharmacist that specializes in HIV/AIDS meds].”

- Key informant #3

Information most important at initial diagnosis. At initial diagnosis, all three key informants felt that it was very important for people to have information regarding where to get help and information for support groups, available funding, and services in Fargo. In addition, they emphasized the need for education about the importance of medication adherence, transmission, and prevention.

Difficult services to access. Key informants described how challenging it was for patients to access specialists, such as pulmonology and immunology at smaller facilities. In addition, having more case managers who specialize in the care of HIV/AIDS (there is only one case manager in Fargo who can help enroll patients in Ryan White funding, and the person is unable to follow up with other services) would help patients to coordinate their care better. Social work, nutrition services, and support groups for positive patients are difficult to find in Fargo.

Services needed. Services that the providers wish were more readily available included more HIV/AIDS support groups, a pharmacist who specializes in HIV/AIDS care, more social workers who specialize in HIV/AIDS care, dental care, psychiatric care, and comprehensive case management. Having case management services would help facilitate care for all of the HIV/AIDS patients.

Table 3
Key Informant Interviews

Services	Services to Help Bridge the Gap
Services most Beneficial at Diagnosis	<ul style="list-style-type: none"> • Case Management • Financial Assistance • Primary Care Provider/Services
Information Most Beneficial at Initial Diagnosis	<ul style="list-style-type: none"> • Educational Materials • Information with Local Resources
Services Needed	<ul style="list-style-type: none"> • Case Management • Support Groups • Pharmacy Specialist
Difficult Services to Access	<ul style="list-style-type: none"> • Case Management • Health Insurance • Specialty Services • Rural Medical Services
Services Needed	<ul style="list-style-type: none"> • Case Management • Support Groups • Dental Care

HIV/AIDS Services Available in Fargo, North Dakota Region

Phase two of the current project examined the current services available in the Fargo, ND region. To determine accessibility of these services for patients in the Fargo region, a resource list was generated to list the available services (Figure 2).

The kind of services offered depends on the type of facility. Services include: primary care, infectious disease, specialty care, social workers, case management, dietician, pharmacy, counseling, interpretive services, dermatologists with cosmetics, optometry,

audiology, physical therapy, occupational therapy, and oral surgery. There was no one site that offered all of the prior-listed services, however, the nonprofit organization and the government-run organization offered most of the services for the HIV/AIDS population.

Several dental facilities were identified that offer services to those who are covered by Medicaid insurance plans. A dentist who specializes in the care of HIV/AIDS was not identified, but several facilities can provide services to this population at little to no cost.

Sanford Health System – 801 Broadway-Fargo, ND 58102 701.234.2000		
☼ Primary Care	☼ Infectious Disease	☼ Specialty Services
☼ Social Workers	☼ Dietician Services	☼ STD & HIV Testing
☼ Pharmacy Services	☼ Counseling Services	☼ Interpretive Services
☼ Dermatology	☼ Eye Care Services	☼ Hearing Services
☼ Physical Therapy	☼ Occupational Therapy	☼ Dental Services
Essentia Health System – 3000 32 nd Ave S- Fargo, ND 58103 701.364.8900		
☼ Primary Care	☼ Infectious Disease	☼ Specialty Services
☼ Social Workers	☼ Dietician Services	☼ STD & HIV Testing
☼ Pharmacy Services	☼ Counseling Services	☼ Interpretive Services
☼ Dermatology	☼ Eye Care Services	☼ Hearing Services
☼ Physical Therapy	☼ Occupational Therapy	
Veterans Affairs Administration– 2101 N Elm St Fargo, ND 58102 701.451.4600		
☼ Primary Care	☼ Infectious Disease	☼ Not all Specialty Services
☼ Social Workers	☼ Dietician Services	☼ STD & HIV Testing
☼ Pharmacy Services	☼ Counseling Services	☼ Interpretive Services
☼ Dental Services	☼ Eye Care Services	☼ Hearing Services
☼ Physical Therapy	☼ Occupational Therapy	☼ Government Funding

Figure 2. Quick Guide to HIV Care and Services in Fargo, ND.

Fargo Public Health – 200 3rd St. N-Fargo, ND 58102
701.241.1310

- ☼ Walk in Care
- ☼ Sliding Scale Fee
- ☼ Interpretive Services
- ☼ Free Rapid Testing
- ☼ only Ryan White Case Manager in Fargo Area
- ☼ Referrals
- ☼ Ryan White Funding Application

Family Health Care Center – 306 4th St N-2nd Floor-Fargo, ND 58102
701.271-3344

- ☼ General Healthcare
- ☼ Counseling Services
- ☼ Pharmacy Services
- ☼ STD & HIV Testing
- ☼ Sliding Scale Fees
- ☼ Dental Services
- ☼ Referrals
- ☼ Interpretive Services
- ☼ Eye Care Services

North Dakota State University – 1707 Centennial Blvd.- Fargo, ND 58102
701.231.8560

- ☼ Walk-in Care
- ☼ STD & Rapid Testing
- ☼ Referrals

North Dakota Department of Health – 2635 E Main Ave-Bismarck, ND 58506
701.328.2378

- ☼ Case Management
- ☼ Drug Assistance Program
- ☼ Outpatient Services: Non-Hospital Medical Costs
- ☼ Supportive Services: Transportation for Appointments and Counseling
- ☼ Emergency Funding: Short-Term Financial needs-\$500 Annually

Minnkota Health Project - Minnesota
218.286.4636

- ☼ Support Groups
- ☼ Food Program
- ☼ Client Advocacy
- ☼ Social Activities

Figure 2. Quick Guide to HIV Care and Services in Fargo, ND (continued).

