

APPENDICES

A. DEFINITION OF TERMS

1. HIV/AIDS

HIV stands for the human immunodeficiency virus and is a sexually transmitted disease. It is mainly transmitted through unprotected anal and vaginal intercourse, blood and blood products, the sharing of intravenous drug equipment, and during childbirth. AIDS stands for acquired immune deficiency syndrome. Immune deficiency means that a person's immune system is prevented from operating properly and he/she is more prone to opportunistic infections. A syndrome is a group of symptoms or illnesses originating from one cause, in this case HIV (Berer, 1993: 5).

2. Sexually Transmitted Diseases (STDs)

An STD is a bacteria, virus or infection that may be passed from one individual to another by sexual contact. It is also referred to as VD (venereal disease). These diseases include herpes, syphilis, gonorrhea, chlamydia, genital warts and HIV (Ontario Aboriginal HIV/AIDS Strategy, 1993: 5).

3. Colonization

Colonization, in the context of this dissertation, "refers to that process of encroachment and subsequent subjugation of Aboriginal peoples since the arrival of Europeans. From the Aboriginal perspective, it refers to the loss of lands, resources and self-direction and to the severe disturbance of their cultural ways and values" (La Rocque, 1994:3). The individual and personal impact of colonization, on the lives of the Aboriginal women profiled in this research, is especially evident.

4. Aboriginal

As stated in the 1982 Constitution of Canada, the term "Aboriginal" refers to all people of Indian, Inuit and Metis heritage, including non-status Indians (Waldram, 1995:Preface: xi).

5. Marginalization

As stated by Gordon Marshall (1994:304) marginalization is defined as, "a process by which a group or individual is denied access to important positions and symbols of economic, religious, or political power within any society...a marginal group may actually constitute a numerical majority...and should perhaps be distinguished from a minority group, which may be small in numbers, but has access to political or economic power".

6. Homophobia

Homophobia refers to the fear by heterosexuals (and by some “gays” i.e. homosexuals) of being in close quarters with homosexuals; among gays themselves, it refers to self-loathing (Feldman, 1990:13).

7. Cultural Oppression

Cultural oppression is derived from the loss of cultural identity, either imposed or denied. Historically, the Aboriginal people of Canada were deprived (“raped” in the words of Lynne (1998:2) of their culture, traditions, language, spirituality, and values.

8. Patriarchy

Patriarchy, “literally means ‘rule of the father’; the term was originally used to describe social systems based on the authority of male heads of household. It has now acquired a more general usage, especially in some feminist theories, where it has come to mean male domination in general” (Marshall, 1994:383).

9. Standpoint Methodology

In the “standpoint” methodology developed by feminist scholars, it is recognized that people in institutionalized positions of power are blinded by their advantaged standpoint and tend to neglect or not fully understand the world-views, issues, and experiences of less empowered or marginalized groups. When describing standpoint methodology they stress that in research concerning marginalized groups, the participation of the marginalized group will generate questions that the institutionalized authorities would not think to ask. In effect, marginalized lives are better places to start asking critical questions about certain issues, practices, and policies. This is particularly true in the area of medical research involving human subjects in which the potential for harm to the study objects cannot be fully appraised by the institutional group conducting the research (Allman, Myers and Cockerill, 1997:25).

10. Ethnography

Hurtig (2000:4) states that ethnography refers to, the research, analysis, interpretation, and representation of social and cultural processes. The dialogue has included anthropologists, for whom ethnography is the principal methodology and narrative form for the discipline, as well as sociologists, psychologists, and other feminist researchers who incorporate cultural inquiry into their studies of gender and sexuality. Among the issues raised by feminist critiques are the androcentrism (male-centeredness) of the analytical categories, “master” theories, and modes of representation found in ethnographic research and writing.

11. Participatory Research

Participatory research refers to research in which the researcher and members of the community share in the way research is designed, carried out, and brought to bear on particular life circumstances (Hurtig, 2000:8).

B. CONSENT FORM

“HIV/AIDS and Aboriginal Women in Saskatchewan: Colonization, Marginalization and Recovery”:

I am Carol Romanow, a graduate student in the Sociology Department at the University of Saskatchewan. I can be reached at (306) 374-1644.

The purpose of this research is to better understand if First Nations women know how they can get HIV/AIDS, how it can be transmitted from one person to another, how they can protect themselves, and if they know what treatment is available and how they can acquire it. This information will be used to conclude whether First Nations women receive adequate education, prevention, and treatment concerning HIV/AIDS.

There is no direct benefit to you from this research, however it will assist in revealing to society the impact that HIV/AIDS has had on First Nations women in Canada.

If you agree to take part, I would like to spend some time with you on an individual basis to discuss how AIDS has affected you and your family. You will be asked to answer questions about your age, education level, general health, and attitudes towards HIV/AIDS, knowledge of HIV/AIDS and sexual behavior. With your permission I will audiotape the interview, as well as make handwritten notes.

