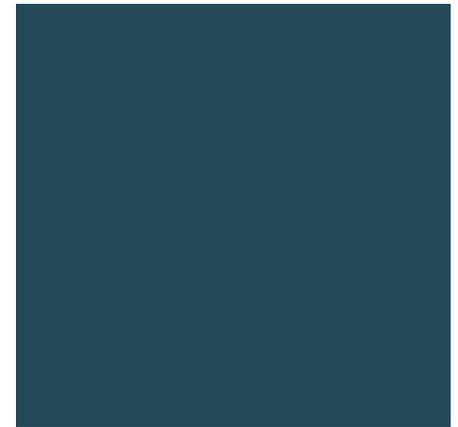




19th Annual
Conference of the
Union-North America
Region
Vancouver, BC



Tipping Points in the TB Experience of
Aboriginal Peoples of the Canadian
Prairies

+ Determinants of the Tuberculosis Transmission (DTT) Project Scientific Team and Study Coordinators

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McGill

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Aboriginal Peoples of the Prairie Provinces

Special thanks to the 56 people
who shared their stories

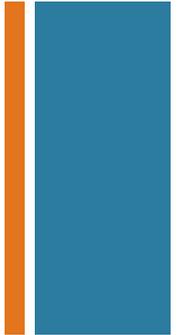
Funding

CIHR & FNIHB



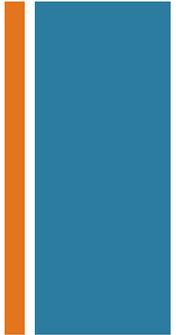
UNIVERSITY
OF MANITOBA

+ Learning Objectives



- Discuss the impetus and impact of ‘normalization’ of TB symptoms
- Describe factors identified in the study that influenced care-seeking
- Compare and contrast the TB disease and diagnosis experience according to location of residence (i.e., urban/non-remote and remote/isolated)

+ Outline



- Incidence Rates Among Aboriginal Peoples
- Determinants of Tuberculosis Transmission (DTT) Project Description
 - Community Involvement
- Methods
- Key Findings
- Conclusion

+ Incidence Rates Among Aboriginal Peoples

- Incidence rates for TB were 29.2 per 100,000 for the total Aboriginal population of Canada (TB in Canada, 2012), compared to the national rate of 4.8. (PHAC, 2012)
- Across the three Prairie Provinces these rates varied (45.6 in Manitoba; 35.3 in Saskatchewan; and 19.9 in Alberta)

Determinants of TB Transmission (DTT) Project Description

- Ultimate Goal - Eliminate TB by determining methods that might interrupt the transmission in the organism in the future
- Of the many determinants of TB disease, the so-called classical “social determinants of health” are perhaps the most important given that the disease has long been called, “a social disease with a medical aspect” (Canadian physician, William Osler).
- Those social determinants of TB transmission can best be understood through the stories of those individuals who have become ill enough with TB that they are also infectious





Community Involvement



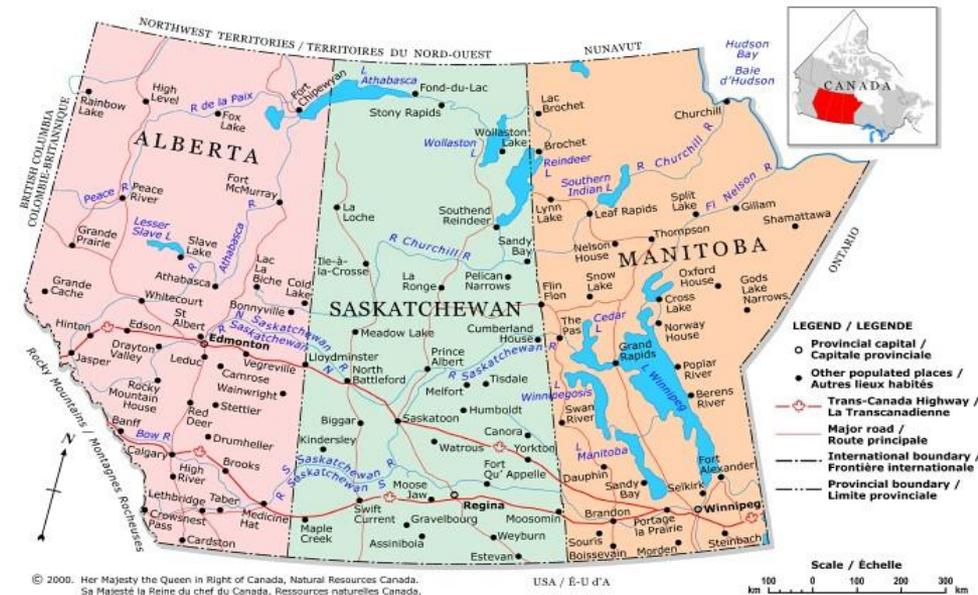
Provincial Network Committees (PNCs) were struck in each province with representatives from high-incidence communities, Aboriginal organizations, TB health providers, and Control programs