North Dakota HIV/AIDS Hotline
1.800.70.NDHIV (1.800.706.3448)

☼ HIV/AIDS-Related Questions for North Dakota Residents

National HIV/AIDS Hotline
1.800.CDC.INFO

☼ HIV/AIDS-Related Questions

OraQuick In Home HIV test kit
1.866.436.6527
www.oraquick.com

☼ Rapid HIV Test at home ☼ Positive Results Indicate Further Testing: Call Toll-free Number for Support Services, for Local Providers, and for Help with Treatment Options

Facilities Offering Dental Services to Medicaid Patients

- ☼ Family Healthcare Center-Fargo, ND/Moorhead, MN
- ☼ Apple Dental-Hawley, MN/Fergus Falls, MN/Moorhead, MN
- ☼ Sanford Health-Fargo (Oral Surgery Services Only)
- ☼ Red River Dental Access-Moorhead, MN (Emergency Services Only)
- ☼ Community Dental Clinic-M State Community & Technical College-Moorhead, MN
- ☼ Caring Hands Dental Clinic-Alexandria, MN (Patients Older than 2 Years Old)
- ☼ Gentle Dentistry-Alexandria, MN
- ☼ Fergus Falls Dental Group-Fergus Falls, MN (Disabled Patients Only)
- ☼ Dr Stephen Whoolery-Fergus Falls, MN (Children Younger than 10 Years Old)
- ☼ Perham Family Dentistry-Perham, MN
- ☼ Dr Brooke Hamann-Perham, MN
- ☼ Chokio Dental Clinica-Chokio, MN
- ☼ Dr Michael Marchetti-Wheaton, MN

Figure 2. Quick Guide to HIV Care and Services in Fargo, ND (continued).

CHAPTER FIVE. DISCUSSION AND RECOMMENDATIONS

Overview of Results

A key factor in decreasing the transmission of HIV/AIDS involves timely linkages to care, including early diagnosis as well as connection to HIV/AIDS-related care, services, and further education (Garland et al., 2011). It is clear that community involvement enriches the effectiveness of a range of biomedical and behavioral HIV/AIDS interventions. HIV/AIDS-affected communities need to take control of the epidemic occurring within their communities (Campbell & Cornish, 2010). Challenges to access HIV/AIDS-related care in North Dakota are further compounded by the lack of services available due to the relatively low regional prevalence rates of HIV/AIDS. A lack of services and specialty providers may lead to fragmented care for patients in this region.

The participants revealed that comprehensive case management is vital to getting patients bridged right into the healthcare system after diagnosis, putting them in contact with the providers they need as well as providing information about services available within the area. Having case managers to help incorporate the community services available to the HIV/AIDS patients will help focus on health promotion for individuals diagnosed with the virus, and for individuals who are negative status, it will help focus on the community's prevention techniques.

For prevention tactics and further spread of disease, some states have incorporated needle exchange sites that are a safe zone for intravenous drug users to come and exchange their contaminated needles for clean needles. Having needle exchange sites for high-risk populations to exchange their needles helps in the reduction of transmission because they are going to use intravenous drugs anyway. Offering new, sterile needles is a way to

prevent the spread of HIV/AIDS to those individuals who are engaging in the high risk activities.

Having case managers who know what services to get connected with will help patients utilize the services that already exist in Fargo. Having someone who knows what services to get patients connected with would help facilitate care for the patient and would help keep patients retained in care. Retaining patients in care will help them to stay compliant with their medication regimens, keep viral loads suppressed, and help stop the progression of the disease. Case managers could assist patients to connect with the services specific to managing symptoms of the disease as well as manage the side effects from the medication regimen. This could include medical service providers, such as infectious disease to specifically manage the HIV/AIDS diagnosis. A primary care provider will manage health promotion, disease progression, and major/minor ailments that may occur. Access to a dietician can aid the patient by helping them to maintain a healthy diet, a healthy weight, and choosing the appropriate nutrition to avoid complications such as wasting syndrome in the affected patient. Access to mental health services is essential for those adjusting to this new diagnosis or who need mental health services on a maintenance level. A pharmaceutical specialist could aid the patient by consulting with them to discuss medication regimen and any side effects they may be experiencing. Referrals to dermatology will help manage chronic skin lesions often associated with the HIV/AIDS virus. These, along with many more services could be better utilized if someone was available to provide information about the facilities and services available and help the patient access these services.

Interpretation of Results

A key factor in decreasing the transmission of HIV/AIDS involves timely linkages to care, including early diagnosis as well as connection to HIV/AIDS-related care, services, and further education (Garland et al., 2011). Clearly community involvement enriches the effectiveness of a range of biomedical and behavioral HIV/AIDS interventions.