The risks of the research are that you may find some of the questions personal. You may also feel reluctant about revealing your HIV/AIDS status. I will take care to minimize these risks.

Your participation in this research is voluntary. You are free to refuse to take part, and you may refuse to answer any questions or may stop taking part at anytime.

Every precaution will be taken to protect your privacy and confidentiality of the records and data pertaining to you in particular and the research study in general, disclosure of which may contribute to identifying you specifically to persons not related to this research. After this research is completed, I may save the tapes and my notes for use in the future. However, the same confidentiality guarantees given here will apply to future storage and use of the materials. The notes and audiotapes will be stored under lock and key in my home.

If you do not understand any portion of what you are being asked to do or the contents of this form the researchers are available to provide an explanation. Questions relating to this research project are welcome at any time. Please direct any questions to Carol Romanow, the researcher, or Patience Elabor-Idemudia, Ph.D., the Supervisor, at the following addresses:

Carol Romanow
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If the purpose of the research or your participation in it changes you will be informed immediately by the researcher. Once the study is completed you will be given a copy of the research as well as an opportunity to discuss its contents with the researcher.
I have read the statements contained herein, have had the opportunity to discuss my concerns and questions, and fully understand the nature of my involvement in this research program as a participant and the attendant risks and consequences. I also acknowledge that I have received a copy of the consent form for my own personal use.

_____ Date: _____

Research Participant

_____ Date: _____

Researcher

D. DEMOGRAPHICS FOR RESEARCH: "HIV/AIDS and Aboriginal Women in Saskatchewan: Colonization, Marginalization, and Recovery"

Interview #: _____

Date: _____

Place: _____

Name: _____

How you wish to be referred to for this research: _____

Age: _____

Marital status: _____

Number of children: _____

Ages: _____

Ethnicity: (Aboriginal, Metis or Inuit) _____

Place of residence: _____

Who you live with: _____

Occupation: _____

Level of education: _____

Attend residential school: _____

Religion/spiritual practices/traditions: _____

Languages spoken at home: _____

Alcohol use: _____ How much _____

Drug use: _____ How much _____

Treatment for alcohol or drug use: _____

Have you ever been a victim of

Sexual abuse: _____ by whom? _____

Physical abuse: _____ by whom? _____

Emotional abuse: _____ by whom? _____

Violence: _____ by whom? _____

Sexually transmitted diseases: _____

Incarcerated: _____ Where? _____

E. QUESTIONS FOR RESEARCH INTERVIEW

The questions for Research Study: “HIV/AIDS and Aboriginal Women in Saskatchewan: Colonization, Marginalization, and Recovery”, will focus upon relevant demographics as well as the following twelve major questions:

Demographics:

- | | |
|------------------------|--|
| a) Name (code #) | h) Ethnicity |
| b) Number of interview | i) Place of residence (urban/rural) |
| c) Date | j) Occupation/household income |
| d) Place | k) Religion/spiritual practices/traditions |
| e) Marital status | l) Language spoken most at home |
| f) Number of children | |
| g) Age | |

- 1) How long have you been living with HIV/AIDS?
- 2) Can you explain how you became infected with HIV? What was happening in your life at that time? How were you diagnosed?
- 3) As an Aboriginal woman, how would you describe your illness and experience with HIV? What has it been like for you? How has it affected you and your personal relationships? (family, friends, and so on)
- 4) Do you know other people who suffer from HIV/AIDS? What do you know about other ways of becoming infected with HIV?
- 5) How much do you know about HIV and AIDS and how it affects women? How and where were you able to obtain information on HIV/AIDS?
- 6) As an Aboriginal woman, what would you say is the worst part of having AIDS or being infected with HIV, personal or medical?
- 7) Do you have a strong support system in your life to help you through the problems with your illness? How do people like your family members, reserve, friends, priest, elder, AIDS Saskatoon or the PLWA Network help you?
- 8) What do you feel would be an important way of preventing this disease from being passed on to young Aboriginal people?
- 9) Do you think that sex education in schools, condom use and safe sex is important? Do you think Aboriginal kids feel that they are invincible to HIV/AIDS or do they just not care what happens to them? Do you think that they feel that they have nothing to look forward to in the future anyway? Do young Aboriginal women face violence if they insist on the use of a condom? Why? Finally, do you think that it is important to have HIV testing programs where a person does not have to give his/her name (anonymous)?

- 10) Who do you feel would be the best person to educate Aboriginal women on how to prevent HIV/AIDS? (doctor, nurse, teacher, and so on)
- 11) In the future, how do you think Aboriginal women with HIV/AIDS can best be helped?
- 12) Is there anything else that you would like to talk about that I might have missed?