

# Resilience, resistance, ability expectations and buy-in to health care: Aboriginal peoples with arthritis speak

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## BACKGROUND

### Alberta Aboriginal Population

- consist of First Nations, Inuit and Métis
- make up 5.8% (N=188 365) of the total Alberta population (N=3,256,360)
- live in urban and rural areas
  - 45 First Nations in 3 treaty areas and 140 Reserves
  - 8 Métis settlements

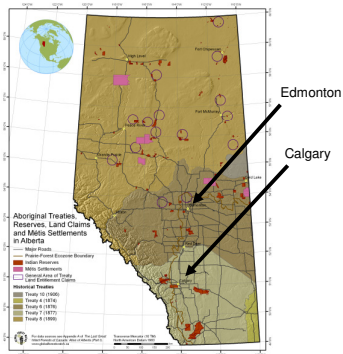


Figure 1: Map of Alberta, including Aboriginal Reserves and Métis Settlements

### Arthritis

- is a leading cause of disability in Canada
- includes approximately 100 types of arthritis,
  - e.g., rheumatoid arthritis (RA) and osteoarthritis (OA)
- is characterized by the breakdown of cartilage in joints causing pain, stiffness, swelling and decreased range of motion in the affected joints



Figure 2: Joint deformity in the hands common in untreated RA

### Arthritis in Aboriginal Peoples

- have 1.3 to 1.6 higher rates of arthritis than non-Aboriginal peoples
- have greater severity and earlier onset of RA
- receive 1/3 fewer appointments with rheumatologists and orthopaedic surgeons and 2/3 fewer hip and knee replacement surgeries than non-Aboriginal peoples

## DESIGN

This qualitative study employed constructivist grounded theory method.

Participants included patients and health care professionals recruited through clinics, community organizations, and professional networks in Edmonton and Calgary, Alberta.

Four trained interviewers conducted semi-structured interviews ranging in length from 27 to 98 minutes.

## ANALYSIS

Each interview was recorded and transcribed verbatim by a trained transcriptionist. Analysis of health professional and patient interviews occurred in parallel, allowing for contrast and comparison of the two groups throughout. Theoretical sampling occurred concurrently with analysis. Preliminary coding was done by S. Coupal, followed by team analysis.

## RESULTS: Sample Description

### Patients

- 16 Aboriginal people with arthritis
- 14 actively receiving care from specialists
  - 8 females, 8 males
  - age: 30 to 76 years
  - arthritis type: rheumatoid (n=5), osteoarthritis (n=3), both (n=1), and didn't know (n=7)
  - experiencing symptoms for a few months to most of their life

### Health Professionals

- 15 healthcare professionals
- 12 females, 3 males
  - professions: nurses (n=6); physiotherapists (n=2); rheumatologists (n=2); general practitioners (n=2); orthopaedic surgeon (n=1); occupational therapist (n=1); physiotherapy/occupational therapy assistant (n=1)
  - at their current position for 2 to 23 years

## RESULTS: Participant Experience

### Patients

Arthritis was constructed as a disease that followed other physical traumas, and was perceived as so common that it was almost normalized

- 11/16 Aboriginal participants named a relative who also had arthritis
- 3 participants named 5 or more family members with arthritis

Pain, stiffness, and loss of mobility were commonly described features of the arthritis experience, as were emotional consequences and depression from this disability.

*"Um, like, um, it makes me, it makes me frustrated 'cause, um....like because I, like I can do all these things, lift heavy things. Like before I started experiencing this and now it makes me frustrated; I couldn't even open that door....and my eyes started crying."*

Family support was key to being strong, to getting information and making choices about when to access healthcare.

Participants with arthritis discussed how health professional behaviour and relationship issues affected their choices.

*"I find the best thing for me to do is just walk away because Lord knows I don't, I don't take kindly to people that treat me that way or anybody else for that matter and the best thing was just to walk off. She [the doctor] was talking to my daughter and my daughter said no, she says you don't, she, my mother is not going to talk to you anymore."*

### Health Professionals

Health professionals found it frustrating that Aboriginal patients

- had delayed contact with the health system
- missed appointments

*"I guess the fact is for a certain segment of our population, you cannot assume that they're going to come back you know so if you have something that you need to tell them, you, it's very problematic to say well I'll re, rebook and we'll go through this when you rebook because I think people need to know in their head that the chances of those people rebooking are very slim right."*

Participants identified material barriers to care that overlap

- socioeconomic status (e.g., homelessness)
- transportation and distance to clinic
- communication challenges (e.g., lack of a phone for follow-up)

## RESULTS: Theoretical Framework

The framing of the problem of access to care differed between health professionals and patients with arthritis (see Figure 3).