HIV/AIDS-affected communities need to take control of the epidemic that is occurring (Campbell & Cornish, 2010). Challenges to access HIV/AIDS-related care in the region of Fargo, ND are further compounded by the lack of services available. The under-utilization of services could be related to the low regional prevalence rates of HIV/AIDS. Facilities throughout Fargo appear to have all the required services to provide comprehensive care for those who need it.

Limitations

This project has several limitations. First, the small sample size limits the generalizability of the projects findings. However, the intent of qualitative methods is not to maximize the ability to generalize the findings but, rather, to provide more in-depth understanding of a particular issue. A larger sample size would have strengthened the project findings, however the sample size is reflective of the low prevalence of HIV/AIDS in North Dakota.

Second, all project participants were from the eastern part of North Dakota and the Fargo region. Efforts to recruit participants from other areas of the state were not successful. In addition, key informants were providers who practice exclusively in the eastern part of the state. Including participants from other areas of North Dakota may have

provided insights about the statewide issues, rather than limiting the findings to the Fargo region.

Application of Theory

The precede-proceed model is a relevant framework for evaluating the services available to the HIV/AIDS population. Educating not only the patients, families, community, and providers, but the community of providers is where the step of prevention comes in to play. Education alone is not enough, so in doing this practice improvement project, findings were used to link the community services available and those deemed most beneficial to the patients, creating a guide for patients and providers to use. Improving the entry of HIV/AIDS patients into the healthcare system will help support health promotion efforts. Working on treatment adherence and staying healthy will help prevent further HIV/AIDS complications from arising.

HIV/AIDS is a community disease that could affect many people. If affected individuals are not in care receiving treatment with suppressed viral loads, they have a higher chance of spreading the virus to other individuals engaging in high risk behaviors. Streamlining patients into care and retaining them so that they are educated about their disease and the extreme importance of medication adherence are vital. When patients get frustrated with their care and do not want to see the provider, the problem magnifies. Patients need to be comfortable with their provider, and they need to focus on staying healthy with health-promotion methods such as avoiding illnesses, the importance of good nutrition, healthy lifestyle choices, mental-health care, and primary-care services to prevent further diseases from occurring.

The precede portion of the model focuses on the community identifying the need in which a change is to occur to help/hinder services. The community needs to determine how changing the way in which HIV/AIDS services are represented and how care is provided will help determine the quality of life. Is the change worth it? Next, the community needs to decide how to make the change work (how to incorporate more case managers to provide better comprehensive, collaborated care). Finally, the community needs to determine what factors support this intervention. Is there enough of an HIV/AIDS patient population, along with enough need, for this change to occur?

Although North Dakota continues to be at the bottom of incidence rates for HIV/AIDS, the state is rapidly changing. The influx of people to the western part of the state makes education about HIV/AIDS and access to services imperative in order to prevent disease transmission and to provide treatment for people who already infected.

Recommendations for Further Research

Further research could be aimed at trying to expand the project to include a larger sample size. Also, the addition of participants from the entire state would allow for a broader base of information to be included. A broader participant base would gain more insight about the care that is available to people in the western part of the state. Living in a rural state, patients have to travel longer distances to receive care, and fewer service providers may be available.

Implications for Advanced Nursing Practice

Advanced practice nurses, have the professional obligation to facilitate treatment and to provide evidence-based care for patients as well as to work with other disciplines to provide cohesive and coordinated care. This practice improvement project was able to

evaluate the services available to individuals living with HIV/AIDS in the Fargo area. The findings of this project will help improve care from the advanced practice nurse by analyzing health care from the patient's and provider's perspective. Revealing the services that the patients perceive to be necessary will help to improve the quality of care that is given by the provider and will, hopefully, increase patient satisfaction as well as improve retention and compliance rates among patients.

Dissemination

I have had several HIV/AIDS training sessions that have allowed me to disseminate my preliminary findings to various members of the healthcare team. This includes infectious disease providers, nurses, social workers, case managers, and dietitians. I attended Mountain Plains AIDS Education training sessions in both Colorado and Utah where my practice improvement project was discussed along with the preliminary findings that had been discovered to that point. I attended the North Dakota Pharmacology Conference last fall and was able to share my preliminary findings with nurse practitioners from across the state.

Opportunities to disseminate the findings on North Dakota State University campus, allowed me to share my findings and discuss the theoretical framework of the precede-proceed model, along with its role in the community prevention of HIV/AIDS to college-aged individuals. The precede-proceed model also has a role for community members to participate and provides availability of programs and services to utilize if virus contraction occurs. I attended a Brown Bag Seminar at the Memorial Union and was part of a discussion on sexually transmitted diseases, and I also spent time at the student wellness center to discuss community involvement at the campus level.

