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An Investigation on HIV Related Stigma to Improve HIV Prevention Efforts in North Dakota

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An Investigation of HIV Related Stigma to Improve HIV Prevention Efforts in North Dakota

By

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Abstract

An Investigation on HIV Related Stigma to Improve HIV Prevention Efforts in North Dakota.

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This study examines HIV stigma to improve HIV prevention in North Dakota. A survey was administered to North Dakotan adults between January 15 and February 15, 2011, in eight selected towns. The study focused on North Dakotan perceptions of HIV in their state. Research found that most North Dakotans do not view HIV as a problem in their state. There is, however, a belief that there is stigma associated with HIV in North Dakota, as 65 percent of survey respondents believe that. The study also shows that there is a need for education regarding the transmission of HIV. Sixty percent of respondents did not identify all four modes of HIV transmission correctly. The results of this survey will be used to improve HIV education in North Dakota.

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Chapter 1

INTRODUCTION

Statement of the Problem

Human Immunodeficiency Virus (HIV) has existed in the United States since at least the mid to late 1970's. From 1972 – 1981 rare types of pneumonia, cancer and other illnesses were being reported to doctors in Los Angeles and New York in a number of male patients who had sex with other men. These conditions were not normally found in individuals with a healthy immune system (HIV/AIDS Basics, 2010). In 1982, the term Acquired Immunodeficiency Syndrome (AIDS) began being used and in 1983 scientists discovered the virus that caused AIDS (HIV/AIDS Basics, 2010). The first two cases of HIV in North Dakota were reported in 1984 (Birk, et al., 2009).

Stigmatizing someone with HIV is behaving unkindly or insensitively toward him or her. This can have negative affects on his/her health, including mental health (Lynon & D'Angelo, 2006). Stigmatization can lead to avoidance of someone by others. So much of our identity depends on how people react to us, for example, if people avoid you, you wonder what is wrong with you. This can then lead to self-blame and shame in the person being stigmatized (Peck, 1987).

Most individuals with HIV have no visible marks and people do not know who has it just by looking at them. Therefore, HIV positive individuals can be listening to others making negative comments about the disease. This can contribute to HIV positive

individuals decision to whom they can disclose their HIV status safely to and whom to avoid telling (Chervin, et al., 2005).

Stigma and social isolation often co-occur. This can cause depression in HIV positive individuals. It may also decrease the likelihood of the individual seeking treatment, which will negatively affect his/her health. In fact, out of fear of people from their community finding out, many individuals go out of their way to get tested and treated in places where no one knows them (Lynon & D'Angelo, 2006).

Many factors that may contribute to HIV/AIDS related stigma and include:

- HIV/AIDS is a life-threatening disease, and therefore people react to it in strong ways.
- Many people who become infected with HIV through sex may often face blame.
- HIV infection is associated with behaviors and sexual actions (such as homosexuality, drug addiction, prostitution or promiscuity) that are already stigmatized in many societies.
- There is a lot of inaccurate information about how HIV is transmitted, creating irrational behavior and misperceptions of personal risk.
- HIV infection is often thought to be the result of personal irresponsibility.
- Religious or moral beliefs lead some people to believe that being infected with HIV is the result of moral fault that deserves to be punished (HIV & AIDS Stigma and Discrimination, 2010, p. 1).

In the beginning of the HIV/AIDS epidemic, people did not understand the disease and how it was transmitted. Early in the epidemic, hemophiliacs, transfusion recipients, and men who have sex with men (MSM) were the "face" of AIDS sufferers. Over time, the epidemic has changed to include heterosexuals and injection drug users. Even though HIV transmission is still commonly associated with homosexuality and drug use behavior, it is considered largely a heterosexual global epidemic. It remains easy to discredit someone by saying he or she has HIV (Lynon & D'Angelo, 2006).

HIV in North Dakota

North Dakota is a rural state with a population of 642,200, according to the 2000 Unites States Census. There are 356 incorporated communities. Seven cities have populations above 16,000; nine cities have populations above 10,000; 15 cities have populations above 2,500. County populations in North Dakota range from 767 to 123,138 people. Four counties, two along the eastern border with Minnesota, account for 49 percent of the state's population, demonstrating the complexity of population dispersion in North Dakota (United States Census, 2000).

According to the 2000 census, the demographic composition of the population was split almost evenly between males and females. The median age was 36.2 years. The majority of the population was white (92.4%), while African Americans and American Indians comprised 0.6 percent and 4.9 percent, respectively. Table 1.1, describes the demographics of the general population in North Dakota (Birk, et al., 2009).

Table 1.1 – Demographics of General Population	Number	Percentage
Gender		
Male	320,524	49.9
Female	321,676	50.1
Age		
Median age (years)	36.2	N/A
Race/Ethnicity		
White	593,181	92.4
Black or African American	3,916	0.6
American Indian and Alaska Native	31,329	4.9
Asian	3,606	0.6
Native Hawaiian and Other Pacific Islander	230	0.0
Some other race	2,540	0.4
Two or more races	7,398	1.2

Note. Table 1.1 taken from the 2009 North Dakota Epidemiological Profile (Birk, et al., 2009).

HIV cases have been a mandated reportable condition in North Dakota since the first cases were reported in the state in 1984. As of December 31, 2009, a cumulative total of 480 HIV/AIDS cases had been reported in North Dakota. Of the 480 cases, 222 are known to still be living in North Dakota (Birk, et al., 2009). According to the CDC, North Dakota ranks 49th in the United States with an AIDS case rate of 1.3 per 100,000 (HIV Transmission Rates, 2010). Similar state comparisons for HIV are not possible because some states do not require HIV reporting but do require reporting AIDS. Table 1.2 outlines the cumulative cases and those still living with HIV/AIDS in North Dakota (Birk, et al., 2009).

Table 1.2 -- Profile of HIV/AIDS Population

	Cumulative Cases		Living in 2009 ND	
	Number	Percentage*	Number	Percentage*
Disease Status at Diagnosis				
HIV	298	62	112	50
AIDS	182	38	110	50
Gender				
Male	401	84	175	79
Female	79	16	47	21
Age Group at Diagnosis				
< 15	25	5	9	4
15 - 24	86	18	31	14
25 - 34	181	38	87	39
35 - 44	123	26	59	27
45 - 54	49	4	29	13
55 - 64	14	3	7	3
≥ 65	2	<1	0	0
Race/Ethnicity				
American Indian	61	13	29	13
Black	56	12	38	17
Hispanic (all races)	14	3	8	4
Asian/Pacific Islander	2	<1	1	<1
White	359	75	154	69
Risk Factors				
Male to male sexual relations (MSM)	240	50	106	1
Heterosexual relations	105	22	64	33
Injecting drug use (IDU)	20	4	11	10
MSM/IDU	38	8	9	44
Sex with IDU	33	7	12	5
Other	13	3	5	2
No risk identified	31	6	15	1
Total	**480**		**222**	

Note. Table 1.2 taken from the 2009 North Dakota Epidemiological Profile (Birk, et al., 2009).

