Partnerships across the Line: Arthritis research in a First Nations community

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Heather McDonald, PhD(c), R.N.

Margaret George, Claudette George

Cheyenne Hood, Connie Thomas

Acknowledgements

- * Tsleil-Waututh Nation
 - Community Advisory Committee
 - Research Assistants
 - Participants
 - Chief and Council
- UBC supervisory committee
- * CIHR, MSFHR, APN Chair

Outline

- * Background
 - Aboriginal health
 - Decolonizing research
- Arthritis in First Nations
 - What happened
 - Community perspectives
 - Lessons learned



- * Aboriginal health: colonization
 - Past legacy of research
 - Bad blood research
- Promising examples of how to do it right

Decolonizing Methodologies

- * Past research
 - Representation of peoples (savage/noble)
 - Interpretations
 - Harvesting indigenous knowledge
 - Best intentions
 - Whose problems?
 - Whose solutions?

Decolonizing Methodologies

- Current predicament
 - Neo-colonialism
 - Health disparities
 - Culture = disease
 - Boundaries
 - Researched to death
 - Only Aboriginals ought to do Aboriginal research

Decolonizing Methodologies

- * Linda Tuhiwai Smith: Self determination
 - Culturally appropriate
 - non exploitive
 - empowering
 - productive

Other Guidelines

- * OCAP
- * CIHR
- * BC ACADRE
- Paradigm of inquiry: Critical
 - Post colonial feminist + Aboriginal epistemology
 - Two-eyed seeing

Arthritis in First Nations

- Understanding the health gap
 - Historical practices
 - Current conditions
 - The health system
 - Organization
 - Delivery
 - Utilization

Ethnographic Methods

- * Researcher as instrument
- Prolonged engagement
- * Reflective journaling/Fieldnotes
- * PO and interviews
 - 15-25 Community members
 - 15-25 HCP
- Document analysis

Arthritis in First Nations

- Becoming known and providing service
- Community Advisory Committee
 - Memo of understanding
 - Culturally relevant; productive
- Research Assistants
 - Training
 - Empowering?

Community Perspectives

- * Go little white girl go
 - Accepted and optimistic about outcomes
- * What are we getting out of it?
 - Learning about arthritis (personal) and the health system (feeling like I'm not alone, chance to talk about my experiences)
 - Training about research
 - Employment
 - Research! (answers?) (improved health services?)
 - An opportunity to participate in a community program

Community Perspectives

Margaret

- One of first researches where there will actually be results.
- Opens the door to better use of the system
- People learning how to work with our own people
- Issues of confidentiality



- Claudette
 - Personal growth
 - Interview processes
 - The benefits of our tag team approach

Community Perspectives

- * Cheyenne
 - Learning to be respectful of people's boundaries
 - Learning about the health system



- * Connie
 - Emotional effects
 - Training/gaining skills
 - Support
 - This is important work

Lessons learned

- * Who does the interviews?
- Interview protocols
- * Who is in control?
 - Community way of life/values
- Learning and growing together
 - Takes time
- Remain open



* The goal of this research is to learn something 'from' rather than 'about' First Nations peoples (Marker, 2003)