When disseminating my findings, reactions were perceived in a variety of ways. Healthcare professionals were not surprised by the finding that a necessary element to care and retention of HIV/AIDS positive patients includes the need for more involved case management services. A variety of disciplines involved in the care of HIV/AIDS patients agreed with the findings that having someone to help facilitate and coordinate care would help retain patients in care. Reactions of some of the smaller facilities asked how they could get ahold of the HIV/AIDS quick guide because they were unaware of what they would need to do in the event that they had someone test positive for HIV/AIDS. Students at the NDSU wellness center as well as students at the Brown Bag Seminar made comments in regards to still not believing HIV/AIDS exists in North Dakota.

Conclusion

Unlike other chronic diseases, HIV/AIDS has never been purely a medical issue; it is a social issue; a political issue; a cultural issue; an economic issue; and perhaps, above all, a personal issues, which invites stigma. People living with HIV/AIDS face social stigmas, discrimination, health concerns, and psychological issues, which have an immeasurable impact on their ability to deal with life and life satisfaction.

Data support what the key informants feel are lacking in regards to services and where patients fall through the cracks. The data supports that patients feel the fragmented services are the same areas in which the patients feel they get lost in the system. Evidence supports the assumption that there are holes in the current healthcare system and that, in order to decrease the spread of this virus, and to ensure quality of care for HIV/AIDS patients, the gaps need to be “bridged.” With North Dakota lacking the infrastructure to fill the gap, it is up to the communities to step up and force a change. The needs have been

identified for which the community now needs to address. In the community of Fargo, the first step would be to start educating the community about prevention and how the virus is spread. If a community member already has the virus a focus on health promotion and further disease progression.

REFERENCES

- Advancing HIV prevention: New strategies for a changing epidemic-United States. (2003). *Morbidity and Mortality Weekly Report*, 52(15) 329-332.
- Bashook, P. G., Linsk, N. L., Jacob, B. A., Aguado, P., Edison, M., Rivero, R., Schechtman, B., & Prabhugate, P. (2010). Outcomes of AIDS education and training center HIV/AIDS skill building workshops on provider practices. *AIDS Education and Prevention*, 22(1) 49-60.
- Beduk, T., Ulnu, H., & Duyan, V. (2011). AIDS knowledge and risky sexual behaviors among registered female sex workers in Turkey. *Turkey Journal of Medical Science*, 4 (3) 521-531.
- Campbell, C., & Cornish, F. (2010). Community mobilization supplementary issue towards a “fourth generation” of approaches to HIV/AIDS management: Creating contexts for effective community mobilization. *AIDS Care*, 22(2) 1569-1579.
- Center for Disease Control and Prevention. (2006). Epidemiology of HIV/AIDS-United States, 1981-2005. *MMWR*, 5 (2) 589-592.
- Center for Disease Control and Prevention. (2011). Retrieved from: <http://www.cdc.gov/>
- Chiou, P. Y., Kuo, B. I. T., Lee, M. B., Chen, Y. M., Chuang, P., & Lin, L. C. (2006). A programme of symptom management for improving quality of life and drug adherence in HIV/AIDS patients. *Journal of Advanced Nursing*, 55(2) 169-179.
- Cichocki, M. (2009). *How do doctors prevent HIV transmission during pregnancy?* Retrieved from: <http://aids.about.com/od/hivprevention/f/verticaltrans.htm>

- Davis, M. J. & Niebes-Davis, A. J. (2010). Ethnic differences and influence of perceived future certainty on adolescent and young adult sexual knowledge and attitudes. *Health, Risk, & Society, 12*(2) 149-167.
- De Cock, K. M., Jaffe, H. W., & Curran, J. W. (2011). Reflections on 30 years of AIDS. *Emerging Infectious Diseases, 17*(6) 1044-1048.
- Diffenbach, C. W., & Fauci, A., S. (2011). Thirty Years of HIV and AIDS: Future Challenges and Opportunities. *Medicine and Public Issues, 154*(11) 766-770.
- Eldred, L., & Malitz, F. (2007). Introduction. *AIDS patients care and STDs, 21*(1), 1-2.
- Garland, P. M., Valverde, E. E., Fagan, J., Beer, L., Sanders, C., Hillman, D., Brady, K, Courogen, M., & Bertolli, J. (2011). HIV counseling, testing and referral experiences of persons diagnosed with HIV who have never entered HIV medical care. *AIDS Education and Prevention, 23*(3) 117-127.
- Goldman, L. & Schafer, A. I. (2011). *Goldman Cecil Medicine*. Philadelphia, PA: Elsevier Saunders.
- Green & Kremer. (1999). Precede-Proceed Model. *Health Promotion and Planning*. Mayfield.
- Green, L. W. & Rabinowitz, P. (2012) Precede-Proceed Tool Box. The University of Kansas. Retrieved from:
http://ctb.ku.edu/en/tablecontents/sub_section_main_1008.aspx
- HIV/AIDS. (2009) Clinical Progression of HIV. *National Institute of Allergy and Infectious Diseases*. Retrieved from:
<http://www.niaid.nih.gov/topics/HIVAIDS/Understanding/Biology/page>
- Kaiser Family Foundation (2009) Ryan White Funding.

Merriam-Webster online dictionary. Retrieved from:

<http://www.merriam-webster.com/medical>

Mountain Plains Aids and Education Center (MPAEC, 2011) Conference training seminar attended November 2011.