There are 31 HIV counseling, testing and referral (CTR) sites throughout North Dakota that provide free HIV testing services to individuals at risk. In 2009, just fewer than 3,000 HIV tests were performed at these sites (Birk, et al., 2009). Other HIV tests are provided free of charge to North Dakotans through the North Dakota Public Health Lab (NDPHL). According to the NDPHL, in 2009, their lab conducted 19,130 HIV tests. Free HIV testing is offered in North Dakota because the main purpose of the HIV

prevention program is to test individuals at risk for HIV (Prevention, N.D., 2010) People at risk for HIV often engage in risky behaviors, such as unprotected sexual conduct and injection drug use. By being tested, individuals become aware of their status and can then prevent the transmission of HIV (HIV/AIDS Basics, 2010).

Significance of the Problem

According to the Center for Disease Control (CDC), an estimated 1.1 million Americans are currently living with HIV/AIDS in the United States. This number should continue to rise with the use of Antiretroviral Therapy (ART). The previous life expectancy of an individual living with HIV was less than 10 years, but now individuals with the disease are living well over 20 years and are dying from other chronic diseases (Sax, 2010). As the number of people living with HIV continues to raise, so will the rise in transmission, as there are more people living with it to transmit it to others (HIV Transmission Rates, 2010). When someone is first infected with HIV, they may have no obvious visual signs and symptoms at all. Individuals with or without symptoms can still transmit the disease to others. Some individuals can stay asymptomatic for years before developing more infections or chronic symptoms (HIV/AIDS Basics, 2010).

However, there has been a significant decline in HIV transmission rates since the epidemic began in 1980, when the disease was still undetected. In the beginning, the transmission rate was 92 percent. This means that there were 92 transmissions per 100 persons living with HIV. This rate dropped dramatically in 2006, as there were only 5 transmissions per 100 people living with HIV. This means that 95 percent of people

living with HIV did not transmit the disease to someone else (HIV Transmission Rates, 2010).

Individuals who test positive for the disease may not change their life styles or get treatment and care for the disease for fear of others finding out their HIV status. All individuals who have an HIV positive status should receive care and treatment without shame or disgrace. This feeling of shame can add to depression of people living with HIV and cause self-imposed isolation. For people living with HIV, stigma may not only prevent them from getting proper medical care, but they also may lack proper education on how to prevent transmitting the disease to others (Aggleton, Malcolm, Parker, & Wood, 2005).

Stigma does not affect only people who know their HIV status but also those individuals who are unaware of their status. That is, some individuals are afraid to know their status. The fear comes from the repercussions that may arise if the test is positive (Aggleton, et al., 2005). This is a major reason that many people who get an HIV diagnosis receive an AIDS diagnosis at the same time (HIV/AIDS Basics, 2010) Almost half of the new HIV diagnosis in North Dakota in 2009 received an AIDS diagnosis at first diagnosis (Birk, et al., 2009).

The stigma of HIV/AIDS can hamper efforts to prevent the disease. Individuals who do not know their status could be transmitting the disease to unaware partners. The CDC believes 25 percent of people living with HIV do not know they are positive, and account for 54 percent of the new HIV infections (HIV/AIDS Basics, 2010).

As the prevalence of HIV is unchanged, an increased effort in prevention is needed. In July, 2010 President Obama rolled out the new National HIV Strategy for the United States. The strategy was developed with three main goals 1) reducing HIV incidence, 2) increasing access to care, and, 3) reducing HIV-related health disparities. Incorporated into these goals are several objectives including; reducing stigma and discrimination against people living with HIV and educating all Americans about the threat of HIV and how to prevent it (Kilness, 2010).

HIV stigma and discrimination exists worldwide, and it takes on a different manifestation depending on geographic location and size of the community. According to United Nations Secretary General Ban Ki Moon, *"HIV stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or talking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world"* (HIV & AIDS Stigma and Discrimination, 2010, p. 1). Stigma makes it more difficult for individuals to come to terms with their HIV illness and manage the disease. It can also make individuals reluctant to access testing (HIV & AIDS Stigma and Discrimination, 2010).

As the program manager for the HIV program for the North Dakota Department of Health, I feel there is a need for an increase in knowledge and awareness of HIV in North Dakota. Sandra Tibke, HIV educator for the North Dakota Department of Public Instruction believes there is a need for an increase in HIV education in North Dakota,

especially in schools. Tibke believes that there is still fear, ignorance and community mores that act as barriers to HIV education and prevention in North Dakota (S. Tibke, personal communication, February 10, 2011).

Examining the public's perception of HIV in North Dakota, through a survey, may give insight on how to better the HIV prevention program. By understanding North Dakotan residents' attitudes about being tested for HIV, an initiative to increase testing availability may be needed. These efforts may increase those individuals who are aware of their HIV status and, in return, may decrease the spread of the disease.

The findings of the survey could then be used to decrease stigma surrounding the disease. If HIV testing was viewed as a social norm, there may be an increase in number of individuals tested. Therefore, more individuals would know their status. This paper will serve as an investigation of HIV related stigma and efforts to improve HIV prevention in North Dakota.

Research Questions

The purpose of this study was to investigate HIV related stigma to improve HIV prevention efforts in North Dakota. In this study the research questions were:

1) Do North Dakotan adults view HIV as a problem in their state?

2) Do North Dakotan adults believe there is stigma (the shame or disgrace attached to something regarded as socially unacceptable) associated with HIV in North Dakota?

3) Does the stigma surrounding HIV prevent North Dakotans from being tested?

4) Do North Dakotans understand how HIV is transmitted?

5) Do North Dakotans think they would treat individuals with HIV differently?

6) Have individuals been exposed to HIV prevention messaging in North Dakota?

7) Is there a correlation between North Dakotans who would treat someone differently with HIV and the understanding of how HIV is transmitted?

8) Is there a relationship between North Dakotans who have been tested for HIV and exposure to HIV prevention messaging?

9) What are the reasons North Dakotan's believe there is a stigma associated with HIV in their state?

Limitations

1) North Dakota has a large land mass and is very rural; the survey did not reach all areas of the state.

2) The research provided funding for this project through personal resources.

3) Individuals may have answered the survey questions in a socially desirable way.

4) The sample may not have accurately represented the diversity of residents in North Dakota.

5) Sample selection method did not allow determination of non-respondents.

Delimitations

1) Respondents were over the age of 18 and residents of North Dakota.

2) Data collection was conducted over a one month period.

Assumptions

1) There is a stigma (the shame or disgrace attached to something regarded as socially unacceptable) associated with HIV in North Dakota.

2) The stigma is hindering North Dakotans from getting an HIV test.

3) There are people in North Dakota who are unaware of their HIV status.

4) The individuals who are unaware of their status are engaging in risky behaviors that could spread HIV in the population.

