

Aboriginal women who
are living with
HIV/AIDS: Findings
from a descriptive-
interpretive study
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ST. PAUL'S HOSPITAL


PROVIDENCE HEALTH CARE




British Columbia
Centre *for* Excellence
in HIV/AIDS




Purpose of the Study

- To explore and understand some Aboriginal women's experiences of living with HIV/AIDS within the context of their everyday lives
 - Gain an understanding of how Aboriginal women who are living with HIV/AIDS experience formal support systems, including AIDS service organizations and health care services
 - Make recommendations for program design and policy development that will address the needs of Aboriginal women who are living with or risk for HIV/AIDS
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The problem with “women”


- In HIV research, “women” is often used as a category of analysis
 - This universal category fails to take into account the diversity of women - bias towards dominant group
 - Nursing is mandated both socially and morally to illuminate the experiences of those people who are marginalized both within society and within healthcare - (Reimer Kirkham & Anderson, 2002).
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Why Aboriginal women?

- Aboriginal women have a disproportionately high rate of HIV infection - (Health Canada, 2000)
- They are less likely to access ART and more likely to progress to AIDS related illnesses
 - (BC Aboriginal HIV/AIDS Task Force, 1997; Legare, Ross & Bognar, 2003; Vernon, 2000, Woods et al, 2003).




Theoretical Underpinnings

- Post colonial perspective
 - Allows the researcher to account for the histories of colonization and frames this history within the intersecting forces of gender, “race” and socioeconomic status
 - It requires the researcher to acknowledge the subjective nature of inquiry
 - Data should be interpreted from within this contextual framework and theory is generated from the context embedded data - (Anderson, 2002)
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Research Objectives

- Explore and understand Aboriginal women's experiences of living with HIV/AIDS within the context of their daily lives
 - Gain an understanding of how Aboriginal women who are living with HIV/AIDS experience the health care system
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Review of the Literature

- Colonization - historical issues and present day impact
 - Health status - mortality and morbidity, HIV/AIDS statistics, health care service utilization
 - Socioeconomic factors - SES, IDU, violence
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- Stigma - concept, relation to HIV/AIDS
 - Vulnerability - concept, impact
 - Related literature - ANAC (1996), Ship and Norton (2000), Mill (2000), Dion Stout et al (1996, 1998, 2001)
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Methodology

- The study utilized an interpretive descriptive approach
 - Interpretive description is a qualitative research method that can be used to enhance our understanding of how people experience health and illness - (Thorne et al, 1997)
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Research Setting

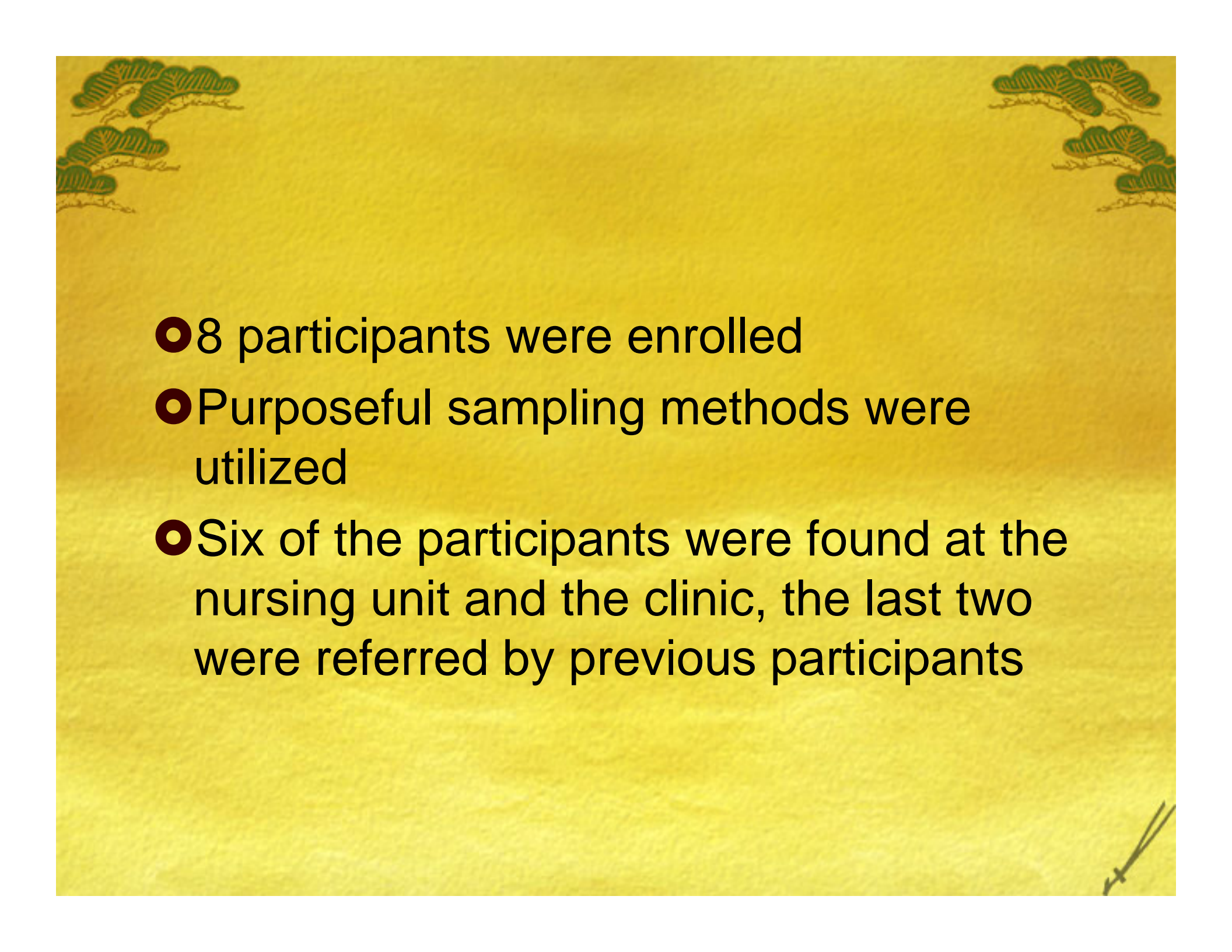
- This study seeks to broaden understanding about the health and illness experiences of Aboriginal women who are living with HIV/AIDS.
 - For this reason, participants were sought on an acute care unit and at a drop-in clinic for people living with HIV/AIDS
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Sampling Strategy