Namakhoma, I., Bongololol, G., Bello, G., Nyirenda, L., Phoya, A., Phiri, S., Theobald, S., & Obermeyer, C., (2010) Negotiating multiple barriers: Healthcare workers access to counseling, testing, and treatment in Malawi. *AIDS Care*. 22 (1) p 68-76.

Neimark, J. (2011). The end of AIDS. *Discover*, 3 (8) 42-50.

North Dakota Department of Health. (2011). Retrieved from:

<http://www.ndhealth.gov/Disease/NewsLetters/EpiArchives/QTR1-11.pdf>

North Dakota Epidemiologic Profile. (2008). Retrieved from:

<http://www.ndhealth.gov/HIV/HIV%20Data/Epi%20Profile%202009.pdf>

North Dakota HIV/AIDS Resources. (2009). United States Centers for Disease Control and Prevention in partnership with the North Dakota Department of Health.

Rhodes, S. D., Malow, R. M., & Jolly, C. (2010). Community-Based participatory research: A new and not so new approach to HIV/AIDS prevention/care and treatment. *AIDS Education and Prevention*, 22(3) 173-183.

Rowan, D. M. & Honeycutt, J. (2010). The impact of the Ryan White treatment modernization act of social work within the field of HIV/AIDS service provision. *Health and Social Work*, 35(1) 71-74.

- Shindel, A. W., Horberg, M. A., Smith, J. F., & Breyer, B. N. (2011). Sexual dysfunction, HIV, and AIDS in men who have sex with men. *AIDS patient care and STDs*, 25(6) 341-349.
- Thomas, F., Aggleton, P. & Anderson, J. (2010) "If I cannot access services, then there is no reason for me to test": The impacts of health service charges on HIV testing and treatment among migrants in England. *AIDS Care*, 2 (4) 526-531.
- Thurman, T. R., Haas, L. J., Dushimimana, A., Lavin, B., & Mock, N. (2010). Evaluation of a case management program for HIV clients in Rwanda. *AIDS Care*, 22(6) 759-765.
- Torian, L. V. (2011). HIV-2 Infection Surveillance-United States, 1987-2009. *Morbidity and Mortality Weekly Report*, 6 (29) 985-988.
- United States Census Bureau. (2011). State and county quick facts. Retrieved from: <http://quickfacts.census.gov/qfd/states/38/38017.html>
- World Health Organization. (2011). Retrieved from: <http://www.who.int/en/>

APPENDIX A. EXECUTIVE SUMMARY

It is estimated that between 252,000 and 312,000 people in the United States are unaware that they are infected with HIV/AIDS and are unaware of their risk for HIV/AIDS transmission to other people (CDC, 2006). Therefore one in five persons in the United States are unaware of their infection status (CDC, 2006). Placed near the bottom in incidence, North Dakota has 227 cases of HIV/AIDS in the hierarchy of prevalence rates for HIV/AIDS cases in the United States (NDDoH, 2011). Having a small prevalence rate, a lack of cohesive healthcare provider groups is a challenge.

The purpose of this project was to identify the needs of persons newly diagnosed with HIV/AIDS and services available to address their needs in the Fargo, ND region. Bridging the Gap between where these patients go from the point of diagnosis to the next step in care is where there are fragmented services that could be addressed by an established coordination of HIV/AIDS-related services in North Dakota. People who are newly diagnosed with HIV/AIDS need to know where to get started in connected with related healthcare services and those who have lived with HIV/AIDS for years need the continuation of services for disease management.

Six HIV/AIDS positive patients from Fargo, North Dakota were interviewed as well as three key informants in the care of HIV/AIDS patients, and needs were identified based on those interviews. Services that benefit the patient as well as the services that are lacking were identified and then compiled to assess where the fragmentation in care exists. An HIV/AIDS quick care directory guide was then developed in relation to the services available and those recommended to “Bridge the Gap” in North Dakota HIV/AIDS care.

Data results from the HIV/AIDS positive patients as well as from the key informants supports the literature that there are gaps within the healthcare system, such as a lack of HIV/AIDS case managers to help the patients coordinate and facilitate their care. Because North Dakota has so few HIV/AIDS patients, the services are not utilized enough, and specialists in the area of expertise are not able to have the patient population apply its services to stay fluent in the disease.

This practice improvement project will help improve the care given by practitioners by providing a resource guide on managing care for individuals living with HIV/AIDS. Resources and referral information are included in this guide and aid the practitioner to get an individual into the healthcare system as well as how to keep them retained once they are in care. Below is the HIV/AIDS quick guide to resources:

Sanford Health System – 801 Broadway-Fargo, ND 58102 701.234.2000		
<ul style="list-style-type: none"> ☼ Primary Care ☼ Social Workers ☼ Pharmacy Services ☼ Dermatology ☼ Physical Therapy 	<ul style="list-style-type: none"> ☼ Infectious Disease ☼ Dietician Services ☼ Counseling Services ☼ Eye Care Services ☼ Occupational Therapy 	<ul style="list-style-type: none"> ☼ Specialty Services ☼ STD & HIV Testing ☼ Interpretive Services ☼ Hearing Services ☼ Dental Services