- Reviewed and approved **data collection tools**
- Assisted with **letters of introduction** on project & visits to Chiefs, Band Councilors, Health Directors, CEO's of Regional Health Authorities (greetings in Indigenous languages)
- Were honored through **ceremony** prior to PNC meetings
- Assisted in **interpretation** of the data

Support and ethical approval was granted from a number of Aboriginal organizations, Health Canada, and Universities involved

Participants and Data Collection

- Age >14 years
- Canadian-born persons diagnosed with culture-positive pulmonary TB
- On the Prairies (AB, SK, MB)
- Between Jan 1, 2007- December 31st 2008



248
Adult, Canadian-born
Culture-positive pulmonary TB cases

65
Without a quantitative questionnaire

183
With a quantitative questionnaire

34
Not invited to see
the study
coordinator

19
Died
(17 Aboriginal)

12
Declined

112
Sputum smear-
positive

71
Sputum smear-
negative

55
With a qualitative interview

Age:	15-34 years (n=23) 41%
	35-64 years (n=32) 58%
Sex:	Female (n=29) 53%
	Male (n=26) 47%
Population Group:	First Nations (n=37) 67%
	Métis (n=17) 31%
	Inuit (n=1) 2%

+ Interview Analysis

- How and why do people arrive at such an advanced stage of disease?



Guided by questions:

- How do participants describe a healthy person?
- What words are people using to describe how they feel?
- What is the baseline 'usual' against which participants are comparing their symptoms?
- What made the participants decide "something is wrong with me and I need help"? "The Tipping Point"

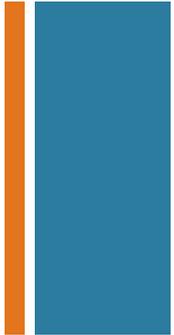
† How do participants describe a “healthy” person?



Overwhelmingly and consistently for men and women at all ages, and in all three provinces, feeling healthy is about being energetic, engaged, and essentially happy

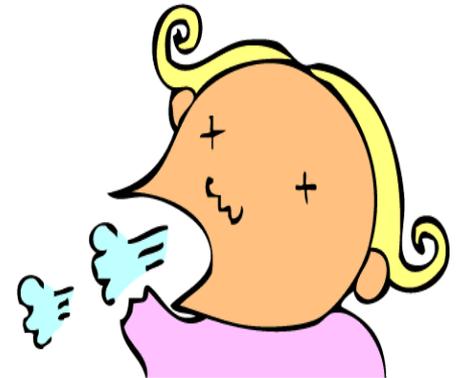


- “if I was healthier my house would be clean every day. I would go to school.... I would walk around everywhere. Go visit. I would have a smile on my face every day.” SK
- “...I don’t feel like lying down or anything. I just wanna go out and do something and I’d be doing it.” MB
- “...well I’d walk around a lot of times, steady I walk. And get up, just walk, walk steady for all day and I don’t feel like lazy and stuff like that”
“Yah... I feel like excited every day” SK
- “Well someone that’s happy (pause)... like stable in life, has a lot of things happening to keep him or her busy, friends, family...” AB



+ What words are participants using to describe how they feel?

- Sleepy,
- Takes too long to do something,
- Spitting up phlegm
- Sore ribs, chest pain,
- Get really tired really fast
- Bones were sore, muscles sore, back sore
- Heartburn
- Couldn't breathe
- Skinny and long-haired and looked terrible



In the weeks and months before their TB diagnosis, many of these symptoms were present and noticeable

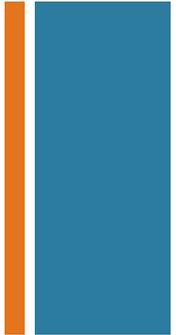
+ What is the baseline 'usual' against which participants are comparing their symptoms?