### Patients

'Toughing it out' was a common theme among all participants with arthritis who also experienced a lot of family, community, and social challenges. 'Toughing it out' was a term used for being strong.

*"the guy [father] showed up what, what strong meant you know you gotta, you gotta be strong. You gotta, you never give up."*

On one hand, 'toughing it out' was linked to resistance to help; on the other hand, it also fostered resilience.

### Health Professionals

Health professionals tended to frame the issue as patients lacking 'buy-in'. Buy-in was defined in terms of patient compliance, adherence, and cooperation.

*"I think it might have to do with access [to health services] but even if the access were there, it, it might also have to do with their own buy in, um, like do they, do they feel that the health professionals that are, that they do see are actually going to be helping them, will they seek the help."*

Health professionals mainly looked to patient education regarding arthritis management to change patient behaviour.

Health professionals expected Aboriginal patients to make the same choices as non-Aboriginal patients thus revealing ability expectations. They expected Aboriginal people to overcome material barriers.

### Systems

Complex health care systems, controlled by multiple levels of governance, exist for Aboriginal participants with arthritis and healthcare providers

- e.g., for some Aboriginal patients medication is paid for by the federal government, and only certain medications are covered

## DISCUSSION AND CONCLUSION

Ability expectations can become normative and slide into ableism (Wolbring, 2012)

- as Wolbring explains, ableism "does not have to be negative: it simply indicates that one has certain ability expectations one lives out...ableism used in a negative way leads to disability" (p. 294-5) and stereotyping
- for example, when a patient's ability to keep appointments is deemed essential by a health professional, the result is ableism
- the ability expectations lens aids in understanding how inequities can be created and reinforced unintentionally when service models are 'one-size fits all'

The tendency to focus on solutions at the level of patients is common in health; however, health promotion suggests alternative approaches to reducing inequities

- international work on creating culturally safe health care
- on-reserve speciality clinics were examples of 'working around the systems' and were highly valued by patients
  - these clinics reduce travel and financial barriers
  - a health professional's willingness to work within the community may improve patient perceptions
  - willingness to change models of service (e.g., drop-ins allowed) increases access
- 'working around the system' is often required of patients and providers
  - e.g., patient outreach workers to reduce communication and transportation challenges

## ACKNOWLEDGEMENTS

We would like to thank the patients and professionals who participated.

This is part of a larger project, and we acknowledge our colleagues Dr. Lynden (Lindsay) Crowshoe, Dr. Joanne Homik, and Dr. Deborah Marshall.

Funding was provided by Alberta Innovates Health Solutions and Canadian Initiative for Outcomes in Rheumatology cARe (CIORA).

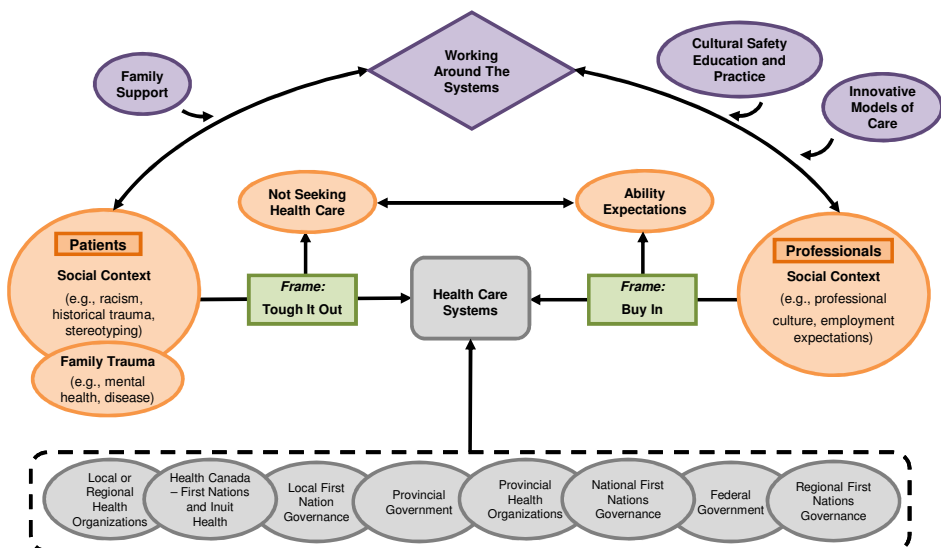


Figure 3: Theoretical Framework