5) Individuals filling out the survey will be honest with their answers.

Definition of Terms

Antiretroviral Treatment (ART). Standard antiretroviral therapy (ART) consists of the use of at least three antiretroviral (ARV) drugs to maximally suppress the HIV virus and stop the progression of HIV disease (HIV/AIDS Basics, 2010).

CD4+ T cells. A type of lymphocyte (white blood cell), which is crucial in helping the body fight off disease (Opportunistic Infections, 2010).

HIV Status. Knowing if you have a positive or negative result on a screening test for HIV antibodies (HIV/AIDS Basics, 2010).

HIV/AIDS Stigma. Refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals or groups associated with which they are associated (Fight AIDS Not People with AIDS, 2011).

Opportunistic Infection. A type of illness developing from the HIV infection (Opportunistic Infections, 2010).

Perinatal Transmission. HIV transmission from mother to child in the womb or at birth (HIV/AIDS Basics, 2010).

Chapter 2

REVIEW OF THE LITERATURE

The purpose of this study was to investigate HIV related stigma in order to improve HIV prevention in North Dakota. This chapter reviews literature including; HIV related stigma around the world, HIV stigma in rural America and rural HIV prevention needs.

HIV Related Stigma around the World

Stigma is the shame or disgrace attached to something regarded as socially unacceptable. Stigma surrounding HIV has been a major barrier to preventing the spread of HIV throughout the world (Aggelton, et al., 2005). The root of HIV stigma may be associated with a lack of education and misunderstanding of the disease. Stigma against the disease will continue until individuals fully understand the mode of transmission. The major factor of HIV related stigma is the disease is an incurable sexually transmitted disease and is also related to drug use, which only adds to the stigmatization. HIV stigma has lead to discrimination of individuals all over the world. Individuals living with HIV have been denied healthcare, work, education, and the freedom of being around those individuals not infected (Aggleton, et al., 2005).

In 2003, residents in 12 villages with former plasma/blood donors in southern Shanxi Province, China were studied. A total of 660 villagers, 18 to 59 years of age were selected randomly from a sampling framework of 9,205 residents in 12 villages. Standardized questionnaire interviews were administered to collect data on participants'

demographic characteristics, medical history and HIV/AIDS knowledge, attitudes and behaviors, including past blood donations. Knowledge about HIV transmission was assessed with seven items focusing on established routes of HIV transmission; sexual intercourse, blood transfusion, sharing a needle, sharing a shaver and transmission during pregnancy. Misconceptions about HIV transmission were measured using five items on risk associated with casual social contacts; shaking hands, sharing meals, speaking face to face, swimming and mosquito bites (Qian, et al., 2007).

A high percentage of respondents (94.8 percent) knew that a person could get HIV from sexual intercourse. Over 96 percent of villagers knew that HIV infection can be acquired from receiving contaminated blood and 93.1 percent identified sharing used needles as mode of transmission. Over 87 percent of participants also knew that an infected mother could transmit HIV to her infant during pregnancy. Over 41 percent of participants believed that HIV infection could be acquired by swimming, 26.5 percent from sharing meals, 24.6 percent from shaking hands and 24 percent from speaking face to face with an infected person; 70.4 percent thought that mosquito bites could transmit HIV (Qian, et al., 2007).

Discriminatory attitudes toward persons with HIV/AIDS were common in these communities. About 80 percent of participants reported that they would not allow their children to play with a child with HIV/AIDS and would not buy fresh vegetables from a stall-keeper with AIDS. Over half said that they would not allow a teacher with HIV to continue teaching in school and would keep away from a neighbor with HIV. About one third of participants said that they would keep away from family members of an HIV-infected person (Qian, et al., 2007).

The AIDS Treatment for Life International Survey (ATLIS), conducted on behalf of the International Association of Physicians in AIDS Care, is the largest, multi-country, comparative, treatment awareness survey of people living with HIV. Between 100 and 200 people living with HIV or AIDS were surveyed in 18 countries, including the United States, to ensure statistically significant sampling (ATLIS, 2008).

A portion of the ATLIS survey addressed concerns and fears about HIV status. Findings from the survey included; 54.4 percent of respondents expressed concern about others knowing their HIV status, with 83 percent of these respondents concerned specifically with social discrimination. There was some concern about repercussions of the disease including disclosing their HIV status, the ability to establish relationships, the risks of losing their jobs and impacts on their reputation. Respondents in North America were most concerned about their HIV status damaging their reputation (ATLIS, 2008).

HIV Related Stigma in the United States

The Kaiser Family Foundation has been tracking U.S. public opinion about HIV/AIDS for more than a decade by conducting surveys. The 2009 Survey of Americans on HIV/AIDS was conducted by telephone, among a nationally representative random sample of 2,554 adults over the age of 18. The survey was conducted from January 26 to March 8, 2009. The margin of sampling error for the overall survey was plus or minus 3 percentage points (Kaiser Family Foundation, 2010).

A large majority of adults (69 percent) say that people would not think differently of them if they found out they had been tested for HIV; this has increased slightly since

2006 (62 percent). There was also a slight decline in individuals responding that people would think less of them if they had an HIV test; this decreased from 21 percent in 2006 to 16 percent in 2009 (Kaiser Family Foundation, 2010).

Many of the individuals surveyed (4 out of 10) indicated they knew someone with HIV, AIDS or has died from AIDS. This survey response has remained fairly constant since the 1980's. Individuals who knew someone with the disease also seem to not harbor stigmatizing attitudes; 83 percent of those who report knowing someone with HIV would be comfortable working with someone with HIV compared to 65 percent who did not know someone with HIV. Some challenges in fighting HIV/AIDS stigma still seem to remain. Twenty-three percent of individuals surveyed would be uncomfortable with an HIV positive co-worker, 35 percent of parents would be uncomfortable with a child's teacher being HIV positive, and slightly over half (51 percent) of adults say they would be uncomfortable with their food prepared by someone who is HIV positive (Kaiser Family Foundation, 2010).

Misconceptions about how HIV/AIDS is transmitted continue to contribute to the stigmatization of the disease. Thirty-four percent of respondents had at least one misconception on how the disease is transmitted such as, not knowing HIV cannot be transmitted through drinking from the same glass (27 percent), touching a toilet seat (17 percent), or swimming in a pool with someone who is HIV positive (14 percent). These statistics have not changed since the 1980's. Most of these misconceptions were more common in older respondents. However, almost one-third of the 18 to 29 year olds think

HIV may be transmitted in one of the previously mentioned ways (Kaiser Family Foundation, 2010).

Individuals who responded to having some discomfort around people living with HIV may have a lack of knowledge about how the disease is spread. Individuals who had misconceptions of HIV transmission were more likely to say they would be uncomfortable working with someone with HIV (43 percent compared to 13 percent of those knowing how HIV is spread), and more likely to be uncomfortable with their food being prepared by someone who is HIV positive (71 percent compared to 40 percent) (Kaiser Family Foundation, 2010).

