Narrative Ethics:

Understanding Marginalized Realities

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Marginalized populations:

- Aboriginal women (interviews)
- People with neuropsychological challenges ("illness narratives")
Native Peoples at time of European contact
Introduction

• CVD (cardiovascular disease) is often viewed as a "white man's sickness."

• Aboriginal women present with the highest rate of cardiovascular disease (CVD) and related mortality of any population group in Canada.

• Literature has focused on prevention and rehabilitation interventions.
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Colonialization

- diverse Aboriginal cultures, but commonality is history of colonialization
- systematic removal of “Indianness” and “aggressive assimilation”
- outlawing of cultural practices
- reserves placed in barren areas, not longer nomadic
- residential schools (until 1980s); formal apology from Canadian government in 2008

Patriarchy

- legacy variable amongst groups, but almost always includes unemployment, low education attainment, high rates of violence and poverty, poor psychological and mental health
Reconciliation Of Ethical Spaces

Ethical space refers to the totality of a community's principles, values and beliefs. When the ethical spaces of two or more communities meet, there may be a need to reconcile differences among those ethical spaces in ways that respect and protect the validity of each.
Community Control And Approval Processes

A community's jurisdiction over the conduct of research should be understood and respected.

A researcher who proposes to carry out research that touches on traditional or sacred knowledge of an Aboriginal community, or on community members as Aboriginal people, should consult the community leaders to obtain their consent before approaching community members individually.
What is sickness and health?

- Aboriginals view sickness as a manifestation of community imbalance therefore:
  1) the sick person does not have to shoulder the stigma or burden of sickness
  2) the root cause of sickness cannot be addressed by providing individualized treatment

- Western medical model localizes sickness with the organism therefore:
  1) the sick person shoulders the stigma or burden of sickness
  2) the root cause of sickness can be addressed by providing individualized treatment
What is sickness and health?
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Sacred Space And Traditional Knowledge

A researcher should understand and respect Aboriginal world views, including responsibilities to the people and culture that flow from being granted access to traditional or sacred knowledge. These should be incorporated into research agreements, to the extent possible.
Participatory Research

Communities should be given the option of a participatory-research approach.

An Aboriginal community should have an opportunity to participate in the interpretation of data and the review of conclusions drawn from the research to ensure accuracy and cultural sensitivity of interpretation.
Benefits

Research should be of benefit to the community as well as to the researcher.

A researcher should support education and training of Aboriginal people in the community, including training in research methods and ethics.
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Marginalized populations:

- Aboriginal women
- People with neuropsychological challenges
Ethical spaces
Ethical spaces
local knowledge
Ethical spaces

local knowledge / local theory of narrative
Ethical spaces

local knowledge / local theory of narrative

*Emic* vs. *etic*
Ethical spaces

local knowledge / local theory of narrative

*Emic vs. etic*

meaningful to the actor vs. meaningful to the observer
Ethical spaces
local knowledge / local theory of narrative

**Emic vs. etic**
meaningful to the actor vs. meaningful to the observer

**Illness narratives**
Ethical spaces
local knowledge / local theory of narrative

*Emic vs. etic*
meaningful to the actor vs. meaningful to the observer

Illness narratives
Narrative co-constructions / Joint narratives
Conversational narratives / Talk-in-interaction
Ethical spaces

local knowledge / local theory of narrative

*Emic vs. etic*

meaningful to the actor vs. meaningful to the observer

Illness narratives

Narrative co-constructions / Joint narratives
Convitational narratives / Talk-in-interaction

Asymmetric ethical spaces
Ethical spaces
local knowledge / local theory of narrative

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**Illness narratives**
Narrative co-constructions / Joint narratives
Conversational narratives / Talk-in-interaction

**Asymmetric ethical spaces**
Scaffolding narratives (supporting)
Ethical spaces

local knowledge / local theory of narrative

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Illness narratives

Narrative co-constructions / Joint narratives
Conversational narratives / Talk-in-interaction

Asymmetric ethical spaces

Scaffolding narratives (supporting)
Elaborative narratives (supplemental)
Ethical spaces
  local knowledge / local theory of narrative

*Emic vs. etic*
  meaningful to the actor vs. meaningful to the observer

Illness narratives
  Narrative co-constructions / Joint narratives
  Conversational narratives / Talk-in-interaction

Asymmetric ethical spaces
  Scaffolding narratives (supporting)
  Elaborative narratives (supplemental)
  Vicarious narratives (substituting)
(1) What is the view of illness and health emerging in the interview, and how is it narratively construed?
(1) What is the view of illness and health emerging in the interview, and how is it narratively construed?

(2) What is the “life story” emerging in the interview, and how is it narratively construed?
(1) What is the view of illness and health emerging in the interview, and how is it narratively construed?

(2) What is the “life story” emerging in the interview, and how is it narratively construed?

(3) What role plays the interviewer? What kind of interaction – what discursive dynamic – is unfolded in the interview?