Essentia Health System – 3000 32nd Ave S- Fargo, ND 58103 701.364.8900		
<ul style="list-style-type: none"> ☼ Primary Care ☼ Social Workers ☼ Pharmacy Services ☼ Dermatology ☼ Physical Therapy 	<ul style="list-style-type: none"> ☼ Infectious Disease ☼ Dietician Services ☼ Counseling Services ☼ Eye Care Services ☼ Occupational Therapy 	<ul style="list-style-type: none"> ☼ Specialty Services ☼ STD & HIV Testing ☼ Interpretive Services ☼ Hearing Services

Veterans Affairs Administration– 2101 N Elm St Fargo, ND 58102
701.451.4600

- | | | |
|---------------------|------------------------|------------------------------|
| ☼ Primary Care | ☼ Infectious Disease | ☼ Not all Specialty Services |
| ☼ Social Workers | ☼ Dietician Services | ☼ STD & HIV Testing |
| ☼ Pharmacy Services | ☼ Counseling Services | ☼ Interpretive Services |
| ☼ Dental Services | ☼ Eye Care Services | ☼ Hearing Services |
| ☼ Physical Therapy | ☼ Occupational Therapy | ☼ Government Funding |

Fargo Public Health – 200 3rd St. N-Fargo, ND 58102
701.241.1310

- | | | |
|-------------------------|-------------------------|----------------------|
| ☼ Walk in Care | ☼ Free Rapid Testing | ☼ Referrals |
| ☼ Sliding Scale Fee | ☼ only Ryan White Case | ☼ Ryan White Funding |
| ☼ Interpretive Services | ☼ Manager in Fargo Area | ☼ Application |

Family Health Care Center – 306 4th St N-2nd Floor-Fargo, ND 58102
701.271-3344

- | | | |
|-----------------------|----------------------|-------------------------|
| ☼ General Healthcare | ☼ STD & HIV Testing | ☼ Referrals |
| ☼ Counseling Services | ☼ Sliding Scale Fees | ☼ Interpretive Services |
| ☼ Pharmacy Services | ☼ Dental Services | ☼ Eye Care Services |

North Dakota State University – 1707 Centennial Blvd.- Fargo, ND 58102
701.231.8560

- | | | |
|----------------|-----------------------|-------------|
| ☼ Walk-in Care | ☼ STD & Rapid Testing | ☼ Referrals |
|----------------|-----------------------|-------------|

North Dakota Department of Health – 2635 E Main Ave-Bismarck, ND 58506
701.328.2378

- ☼ Case Management
- ☼ Drug Assistance Program
- ☼ Outpatient Services: Non-Hospital Medical Costs
- ☼ Supportive Services: Transportation for Appointments and Counseling
- ☼ Emergency Funding: Short-term Financial Needs-\$500 Annually

Minnkota Health Project - Minnesota
218.286.4636

- ☼ Support Groups
- ☼ Client Advocacy
- ☼ Social Activities
- ☼ Food Program

North Dakota HIV/AIDS Hotline
1.800.70.NDHIV (1.800.706.3448)

- ☼ HIV/AIDS-Related Questions for North Dakota Residents

National HIV/AIDS Hotline
1.800.CDC.INFO

- ☼ HIV/AIDS-Related Questions

OraQuick In Home HIV test kit
1.866.436.6527
www.oraquick.com

- ☼ Rapid HIV Test at home
- ☼ Positive Results Indicate Further Testing: Call Toll-free Number for Support Services, for Local Providers, and for Help with Treatment Options

Facilities Offering Dental Services to Medicaid Patients

- ☼ Family Healthcare Center-Fargo, ND/Moorhead, MN
- ☼ Apple Dental-Hawley, MN/Fergus Falls, MN/Moorhead, MN
- ☼ Sanford Health-Fargo (oral surgery services only)
- ☼ Red River Dental Access-Moorhead, MN (Emergency services only)
- ☼ Community Dental Clinic-M State Community & Technical College-Moorhead, MN
- ☼ Caring Hands Dental Clinic-Alexandria, MN (patients older than 2years old)
- ☼ Gentle Dentistry-Alexandria, MN
- ☼ Fergus Falls Dental Group-Fergus Falls, MN (disabled patients only)
- ☼ Dr Stephen Whoolery-Fergus Falls, MN (children younger than 10 years old)
- ☼ Perham Family Dentistry-Perham, MN
- ☼ Dr Brooke Hamann-Perham, MN
- ☼ Chokio Dental Clinica-Chokio, MN
- ☼ Dr Michael Marchetti-Wheaton, MN

APPENDIX B. PERMISSION TO USE PRECEDE-PROCEED MODEL

Preceed Proceed Model

Lawrence Green [lwgreen@comcast.net]

Actions

To: Leah Spicer

Cc: Marshall Kreuter [mkreuter122@comcast.net]