In order to educate the public about misconceptions surrounding HIV, we must first understand the source of this information. The KFF survey respondents indicated that the media is the main source of information, six in ten said most of what they know about the disease comes from things they have seen and heard from television, radio, newspaper and the internet (Kaiser Family Foundation, 2010).

HIV Related Stigma in Rural America

Rural America tends to have the reputation of being a "safe" place to live, free of drugs, risky sexual behavior and disease. However, rural communities are not immune to such problems associated with living in urban areas including HIV and other sexually transmitted diseases (Rural HIV/STD Prevention Work Group, 2009).

The United States Census Bureau (2000) defines urban areas as continuously built up areas with a population nucleus of 50,000 or more and a population density greater

than 1,000 people per square mile. Based on the definition, the Census Bureau (2000) found that 59 million people (21 percent of the United States population) were living in rural settings. North Dakota has only three cities considered urban areas, with two on the eastern border of Minnesota (United States Census, 2000).

Evidence has demonstrated that rural Americans experience a broad range of health disparities, especially in comparison to persons living in suburban areas. Findings from a study in the early 1990s show that rates of premature mortality from all causes were highest among rural Americans (Rural HIV/STD Prevention Work Group, 2009). Why rural Americans experience greater disease and premature death are not completely understood. Some reasons may be that rural populations have a tendency to be low-income and do not have health insurance (Rural HIV/STD Prevention Work Group, 2009).

Another difference between rural America and the rest of the country pertains to mental health. Rural residents are more likely to stigmatize mental illness, be under-diagnosed, and receive inadequate treatment for mental illness. This may contribute to behaviors such as drug use, early initiation of sexual activity, or unprotected sex with multiple partners that put individuals at greater risk for HIV infection and other STDs (Rural HIV/STD Prevention Work Group, 2009).

Stigma surrounding HIV in rural areas appeared to be present, which could create a barrier to HIV prevention, testing and treatment. There were tendencies for men who have sex with men (MSM) in rural communities to remain “hidden,” because of the

stigmas that may exist against their sexual orientation. This may encourage MSM to travel to urban areas to meet their partners. The urban areas where MSM go may have higher rates of HIV that they bring back to their rural communities. Regarding HIV/AIDS there may be a lack of anonymity for individuals living in rural America face compared to those living in urban areas. For example, individuals in urban areas can walk into a gas station and buy condoms or go to a clinic to be tested without anyone knowing who they are compared to small rural areas where everyone knows who you are (Rural HIV/STD Prevention Work Group, 2009).

Rural HIV Prevention Needs

Rural areas tend to be behind urban areas when dealing with HIV prevention and intervention programs. This is partially due to stigma, geographic factors and lower rates of HIV incidence (Rural HIV/STD Prevention Work Group, 2009). Because resources are limited in rural areas, prevention activities need to be geared toward target populations at the highest risk. It is critical to expand and improve HIV prevention in rural areas. Rural healthcare providers need better training and support on delivering HIV prevention messaging, assessing risk behavior, and cultural sensitivity and confidentiality issues (Center for AIDS Prevention Studies, 2010).

Strategies to address HIV in rural areas are not solutions that fit every situation. Many behavioral interventions that have been developed will not work in rural areas due to the unique geographical area and different demographics. There has been very little research done to develop the interventions in rural areas or test the validity of the

outcomes (Rural Center for AIDS/STD Prevention, 2009). Strategies need to be created in order to build on the strengths of the rural community (Rural Center for AIDS/STD Prevention, 2009).

> By combining knowledge of disease patterns, community risks, assets and needs with the knowledge of what works to change risk behaviors, rural prevention specialists can decide; if a behavior intervention is needed, what intervention would be best suited to change the risk factors and what adaptations may be needed to make the intervention successful in the rural area (Rural HIV/STD Prevention Work Group, 2009, p. 74).

According to the Rural HIV/STD Prevention work group (2009), effective HIV behavioral interventions should include: 1) an emphasis of safer sex knowledge 2) safer sex skills training and practice of these new skills 3) a focus on a well-defined audience and specific messages tailored to the targeted audience 4) research on the targeted audience to determine reactions to program content 5) goals, methods and materials that are appropriate for different ages, sexual experience and culture of participants, and 6) deliver in multiple sessions over many weeks.

Schools reach nearly all youth, which opens up opportunity to increase knowledge and skills to avoid HIV and other STDs during their lifetime. Schools can be an important partner in HIV prevention education efforts (Rural HIV/STD Prevention Work Group, 2009). Sandra Tibke, HIV educator for the North Dakota Department of Public Instruction, believes there is a need for more education about HIV in North

Dakota, especially within the school systems. In 2010, only 20 percent of lead health education teachers reported receiving professional development during the past two years in regards to HIV, because of this there is concern regarding what type of information is getting to the students concerning HIV. According to Tibke, HIV education is the only statewide mandate for schools concerning adolescent sexual health. Because of this mandate, there are few obstacles to prevent proper HIV education in schools. The one obstacle she is most concerned about is the professional development of the lead health education teachers (S. Tibke, personal communication, February 10, 2011).

> Many obstacles stand in the way of rural schools implementing effective HIV/STD education. Because rural Americans generally hold more traditional values, some may be resistant to sexuality education (Rural HIV/STD Prevention Work Group, 2009, p. 22).

The Youth Risk Behavioral Surveillance System (YRBSS) includes a national school-based survey conducted by the CDC and state, territorial, tribal, and district surveys conducted by local and state education and health agencies and tribal governments. North Dakota 2009 YRBSS data included:

- 88.1 percent of North Dakotan students had been taught in school about AIDS or HIV infection
- 11.9 percent of North Dakotan students had been tested for a sexually transmitted disease including HIV, the virus that causes AIDS

- 44.6 percent of North Dakotan students engaged in sexual intercourse (2009 Results for 9th Through 12th Grade Sexual Behaviors, 2009).

A little over 44 percent of students under the age of 18 have had sexual intercourse in North Dakota and only 11.9 percent have been tested for a sexually transmitted disease (STD) including HIV, the virus that causes AIDS (2009 Results for 9th Through 12th Grade Sexual Behaviors, 2009).

This may assume that North Dakotan students do not think they are at risk for HIV/AIDS. According to Ms. Tibke, we need to educate more about this issue in the school systems (S. Tibke, personal communication, February 10, 2011).

Chapter 3

METHODS

The purpose of this paper was to investigate HIV related stigma to improve HIV prevention efforts in North Dakota. In this study the research questions were:

1) Do North Dakotan adults view HIV as a problem in their state?

2) Do North Dakotan adults believe there is stigma (the shame or disgrace attached to something regarded as socially unacceptable) associated with HIV in North Dakota?

3) Does the stigma surrounding HIV prevent North Dakotans from being tested?

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6) Have individuals been exposed to HIV prevention messaging in North Dakota?