Lots of things that were typical of their usual day made it easy to ignore/normalize/mask symptoms





- **Fatigue = unhappiness and loss (relationship, loved one)**
- **Coughing = smoking**
 - I'd have to always spit up a lot of sputum and in the morning I just thought it was like my smoker's cough or you know like just a mild cold AB
- **Weight loss/lack of appetite = substance use**
 - "...started coughing couldn't stop....quit drinking –still not feeling good, losing weight..." MB
- **"Lazy"/Tired = aging**
 - "...Generally I've been, for the last couple of years I guess, I've been kind of lazy maybe because I am getting old but that's just an excuse." MB



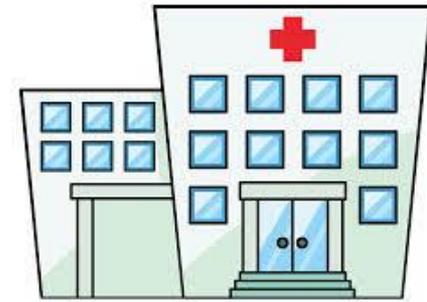
+ Keep Going

Symptoms of increasing severity that they cope with by sleeping, or medicating with painkillers.



- “...and I started coughing lots. I couldn’t, I can’t walk long ways. I get tired really fast so I figure it’s just the flu you know and then it just went on and on like that... then I started taking these, uh, seeing doctors about pain killers. I started taking Tylenol 3s...That kept me going. I lived with this thing all winter like that... I was boarding with my sisters... I slept lots. I didn’t even eat very much. I smoked a lot of cigarettes.” AB.
- I’d take either an Advil or Aspirin and keep on going. AB

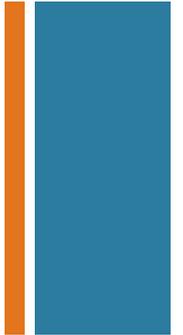
+ Fears



What drives participants to keep going, even when it begins to come clear to them that they are not well, is a constellation of fears

“ That’s when he told me. ‘Ah no. Come on. And I have heard of this where, where you have a hospital in _____ where I knew this one Inuit guy who was stuck in there for about three years, eh...’ He told me that. He says, ‘If they take, take you and throw you in there, you won’t get out there’ ...”

+ Fears



Others are worried they will lose their jobs if they become ill, citing the negative stereotype of Aboriginal peoples and alcohol as a factor.

- “I wanna keep working.. cause Aboriginals were getting fired there and I...if I’m...gonna call in sick... (they’ll) think that it’s just from drinking... I started brainwashing myself like that, you know. I don’t wanna go home, I’m not that sick, so I just kept going to work like that...” AB0040

+ What made the participants decide “something is wrong with me and I need help”?



The Tipping Point for participants was that they were no longer able to get through a day with the tasks they set out for themselves complete

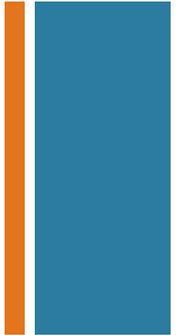
“I even knew I had to come to hospital but I just couldn’t face myself that I had to. And finally, finally, when I started falling down I, I had no choice then...”AB



Role of families and friends

Of key importance is that friends and family played an important role in getting the participants to see a health professional

“When I was getting sick at my brother’s place, he says “you’re sick man. Look at you. You’re dying on me....let’s go to the hospital.” Then he recruited [my other brother] to go on his side so now they’re ganging up on me. “Come on. You gotta go there.” “Ah come on you guys, quit bugging me now” and then I kept drinking. Then I started to pass out and stuff like that. That’s where I noticed that I’m pretty sick. [My brother] said “sometimes you just look like it’s not you. Your skin is grey” and I said “ya well I’ll go see a doctor.” (Alberta)

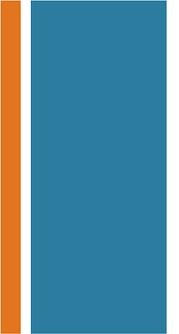


+ Healthcare encounters

- While participants had reached a point where they and their family members recognized the extent of illness, delays were commonly experienced in arriving at a TB diagnosis