- Participants self-identified as Aboriginal, self-identified as HIV positive, were female, English speaking and over the age of eighteen
 - They were cognitively capable of understanding the terms of the study and the consent process.
 - The input of the nursing and clinic staff was sought by the researcher to ensure that the potential participants' illness did not preclude their ability to take part in the study and to ensure that their participation did not interfere in any way with their ongoing care and treatment.
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- Nurses on the acute care unit and clinic staff were advised of the study and were asked to identify and approach potential participants to advise them of the study and provide them with information about it
 - If the patient agreed, the researcher approached the participant to explain the research and ask for their consent to participate
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- 8 participants were enrolled
 - Purposeful sampling methods were utilized
 - Six of the participants were found at the nursing unit and the clinic, the last two were referred by previous participants

Who were they?

- 8 Aboriginal women, between the ages of 31 and 47
- 7 identified as First Nations, one as Metis
- 4 of the women were originally from out of the province of BC
- All of the women had children but only two had custody
- 4 had unsafe, unstable housing
- 5 were struggling with substance use
- 7 were on welfare
- 3 of the women have died of AIDS related illnesses since the study was completed




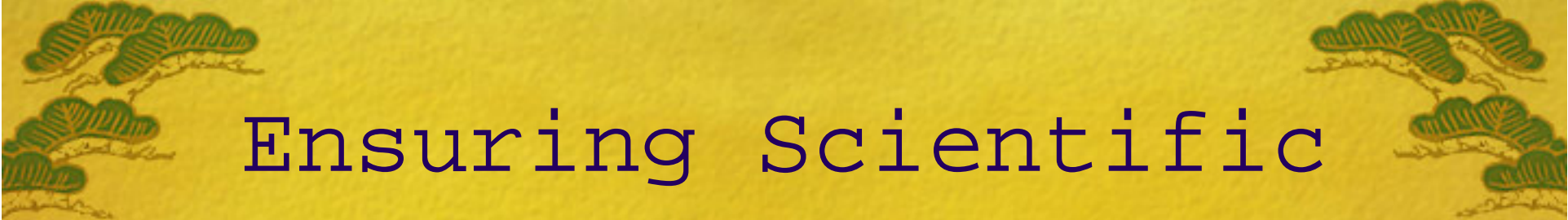
Data Collection Methods

- In depth, audiotaped interviews which were transcribed verbatim
 - Two follow up interviews were conducted to clarify findings
 - A discussion group was facilitated at an Aboriginal HIV conference to review the findings
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Data Analysis Methods

- Immersion in the narrative accounts allowed for the development of themes within and across the narratives
 - As the data was reviewed, emerging concepts and themes were developed, and used to categorize and code the data. As each transcript was coded, they were compared to identify similarities and differences
 - The data, concepts and themes that arose from the analysis were reviewed with a sub-sample of participants in a second interview and with a discussion group at an Aboriginal HIV conference
 - The insights and feedback from the participants was incorporated as analysis continued.
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Ensuring Scientific Quality