7) Is there a correlation between North Dakotans who would treat someone differently with HIV and the understanding of how HIV is transmitted?

8) Is there a relationship between North Dakotans who have been tested for HIV and exposure to HIV prevention messaging?

9) What are the reasons North Dakotan's believe there is a stigma associated with HIV in their state?

The findings of this research may contribute to understanding what is necessary to reduce stigma, increase testing and improve HIV prevention messaging in North Dakota. In the review of the literature, I examined professional literature relating to stigma, HIV related stigma and HIV in rural areas of the world. However, the literature review revealed a lack of research referring to HIV related stigma in rural America, specifically rural frontier states, including North Dakota. This research was intended to address this gap.

Research Design

A written survey was used for the data collection (see Appendix A). This qualitative data was quantified by categorically coding the survey questions. The relationships between two constructs such as: HIV transmission and how individuals would treat people with HIV, HIV stigma and HIV testing, HIV testing and exposure to HIV prevention messaging were examined using a Pearson R correlation. This correlation describes the relationship between the two variables.

The survey was chosen as the method for data collection to provide insight into North Dakotan adults' perceptions of HIV related stigma and knowledge of HIV. To determine feasibility of this study, a preliminary discussion was conducted with staff of the HIV program at the North Dakota Department of Health to ensure the questions asked would benefit the work of the program. A focus group made up of five individuals was gathered to read the questions to ensure they were clear and concise. The focus group suggested changes to some of the terminology used in the original survey and questions

were put more in laypersons terms. Changes were then made to the survey from those suggestions. Permission to conduct the study was obtained through the North Dakota Department of Health and the Minnesota State University-Mankato IRB (see Appendix B).

Subject Selection

A survey was administered using quota sampling. Two strata were identified; one stratum was towns with less than 16,000 people and the second strata were towns with over 16,000 people. These two strata were identified because about half the population in North Dakota lives in towns under 16,000 people and half in towns with more than 16,000 people. The survey was administered to four communities in each of these two strata (total of eight towns). The eight towns were chosen randomly from the two strata. The subject selection was done this way to ensure that the demographics of the individuals surveyed would represent the demographics of North Dakota as a whole. The number of individuals selected in the community to complete the survey varied depending on the number of willing participants.

All towns with a population of over 700 people were placed in an excel spreadsheet divided into two columns, those with over 16,000 individuals and those with under 16,000 individuals. Only towns with a population of over 700 were chosen to allow for a large enough sample size. Excel placed the towns in random order. From there, integers were selected by taking the number of towns in the sample size divided by

four the number of towns needed to survey. The integer selected was then used to select the towns by numbering off by the chosen numbers.

Data Collection Methods

Data were collected at community gatherings (such as craft fairs, town hall meetings, concerts, dances or town parties) in the eight chosen towns between January 15 and February 15, 2011. Contact was made to the individuals in charge of the community gathering to set up a location to administer the survey. The investigator, Krissie Guerard, distributed and collected the surveys. If there were no community gatherings found in the town, the survey was administered in the community at various locations. When the survey was administered in non-community events the owner of the business where the patrons were asked to fill out the survey were contacted prior to make sure it was appropriate to recruit their patrons for this study.

Subjects were chosen because they were attending the community event or located in the community and a member of the population (North Dakotan over the age of 18). If individuals solicited chose to complete the survey, a private area was offered for them to complete the survey. The individual placed the survey in a sealed envelope after completion. The sealed envelopes were not opened until all data from the stratum had been collected and were ready for data analysis. This ensured the investigator did not know what survey came from which subject and from what location. The amount of surveys disseminated at each event or business varied from two to thirty. All demographic questions and at least 10 of the HIV questions needed to be answered in order to be included in data analysis.

Instrumentation

The HIV survey developed for this research provided an indication of North Dakotans attitudes toward HIV in North Dakota. The survey, which consisted of nineteen questions, which was administered to selected individuals in North Dakota, and required approximately five minutes to complete. The first six questions were basic demographic information followed by thirteen questions related to perceptions of HIV in North Dakota (see Appendix B).

Prior to participating in data collection, participants were given a consent form (see Appendix C) and a verbal description of the survey from the investigator. The investigator was present to answer participants' questions.

Data Analysis

A form was created in Microsoft Access to input each completed survey's answers and to keep data organized. The incomplete surveys were not entered into the Access form. Once all the data were entered into Access, a query was developed to perform the data cleaning. Data input mistakes were then corrected in the Access database to ensure accurate data analysis. The data was then exported from the Access database into Excel and then imported into Statistical Analysis Software (SAS) for data analysis.

A coding sheet was developed using the survey questions (see Appendix D). The code that was developed was used in SAS to extract the data in order to answer the research questions.

Chapter 4

FINDINGS

This study surveyed adults' perceptions of HIV in North Dakota in order to improve HIV prevention. This chapter presents the findings of this study and analysis for each research question. There were 222 surveys collected and 206 analyzed. After each research question the relevant findings, analysis and discussion are included in this chapter.

Respondents

Table 4.1 shows the demographics of the 206 North Dakotans who completed the survey. The majority of North Dakotas who completed the survey were white, 92.23 percent and non-Hispanic, 92.3 percent. The percentage of white individuals who live in North Dakota is 92.4 (see table 1.1); the data collected is accurate of that representation. Males and female participants were almost equally represented with 46.6 percent male and 53.4 percent female, which closely reflects the demographics in North Dakota with 49.9 percent male and 50.1 percent female (see table 1.1). The age group with most respondents was ages 18 to 24 years with 68 (33.4 percent), this does not correspond with the median age in North Dakota that is 36.2, and only 11.65 percent of respondents were in that age group. The majority of respondents identified as being heterosexual with 96.6 percent. The sample of respondents included 51.46 percent living in towns over 16,000 and 48.54 percent living in towns under 16,000. This is representative of geographic distribution of the population in the state of North Dakota.

Table 4.1

Survey Demographics

Race	Frequency	Percent
American Indian/Alaska Native	4	1.94%
Asian	2	0.97%
Black	7	3.40%
White	190	92.23%
Other	3	1.46%
Total	206	100.00%
Ethnicity	**Frequency**	**Percent**
Hispanic	3	1.46%
Non-Hispanic	192	93.20%
Unknown	11	5.34%
Total	206	100.00%
Gender	**Frequency**	**Percent**
Female	110	53.40%
Male	96	46.60%
Total	206	100.00%
Age Group	**Frequency**	**Percent**
18-24	68	33.01%
25-34	42	20.39%
35-44	24	11.65%
45-54	36	17.48%
55+	36	17.48%
Total	206	100.00%
Sexual Orientation	**Frequency**	**Percent**
Heterosexual	199	96.60%
Homosexual	1	0.49%
Bisexual	6	2.91%
Total	206	100.00%
Population	**Frequency**	**Percent**
16,000+	106	51.46%
<16,000	100	48.54%
Total	206	100.00%

Research Question 1

Do North Dakotan adults view HIV as a problem in their state?