Thursday, April 05, 2012 6:10 PM

Dear Ms Spicer,

I'm a big fan of Nurse Practitioners and have one for most of my primary care. Good luck in your training and in your doctoral research project. Of course you should adapt the model, as everyone does, to fit the particulars of your population and circumstances. You'll find a searchable bibliography of over 1000 published applications of the model on www.lgreen.net, click on bibliography. Other resources for working with the Precede-Proceed model are on this website and in the 4th edition of our textbook, Green & Kreuter, *Health Program Planning: An Educational and Ecological Approach*, New York: McGraw-Hill, 2005. Let me know if we can be of further help. --Larry Green

Lawrence Green

Professor, Dept of Epidemiology & Biostatistics

School of Medicine

University of California at San Francisco

& Clinical Translational Science Institute

& Helen Diller Comprehensive Cancer Center

& Center for Tobacco Research & Education

web: www.lgreen.net; www.epi.ucsf.edu

e-mail: lwgreen@comcast.net

APPENDIX C. HIV/AIDS PATIENT CONSENT

NDSU

NORTH DAKOTA STATE UNIVERSITY

*Department of Nursing
College of Pharmacy, Nursing, and Allied Sciences
NDSU Dept. 2670
136 Sudro Hall, P.O. Box 6050
Fargo, ND 58108-6050
701.231.7395*

Title of Research Study: “I am AIDS” – Bridging the gap

This study is being conducted by:

Dr. Molly Secor-Turner, PhD, RN
molly.secor-turner@ndsu.edu
(701) 231-7517

Leah Brewster, RN (DNP Student)
leah.brewster@ndsu.edu
(218)791-2030

Why am I being asked to take part in this research study?

You are being asked to participate in this research study because you have been diagnosed with HIV/AIDS and are receiving medical care within the state of North Dakota.

What is the reason for doing the study?

The purpose for this study is to examine and understanding the experience of accessing services community-based services to persons diagnosed with HIV/AIDS in the state of North Dakota.

What will I be asked to do? And What Information will be collected about me?

If you decide to participate in this study, you will be asked to answer several questions in regards to your experience within the North Dakota health care system since being diagnosed with HIV/AIDS. They will simply be questions about what you feel you have benefited from and what services you feel are lacking in North Dakota.

Where is the study going to take place, and how long will it take?

The study will be conducted at a mutually agreed upon location that is private and confidential. If you agree to participate in the research, it will take about 15-30 minutes of your time to answer the questions.

What are the risks and discomforts?

The interview will be directed at issues related to service provision for HIV/AIDS care in North Dakota. However, you may experience emotional distress or discomfort in answering some of the questions. If this should occur, you may stop the interview at any point and referral for counseling is available.

What are the benefits to me?

There are no direct benefits to participating in this study. By collecting this data, it is the intent of the researcher to improve the quality of care for the HIV/AIDS patients within the North Dakota health care systems.

What are the benefits to other people?

By collecting this data, it is the intent of the researcher that people who have been diagnosed with HIV/AIDS will benefit from the data collected as to improve quality of care for the HIV/AIDS patients within the North Dakota health care systems.

Do I have to take part in the study?

Your participation in this research is strictly voluntary. If you decide to participate in the study, you may change your mind and stop participating at any time without penalty or loss of benefits to which you are already entitled. You may also wish to only answer the questions that you feel comfortable answering.

What are the alternatives to being in this research study?

Instead of being in this research study, you can choose not to participate.

Who will see the information that I give?

Only the study team will see any and all of the information collected. However, all data will still be confidential and will be stored on a password projected computer with a password protected file that is current and up to date with the most recent antiviral software and firewall protection in accordance with NDSU’s ITS standards. No identifying information will be collected and no information will be attached to the forms at the time of collection that will identify the participants. Information will be kept confidential and will be destroyed after three years of the completion of the study. All data collected will be compiled and summarized. No individual responses will be noted in the final results.

Will I receive any compensation for taking part in this study?

If you choose to participate in this study, you will be given a \$10.00 gift card to as a token of appreciation for their time for participating.

What if I have questions?

Before you decide whether to accept this invitation to take part in the research study, please ask any questions that might come to mind now. Later, if you have any questions about the study, you can contact the researcher, Dr Molly Secor-Turner at (701) 231-7517.

What are my rights as a research participant?

You have rights as a participant in research. If you have questions about your rights, or complaints about this research you may talk to the researcher or contact the NDSU Human Research Protection Program by:

- Telephone: 701.231.8908
- Email: ndsu.irb@ndsu.edu
- Mail: NDSU HRPP Office, NDSU Dept. 4000, PO Box 6050, Fargo, ND 58108-6050.

The role of the Human Research Protection Program is to see that your rights are protected in this research; more information about your rights can be found at: www.ndsu.edu/research/irb .

Documentation of Informed Consent:

You are freely making a decision whether to be in this research study. Signing this form means that

1. you have read and understood this consent form
2. you have had your questions answered, and
3. you have decided to be in the study.

You will be given a copy of this consent form to keep.