- Findings were validated through follow-up interviews, the use of an expert informant and a discussion group at an Aboriginal HIV conference
 - Observational and methodological field notes were kept throughout the data collection and analysis phase
 - Reflexive notes aided the researcher in locating herself in relation to the study and the participants
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Ethical Considerations

- Face to face interviews do not allow for anonymity but confidentiality of the participants was upheld
 - Specific strategies to protect participants' identities included the use of a unique code number for each person on all data sheets, avoidance of identifying participants on transcripts and analytic memos, and the use of fictitious names in the final report.
 - The audiotapes, codebook and all transcribed interview data are maintained in a locked file cabinet.
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Findings

- Five findings or themes arose from the data:
 - Fear of rejection
 - Looking for friendship
 - Finding strength in adversity
 - The struggle to stay well
 - HIV is just one problem among many
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Fear of Rejection

- Feelings of being judged
 - Guilt and shame
 - Keeping a secret
 - Stigmatizing experiences
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Feelings of being judged

- Fiona talked about how she was reluctant to disclose because of her fears of how people would treat her “I think that’s what I’m afraid of like to find out.”
 - Elizabeth related her experience of being in hospital “...I told them I was HIV+, pregnant, they just, they were so cold.”
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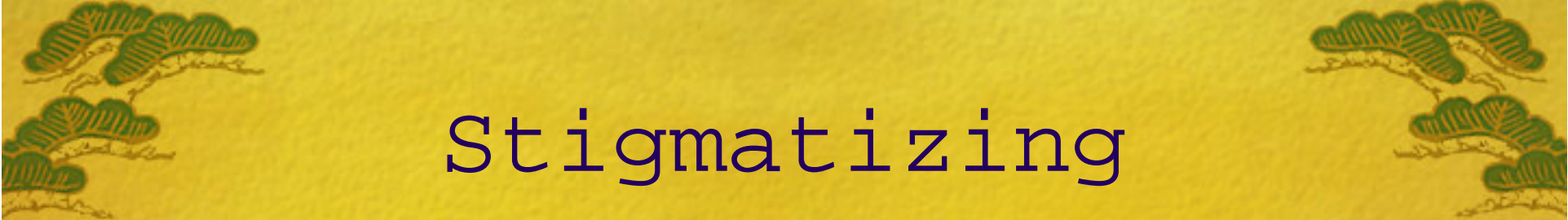
Guilt and Shame

- Elizabeth talked about how the worst thing about her diagnosis was “knowing that I ruined people’s lives, that’s really huge.”
 - Cathy, who got HIV as a result of a sexual assault, blamed herself “mostly I felt like I was to blame...I knew all about HIV. I should have known better.”
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Keeping a secret

- Fiona tells no-one unless she has to
“And right to this day nobody, not even my family knows. Not even my mother.”
 - Justine spoke about how she won't tell anyone in her home community “...its very difficult to go in to see [a health care provider] when you're on a small reserve...because gossip runs very high.”
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Stigmatizing experiences

- Cathy stated “Oh yeah, I have family members that won’t even let me play with their kids. Yeah, I have people who, um, who don’t even want to touch me...”
 - Justine talked about the stigma in reserve communities “You know, they’re still lying on bands about people dying with this disease, you know, they’re still saying well if we bury them on our lands they’ll be contaminated.”
 - Natalie talked about how her family “won’t even let me drink from the same cup.”
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Looking for Friendship

- Lack of social support
 - Isolation
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Lack of social support

- Cathy spoke about how “Confidentiality and support are a problem in northern communities...I feel safer in Vancouver.”
 - Justine spoke about how few resources there were for women “There are a few places around here like I said of them are for gay men...[it’s] getting better but they’re still not there for heterosexual women.”
 - Coralee talked about how her partner won’t come to medical appointments with her “Fear I guess.”
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Isolation

- Mary spoke about how she limited her social circle to other positive women “[they] are the only friends I have.”
 - Justine talked about how difficult it was to establish a relationship with a man ‘...if you say you have HIV, you just see the fear in their eyes.’
 - Natalie spoke about how the worst thing about HIV was “...the loneliness, it’s the loneliness.”
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Finding Strength in Adversity

- Focus on children
 - Inner resources
 - Activism
 - Use of social support, both formal and informal
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Focus on children

- Elizabeth stated “Even though I don’t see my kids, they’re the ones that keep me alive.”
 - Fiona said “I wanted to kill myself...but then I just started really thinking about my children and that’s what really kept me going.”
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Inner resources

- Fiona draws on her First Nations identity “We have to be strong, eh. We’ve put up with so much shit.”
 - Justine spoke of how important her mixed heritage was to her “I just made sure I took care of me, my medicine world, my spiritual, my mental, my emotional....it’s important...both sides of my heritage.”
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Activism