Most North Dakotans did not view HIV as a problem in their state. One hundred twenty-seven respondents (61.65 percent) believed HIV is not a problem in North Dakota, while 77 respondents (37.38 percent) believed it is a problem and less than 1 percent is not sure.

The findings of this research question could be an issue for individuals being tested because if they don't believe it is a problem they may not take the necessary precautions to avoid the disease. Even though North Dakota has a low incidence of HIV, it is important to educate the population of North Dakota that HIV is present and it only takes one time to contract it.

Research Question 2

Do North Dakotan adults believe there is stigma (the shame or disgrace attached to something regarded as unacceptable) associated with HIV in North Dakota?

Most North Dakotans believe there is a stigma associated with HIV in their state. A total of 134 of respondents (65.37 percent) believe there is stigma compared 71 respondents (34.63 percent) who did not believe there is stigma, one answered not sure.

The findings of this research question suggest that a behavioral intervention might be needed to reduce the amount of stigma associated with the disease in North Dakota. By decreasing stigma, more people will become comfortable with being testing and

therefore decreasing the amount of HIV that is spread. It may also enable those who are already affected by the disease to be comfortable seeking medical care, which will ensure them a longer and better quality of life. They may also feel more comfortable sharing their HIV status with their family, which can give an HIV positive individual the support they need.

Research Question 3

Does the stigma surrounding HIV prevent North Dakotans from being tested?

The focus of research question 3 was the relationship between HIV stigma and North Dakotan's being tested for HIV. Variables tested were compared using the Pearson R Correlation test. The Pearson R Correlation of -0.04738 suggests that there is no evidence of correlation between the two variables.

The analysis of this data found that there is no correlation between HIV stigma and preventing North Dakotans from being tested. Fifty-one percent of survey respondents stated they have not been tested for HIV. Of the respondents who were not tested, 87 percent have not been tested because they don't feel they are at risk. The results show that it may be more likely a belief that individuals are not at risk rather than stigma that prevents North Dakotans from being tested. This finding can support efforts to increase testing.

Research Question 4

Do North Dakotans understand how HIV is transmitted?

Table 4.2 describes all possible answers to HIV survey question 2; that is, "do you know how you can get HIV/AIDS?" Survey participants were asked to check all answers that applied. There were eight possible answers and four correct answers. Forty percent of participants answered all four modes of transmission correctly without choosing any of the wrong modes of transmission. Sixty percent of participants did not answer the four correct modes of transmission; they may have answered some correctly but failed to get all four modes correct.

Table 4.2

Modes of Transmission

Type of Transmission	**Yes Number**	**Yes Percent**	**No Number**	**No Percent**
Vagina/Anal Sex	200	97.09%	6	2.91%
Sharing Needles	194	94.17%	12	5.83%
Kissing	22	10.68%	184	89.32%
Exposure to Blood	190	92.23%	16	7.77%
Hugging	1	0.49%	205	99.51%
Mosquito Bites	34	16.50%	172	83.50%
Sharing Toilet Seats	15	7.28%	191	92.72%
Oral Sex	129	62.62%	77	37.38%

The majority of individuals knew that HIV is transmitted by vaginal and/or anal sexual interaction, and exposure to blood and sharing needles. However, only 62.62 percent of respondents knew that HIV can be transmitted through oral sex. The only four modes of transmission are vaginal/anal sex, injecting drug use, exposure to blood and oral sex. Education is needed so North Dakotans know how HIV is and isn't spread.

Research Question 5

Do North Dakotan's think they would treat individuals with HIV differently?

Most North Dakotan's responded that they would not treat individuals with HIV differently. According to the data, 76.70 percent of individuals would not treat someone with HIV differently.

It doesn't appear that the majority of survey respondents would treat individuals with HIV differently. This is a positive finding, as even though respondents believe there is stigma associated with HIV in North Dakota they would not treat HIV positive individuals differently.

Research Question 6

Have individuals been exposed to HIV prevention messaging in North Dakota?

One hundred seventy-six survey respondents stated that they have seen or heard HIV prevention messaging (85 percent). Table 4.3 describes prevention messaging those respondents were exposed to.

Table 4.3

Types of Prevention Messaging

Type of Prevention Messaging	Number	Percent
Billboards	80	38.83%
Posters	64	31.07%
Bathroom Ads	44	21.36%
Web Site	30	14.56%
Brochure	78	37.86%
Radio	62	30.10%
Good Health TV	27	13.11%

Participants were asked to select as many types of prevention messaging they had seen or heard in North Dakota. Billboards were the most seen type of prevention messaging in North Dakota (38.83 percent) followed by brochures (37.86 percent) and posters (31.07 percent).

This corresponds with the advertising done by the North Dakota Department of Health. Billboards were placed in 12 towns in North Dakota in 2009 and 2010. Posters and brochures were revised and disseminated in North Dakota in 2009 (Unpublished Internal Document, 2009). This information is important to realize what information North Dakotans are seeing and/or hearing. This may help develop HIV prevention campaigns in the future.

Research Question 7

Is there a correlation between North Dakotans who would treat someone differently with HIV and their understanding of how HIV is transmitted?

The focus of research question 7 was the relationship between North Dakotans treating someone with HIV differently and the knowledge of how HIV is transmitted. Variables tested were compared using the Pearson R Correlation test. The Pearson R Correlation of -0.09722 suggests that there is no evidence of correlation between the two variables.

Further research will need to be conducted to determine what would make a person treat someone with HIV differently as this showed no correlation with the lack of HIV knowledge.

Research Question 8

Is there a relationship between North Dakotans who have been tested for HIV and had exposure to HIV prevention messaging?

The focus of research question 8 was the relationship between North Dakotan's getting tested for HIV and whether they have been tested for HIV. Variables tested were compared using the Pearson R Correlation test. The Pearson R Correlation of -0.00154 suggests that there is no evidence of correlation between the two variables.

The results of this question will need to be researched further as there is no relationship of exposure to prevention messaging and being tested. This could mean that HIV prevention messaging is not adequately increasing HIV testing in North Dakota.

Research Question 9

What are the reasons North Dakotans believe there is a stigma associated with HIV in their state?

Individuals surveyed who agreed that there was stigma associated with HIV in North Dakota were asked why there is stigma. One hundred thirty-four of respondents (65.37 percent) who believed there is stigma. Table 4.4 describes the reasons North Dakotans feel there is stigma associated with HIV. Individuals were asked to check all answers that applied.

Table 4.4

Why is there stigma associated with HIV in North Dakota?

Why is there stigma associated with HIV in North Dakota?	**Number**	**Percent**
Lack of Education	84	40.78%
Religious Beliefs	51	24.76%
Personal Bias	77	37.38%
Lack of HIV Prevention Messaging	80	38.83%

North Dakotans believe that a lack of education (40.78 percent) is a major contributor to HIV stigma followed by, lack of HIV prevention messaging (38.83 percent), personal bias (37.38 percent), and religious beliefs (24.76 percent).