Your signature

Date

Your printed name

Signature of researcher explaining study

Date

Printed name of researcher explaining study

APPENDIX D. HIV/AIDS PATIENT QUESTIONNAIRE

1. What age group are you in?
[20-29] [30-39] [40-49] [50-59] [60-69] [70-79] [80-89] [90-99]
2. How old were you when you were diagnosed?
3. What state were you diagnosed in?
4. What services did you find the most beneficial when you were diagnosed?
5. What information did you feel you needed the most at diagnosis?
6. What information/services do you wish you had available when you were first diagnosed?
7. What was your biggest barrier to services at the time of diagnosis?
8. What are the most important services that you feel you need to live with this chronic disease?
9. What services are the hardest to access on a routine basis?
10. What services aren't available that you wish were?

APPENDIX E. HIV/AIDS KEY INFORMANT CONSENT

NDSU

NORTH DAKOTA STATE UNIVERSITY

*Department of Nursing
College of Pharmacy, Nursing, and Allied Sciences
NDSU Dept. 2670
136 Sudro Hall, P.O. Box 6050
Fargo, ND 58108-6050
701.231.7395*

Title of Research Study: “I am AIDS” – Bridging the gap

This study is being conducted by:

Dr. Molly Secor-Turner, PhD, RN
molly.secor-turner@ndsu.edu
(701) 231-7517

Leah Brewster, RN (DNP Student)
leah.brewster@ndsu.edu
(218)791-2030

Why am I being asked to take part in this research study?

You are being asked to participate in this research study because you provide services for persons infected with HIV/AIDS in the upper Midwest.

What is the reason for doing the study?

The purpose of this study is to examine and understand the experience of accessing community-based services for persons diagnosed with HIV/AIDS and for service providers.

What will I be asked to do? And What Information will be collected about me?

If you decide to participate in this study, you will be asked to participate in an interview either in person, by telephone, or via email. The interview will ask you questions about the challenges and supports to accessing comprehensive services for HIV/AIDS in the upper Midwest.

Where is the study going to take place, and how long will it take?

The study will be conducted either via telephone or email correspondence once written consent has been obtained. If you agree to participate in the research, it will take about 15-30 minutes of your time to answer the questions.

What are the risks and discomforts?

The interview will be directed at issues related to service provision for HIV/AIDS care in the upper Midwest. Risks involved in participating are that discussing HIV/AIDS care could make you feel uncomfortable and if you chose not to answer a question, you may skip it or chose to terminate the questionnaire at any point.

What are the benefits to me?

There are no direct benefits to participating in this study. By collecting this data, it is the intent of the researcher to improve the quality of care for the HIV/AIDS patients within the North Dakota health care systems.

What are the benefits to other people?

By collecting this data, it is the intent of the researcher that people who have been diagnosed with HIV/AIDS as well as providers to this medical population will benefit from the data collected as to improve quality of care for the HIV/AIDS patients within the North Dakota health care systems.

Do I have to take part in the study?

Your participation in this research is strictly voluntary. If you decide to participate in the study, you may change your mind and stop participating at any time without penalty or loss of benefits to which you are already entitled. You may also wish to only answer the questions that you feel comfortable answering.

What are the alternatives to being in this research study?

Instead of being in this research study, you can choose not to participate.

Who will see the information that I give?

Only the study team will see the information collected. All data are confidential and will be stored on a password protected computer with a password protected file that is current and up to date with the most recent antiviral software and firewall protection in accordance with NDSU’s ITS standards. No identifying information will be collected and no information will be attached to the forms at the time of collection that will identify the participants. Information will destroyed after three years of the completion of the study. All data collected will be compiled and summarized. No individual responses will be noted in the final results.

Will I receive any compensation for taking part in this study?

There is no direct compensation involved in participating as a key informant for this study.

What if I have questions?

Before you decide whether to accept this invitation to take part in the research study, please ask any questions that might come to mind now. Later, if you have any questions about the study, you can contact the researcher, Dr Molly Secor-Turner at (701) 231-7517 or the co-investigator Leah Brewster at (218) 791-2030.

What are my rights as a research participant?

You have rights as a participant in research. If you have questions about your rights, or complaints about this research you may talk to the researcher or contact the NDSU Human Research Protection Program by:

- Telephone: 701.231.8908
- Email: ndsu.irb@ndsu.edu
- Mail: NDSU HRPP Office, NDSU Dept. 4000, PO Box 6050, Fargo, ND 58108-6050.

The role of the Human Research Protection Program is to see that your rights are protected in this research; more information about your rights can be found at: www.ndsu.edu/research/irb .

Documentation of Informed Consent:

You are freely making a decision whether to be in this research study. Signing this form means that

4. you have read and understood this consent form
5. you have had your questions answered, and
6. you have decided to be in the study.

You will be given a copy of this consent form to keep.

Your signature

Date

Your printed name

Signature of researcher explaining study

Date

Printed name of researcher explaining study

APPENDIX F. HIV/AIDS KEY INFORMANT QUESTIONNAIRE

1. About how many patients do you treat with the diagnosis of HIV/AIDS?

2. What services do you feel are most beneficial when a patient is diagnosed?

3. What information do you feel is essential for them to have initially?

4. What services do you feel are vital for them to be retained in care?

5. What services do you feel are hardest to access in the state of ND?

6. What services aren't available that you wish were to your patients?

7. Have you worked in other states in which you can compare ND services to?