- Cathy talked about how working as an educator has “...actually helped me...I feel worthwhile, worthy, worthy, yeah.”
 - Justine spoke about how “...I talked about my life...I found it as being very healing.”
 - Coralee has continued involvement in the field. They are “...like family for me.”
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The importance of women centred HIV/AIDS support services

- All of the women utilized an ASO that was specifically for women and universally they liked it.
 - Natalie talked about how it was “...like one big family...the staff are really supportive...”
 - All of the women primarily looked to their positive friends for social support
 - Mary said “[they’re] the only friends I have...[and]...we try to support each other.”
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The Struggle to Stay Well

- Lack of HIV knowledge
 - Underutilization of health care services
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Lack of HIV knowledge


- Many of the women were surprised about their diagnosis, despite their vulnerabilities for infection
- Cathy talked about how she expected her test to be negative because “I didn’t think it was ever going to happen to me.”
- Justine is not on treatment despite a CD4 of 30 because she thinks “...ART is not a hundred percent...I chose to fight and do it on my own.”


Underutilization of health care services

- When Natalie was pregnant and living out in a rural community her partner had to “...just stay home, he took off some time...” to drive her to appointments
- Elizabeth talked about how “leaning on the crack pipe” made it difficult to make her appointments
- Coralee stated “...women have to leave their community to come and see their doctors...the HIV specialists and that.”
- The women did not want to access services because of the treatment they had received “...I miscarried a baby and I went to the hospital and I got such horrible treatment like as soon as I told them I was HIV+”




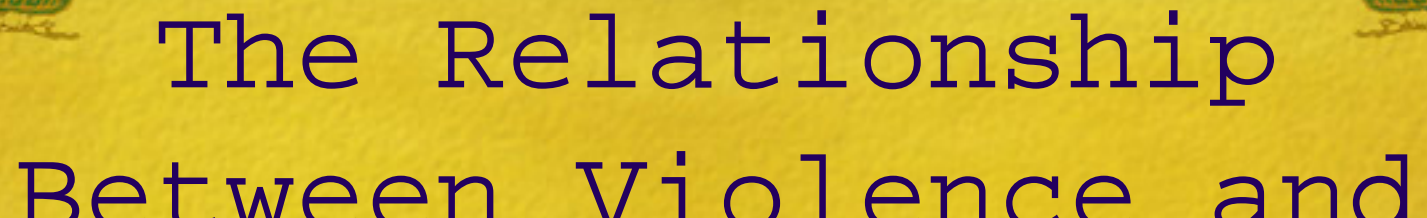
HIV is Just One Problem Among Many

- The effect of poverty and unstable housing
 - Struggles with substance use
 - The burden of history
 - The relationship between violence and HIV/AIDS
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The Effect of Poverty and Unstable Housing

- Many of the women had substandard housing, which has been clearly linked to poor health
 - Cathy talked about the insecurity of her housing “...I have people fucking ripping me off, I have people come in my house fucking stealing my food...”
 - Elizabeth talked about the difficulty of managing her ART “The dietitian wants me to eat and right now it’s virtually impossible.”
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The Relationship Between Violence and HIV/AIDS

- Elizabeth related a long history of violence from her partner and as a child and its impact on her life “I try to get to [the specialty clinic] but it’s hard.”
 - Coralee talked about her second marriage, which was “...extremely violent.”
 - Elizabeth’s partner has convinced her that she infected him and she keeps going back despite the abuse because “...of the guilt.”
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The Burden of History

- The judgement and discrimination that these women have experienced throughout their lives have left them vulnerable
 - Justine said "...being a First Nations or Aboriginal woman has certainly left them very vulnerable to being infected with HIV just because of things, the history of their lives. It's called loving in all the wrong places."
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Struggles with Substance Use

- Drug addiction was a barrier for most of these women
 - As Elizabeth said “...I hate leaning on the crack pipe...I don’t even enjoy it anymore...but that’s all I think about.”
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Overarching Themes that Link the Findings

- Intersectionality - a powerful constellation of inequities impacted on the ability of the women to live well
 - Social suffering - the long term, institutionalized and ultimately invisible suffering which has been referred to as the “soft knife” of long term oppression (Adelson, 2001)
 - Resilience - the innate resilience of the women in the face of insurmountable odds must be acknowledged and fostered
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Recommendations

- Disseminate research findings: conferences, journals, etc.
- Recommend policy change re: apprehending children - these women would probably do much better if they had custody or at least liberal access
- Accessible health care services for Aboriginal women with HIV around the province - need to be general in nature, not specifically aimed at HIV+ women
- Better HIV/AIDS education for health care providers
- Integration of cultural safety principles into professional practice
- Interventions that support and facilitate resilience
- Aboriginal leaders need to take ownership of the problem
- Ethnographic and quantitative research to further explicate and understand the experiences of Aboriginal women who are living with HIV/AIDS as well as to identify the resilient characteristics that they bring to their experiences