This research finding shows that there is a need for an increase in HIV education in North Dakota. The HIV prevention program should look at ways to improve education in order to curve personal bias to prevent HIV related stigma. This could potentially increase testing and prevention in North Dakota.

Summary

The majority of North Dakotans believe there was stigma associated with HIV in North Dakota (65.37 percent). However, there did not seem to be a correlation between not being tested for HIV because of the stigma or because of lack of education. Only 40 percent of respondents know that HIV was only transmitted through vaginal/anal sex, oral sex, exposure to blood, and sharing needles. There is a need for general education about what is not a cause of HIV and specific education to increase knowledge that HIV can be spread through oral sex.

Chapter 5

SUMMARY, DISCUSSION, CONCLUSION, AND RECOMMENDATIONS

This chapter presents the summary discussion, and conclusion of the findings of this study. Also, included in this chapter are recommendations for further research regarding HIV related stigma and prevention in rural states.

Summary

The survey design was chosen as the method for data collection to provide insight into North Dakotan adults' perceptions of HIV related stigma and knowledge of HIV. To determine feasibility of this study, a preliminary discussion was conducted with the HIV program staff at the North Dakota Department of Health to ensure the questions asked would benefit the work of the program.

The survey was conducted in eight selected North Dakota towns with 226 participants between January 15 and February 15, 2011. Subjects were selected because they were attending a community event or located in the selected communities, and they were North Dakota residents over the age of 18. Prior to data collection, participants were given a consent form and a verbal description of the survey from the investigator. The investigator was present to answer participants' questions as needed.

The data were entered into an Access database to ensure the data was organized and easy to analyze. A coding sheet was developed using the survey questions. The code

that was developed was used in SAS to extract the data in order to answer the research questions.

Discussion

Rural America tends to have the reputation of being a "safe" place to live, free of drugs, risky sexual behavior and disease. However, rural communities are not immune to problems associated with living in urban areas including HIV and other sexually transmitted diseases (Rural HIV/STD Prevention Work Group, 2009). This study was intended to investigate HIV stigma in order to improve HIV prevention in North Dakota, which has only three urban cities. There was a lack of research on HIV stigma and prevention in rural states. Many studies that were identified for the literature review were conducted in rural Africa or rural parts of larger populated states. The demographic makeup of the population of North Dakota is very different from those areas. It is important to understand that HIV exists in rural areas in the United States and there is a need for better prevention efforts.

Demographic questions were asked in the survey to try and best represent the population of North Dakota. HIV specific questions were asked in the survey to answer the research questions regarding North Dakotans' perceptions of HIV. HIV knowledge questions were analyzed to improve HIV prevention in North Dakota.

Conclusion

This study provided information that is necessary in order to improve HIV testing, education and reduce stigma in North Dakota. The majority of respondents (61.65

percent) did not believe that HIV is a problem in North Dakota. This could be an issue for individuals being tested because if they do not believe it is a problem they may not take the necessary precautions to avoid the disease.

More than half (60 percent) of respondents did not know the only four ways HIV can be transmitted. Education is needed in North Dakota to provide information on how HIV is transmitted, especially through oral sex, as only 62.62 percent of respondents knew this is a risk for HIV. Education is also needed to inform North Dakotans know how HIV is not spread. Many individuals (40 percent) completing the survey identified correctly the 4 modes of HIV transmission but chose other transmission modes that were not correct.

The strategy of selecting towns in which to administer the survey resulted in a sample that closely represented the demographics of North Dakota. However, for future research it is not recommended to select the survey sample in this manner. Some towns that were chosen were quite small and the sample size desired initially was not attained. By choosing more towns, a larger sample would have been collected.

There were few homosexual respondents. This survey could be administered in the homosexual population to see if perceptions of HIV would differ. The survey could be administered at Pride Fest, gay/lesbian dances, and other events.

There were also few American Indian respondents. This population makes up five percent of the population of North Dakota and it would have enhanced the diversity of the sample. This survey could be administered to the American Indian community to

see if perceptions would differ. There are many American Indian events held in North Dakota, which would be an avenue to administer the survey.

With financial resources for the research, more individuals could have participated in data collection. This could have allowed for both mail surveys and in person surveys in more areas of North Dakota, ultimately resulting in a larger sample size. The sample size could also be increased by including community partners in North Dakota such as community action agencies and local public health units.

There is a lack of research done on HIV stigma in rural states like North Dakota. Future study is needed to address perceptions of HIV in all rural frontier states. This would set a precedence to begin creating more interventions that would work in these types of areas.

Recommendations

This study findings indicated that this sample of North Dakotans believe that there is stigma associated with HIV (65.37 percent). A behavioral intervention should be developed to help reduce stigma associated with the disease in North Dakota. By decreasing stigma, more people may become comfortable with being testing which may decrease the transmission of HIV. It will also enable those who are already affected by the disease to be comfortable seeking medical care, which will ensure them a longer high quality life. They may also feel more comfortable sharing their HIV status with their family, which can give HIV positive individuals the support they need.

More education is needed in North Dakota to provide information on how HIV is transmitted, especially through oral sex. Education is also needed so North Dakotans know how HIV is not transmitted. By increasing education on HIV transmission, there may be a decrease in HIV transmission rates. With further education on how HIV is not spread stigma of the disease may decrease.

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Appendix A

NORTH DAKOTA HIV SURVEY

General

1. **What is your race?**

☐ American Indian or Alaska Native

☐ Asian
☐ Black or African American

☐ Native Hawaiian or Other Pacific Islander
☐ White

☐ Other

☐ Refused

2. **What is your ethnicity?**

☐ Hispanic or Latino ☐ Not Hispanic or Latino ☐ Unknown

3. **What is your gender?**

☐ Male ☐ Female

4. **What is your age?**

☐ 18-24 ☐ 25-34 ☐ 35-44 ☐ 45-54 ☐ 55+

5. **What is your sexual orientation?**

☐ Heterosexual ☐ Homosexual ☐ Bisexual

6. **What is the population of the city/town in which you reside?**

☐ <16,000 ☐ >16,001

HIV Questions

1. **Do you think HIV/AIDS is a problem in North Dakota?**

   ☐ Yes ☐ No

2. **Do you know how you can get HIV/AIDS? (check all that apply)**

   ☐ Vaginal and/or Anal Sex ☐ Kissing ☐ Exposure to Blood

   ☐ Sharing Needles ☐ Oral Sex ☐ Hugging

   ☐ Sharing toilet seats ☐ Mosquito Bites

3. **Have you ever been tested for HIV?**

   ☐ Yes ☐ No ☐ Not sure

4. **If you answered yes to #3, did you get tested in the city in which you reside and where?**

   ☐ Yes _____ ☐ No _____

5. **If you answered no to #3, why haven't you been tested for HIV? (check all that apply)**

   ☐ I do not feel I am at risk

   ☐ I don't know where to get tested

   ☐ I don't want people to know I am getting tested
   ☐ I have never been asked to get tested

   ☐ I am at risk and don't want to know the results

6. **What types of methods do you use to prevent acquiring HIV or giving HIV to others?**
   (check all that apply)

   ☐ Condoms ☐ Abstinence ☐ Dental Dams

   ☐ I get routine HIV tests ☐ I am in a monogamous relationship

7. **Do you know anyone with HIV?**

   ☐ Yes ☐ No ☐ Not sure

8. **Do you think you would treat someone who has HIV differently then someone who doesn't?**

   ☐ Yes ☐ No

9. **Would you be willing to disclose your HIV status?**

   ☐ Yes ☐ No

10. **If you answered yes to #9, what is your HIV status?**

    ☐ Positive ☐ Negative

11. **Do you think there is a stigma (the shame or disgrace attached to something regarded as socially unacceptable) surrounding HIV in North Dakota?**

    ☐ Yes ☐ No

12. **If you answered yes to #11, why do you think there is a stigma associated with HIV in North Dakota? (check all that apply)**

    ☐ Lack of education ☐ Religious Beliefs ☐ Personal Bias
    ☐ Lack of HIV Prevention Messaging

13. **What types of HIV prevention messaging have you seen or heard in North Dakota?**
    (check all that apply)

    ☐ Billboards ☐ Posters ☐ Bathroom Ads ☐ Website

    ☐ Brochures ☐ Radio ☐ Good Health TV ☐ TV commercials

Appendix B

MINNESOTA STATE UNIVERSITY
MANKATO

Bikash Nandy, Ph.D.
Department of Health Science
213 Highland North
Mankato, MN 56002

Krissie Guerard
511 North 35th Street
Bismarck, ND 58501

November 9, 2010

Dear Bikash & Krissie:

Re: IRB Proposal, Log **#3677** entitled *"An Evaluation on HIV Related Stigma to Improve HIV Preventions in North Dakota"*

Your IRB Proposal has been approved as of November 9, 2010. On behalf of the Institutional Review Board I wish you success with your study. Remember that you must seek approval for any changes in your study, its design, funding source, consent process, or any part of the study that may affect participants in the study. Should any of the participants in your study suffer a research-related injury or other harmful outcome, you are required to report them to the IRB as soon as possible.

The approval of your study is for one calendar year from the approval date. When you complete your data collection, or should you discontinue your study, you must notify the IRB. Please include your log number with any correspondence with the IRB.

This approval is considered final when the full IRB approves the monthly decisions and active log. The IRB reserves the right to review each study as part of its continuing review process. Continuing reviews are usually scheduled. However, under some conditions the IRB may choose not to announce a continuing review.

Sincerely,

Patricia Hargrove

Patricia M. Hargrove, Ph.D.
IRB Coordinator
Cc: File

Appendix C

CONSENT FORM

This is a survey of stigma associated with HIV in North Dakota. You will be asked questions about your personal beliefs about HIV. All of your information will be kept private. It can be viewed only by authorized research staff members. The survey takes about 5 minutes to complete.

I understand that I can contact Dr. Bikash Nandy at 507-389-5935 or bikash.nandy@mnsu.edu about any concerns I have about this project. I understand that I also may contact the Minnesota State University, Mankato Institutional Review Board Administrator, Dr. Terry Flaherty, at 507-389-2321 or terrance.flaherty@mnsu.edu with any questions about research with human participants at Minnesota State University, Mankato.

I understand that participation in this project is voluntary and I have the right to stop at any time. By completing this survey, I agree to participate in this study and state that I am at least 18 years of age.

I understand that none of my answers will be released and no names will be recorded. I understand that the risks of participating in this study are minimal. I understand that participating in this study will help the researchers better understand the stigma associated with HIV.

If you are concerned about your mental health after answering your questions, you can seek a referral for mental health services at http://locator.apa.org/ or http://www.nmha.org/help/. Neither the investigators nor Minnesota State University, Mankato will be responsible for the cost of mental health services if you decide to request them.

Appendix D

Data Analysis Code

ID-Unique

Race_Ai 1=yes 0=no

Race_A 1=yes 0=no

Race_B 1=yes 0=no

Race_HPI 1=yes 0=no

Race_W 1=yes 0=no

Race_O 1=yes 0=no

Race_R 1=yes 0=no

Race_X 1=white, 2=AI, 3=A, 4=B, 5=HPI, 6=O, 7=R

Ethnicity 1=Hispanic 2=Not Hispanic 3=Unknown

Gender 0=male 1=female

AgeGroup 1=18-24, 2=25-34, 3=35-44, 4=45-54, 5=55+

Age_1824 1=yes 0=no

Age_2534 1=yes 0=no

Age_3544 1=yes 0=no

Age_4554 1=yes 0=no

Age_55 1=yes 0=no

Sexual_Orient 1=Hetero, 2=Homo, 3=Bi

Sex_He 1=yes 0=no

Sex_Ho 1=yes 0=no

Sex_Bi 1=yes 0=no

Population 1=over16 0=under16

Pop_more 1=yes 0=no

HIV_ 1 1=yes 0=no

HIV_2_Vag 1=yes 0=no

HIV_2_Kiss 1=yes 0=no

HIV_2_Blood 1=yes 0=no

HIV_2_Need 1=yes 0=no

HIV_2_Oral 1=yes 0=no

HIV_2_Hug 1=yes 0=no

HIV_2_Toilet 1=yes 0=no

HIV_2_Mosq 1=yes 0=no

HIV_3 1=yes 0=no X=not sure

HIV_4 1=yes 0=no

HIV_4_yes

HIV_4_no

HIV_5_ no risk 1=yes 0=no

HIV_5_WhereTest 1=yes 0=no

HIV_5_KnowTest 1=yes 0=no

HIV_5_NotAsked 1=yes 0=no

HIV_5_RiskAfraid 1=yes 0=no

HIV_6_Condoms 1=yes 0=no

HIV_6_Abst 1=yes 0=no

HIV_6_Dental 1=yes 0=no

HIV_6_HIVTest 1=yes 0=no

HIV_6_Mono 1=yes 0=no

HIV_7 1=yes 0=no x=not sure

HIV_8 1=yes 0=no

HIV_9 1=yes 0=no

HIV_10 1=positive 0=negative

HIV_11 1=yes 0=no

HIV_12_Edn 1=yes 0=no

HIV_12_Relig 1=yes 0=no

HIV_12_Bias 1=yes 0=no

HIV_12_Prev 1=yes 0=no

HIV_13_Bill 1=yes 0=no

HIV_13_Post 1=yes 0=no

HIV_13_Bath 1=yes 0=no

HIV_13_Web 1=yes 0=no

HIV_13_Broch 1=yes 0=no

HIV_13_Radio 1=yes 0=no

HIV_13_GHTV 1=yes 0=no

HIV_13_TV 1=yes 0=no