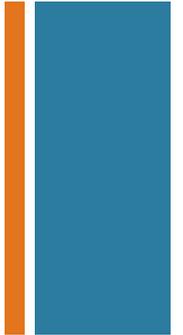


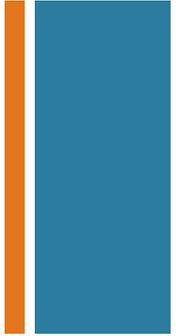
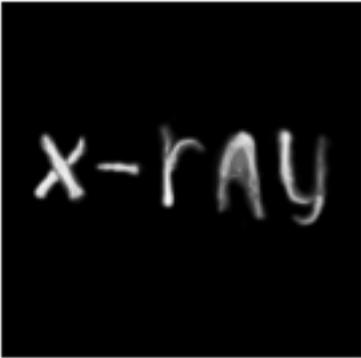
+ I kept going to the doctor. I kept going to walk-in clinics because I was feeling so, like my back was killing me, like I just felt like I had the flu all the time, and then my doctor thought it was the flu, and then when I'd run out, of course I'd been taking Tylenol all the time and if I knew I was gonna run out by the weekend, I'd go to the walk-in clinic. And then they looked at you kind of funny like, "oh you know, you're coming here for Tylenol." Well just give me regular Tylenol. I'm not popping pills but some of them kinda look at you funny, but I made sure that I had Tylenol all the time just to get rid of that pain, you know. (SK)





- He said “you should go see your family doctor. This is for emergencies.” I said, “doesn’t this sound like an emergency? It took me three times to come in here and you guys couldn’t prescribe anything right for me being better. There’s something going on here. First you guys told me it was bronchitis, now it’s pneumonia. There you go. Not only that. You’re the third different doctor that I’ve seen in emergency so I got three different doctors that don’t know what the fuck they’re doing.” And he said “yah, well don’t come. Go see your doctor next time.” So right when I left there I made an appointment to go see my doctor a week later. Same fucking thing when I went to see that other doctor. I said “Those people in emerg told me I should come see you” and he wasn’t really my family doctor but he was a different doctor. (Alberta)



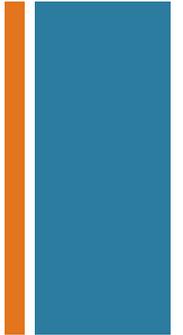


Most alarmingly, even when participants explained what they thought was wrong, the diagnosis could still be delayed.

- “My cousins were saying I had the signs of TB... asked her to bring me to the hospital....they gave me an x-ray and told me I had pneumonia. They gave me enough antibiotics for two weeks and it seemed like it didn’t work, so I went back to the same hospital... I told them I was in contact with someone with TB. It was a lie but I wanted to be tested...”

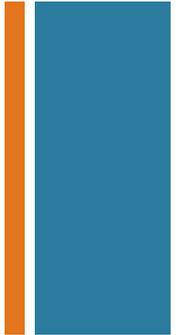
+ Objectives 1 and 2

- Discuss the impetus for and impact of ‘normalization’ of TB symptoms
 - What was the impetus for the normalization of TB symptoms?
 - **Living with poor health** (coughing, fatigue, weight loss)
 - What was the impact of the normalization of TB symptoms?
 - **Delayed seeking treatment**
- Describe factors that influenced care-seeking
 - What are the factors that influenced seeking of health care?
 - **Fears, Friends and Family, Misdiagnoses**



+ Key Message

- A constellation of population health determinants, a historically negative experience of healthcare under policies of colonization, and ongoing systemic negative perceptions of Aboriginal peoples are recognized as important conditions under which individuals evaluate their state of health and make decisions about accessing treatment



+ However, there is more to this story

- Objective:

- Compare and contrast the TB disease and diagnosis experience according to location of residence

- RQ: How does community setting (i.e., urban/no-remote and remote/isolated) influence the TB experience?

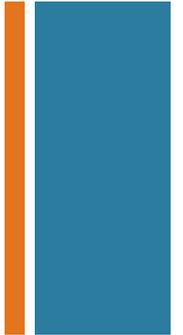


+ Urban/Non-Remote Reserve

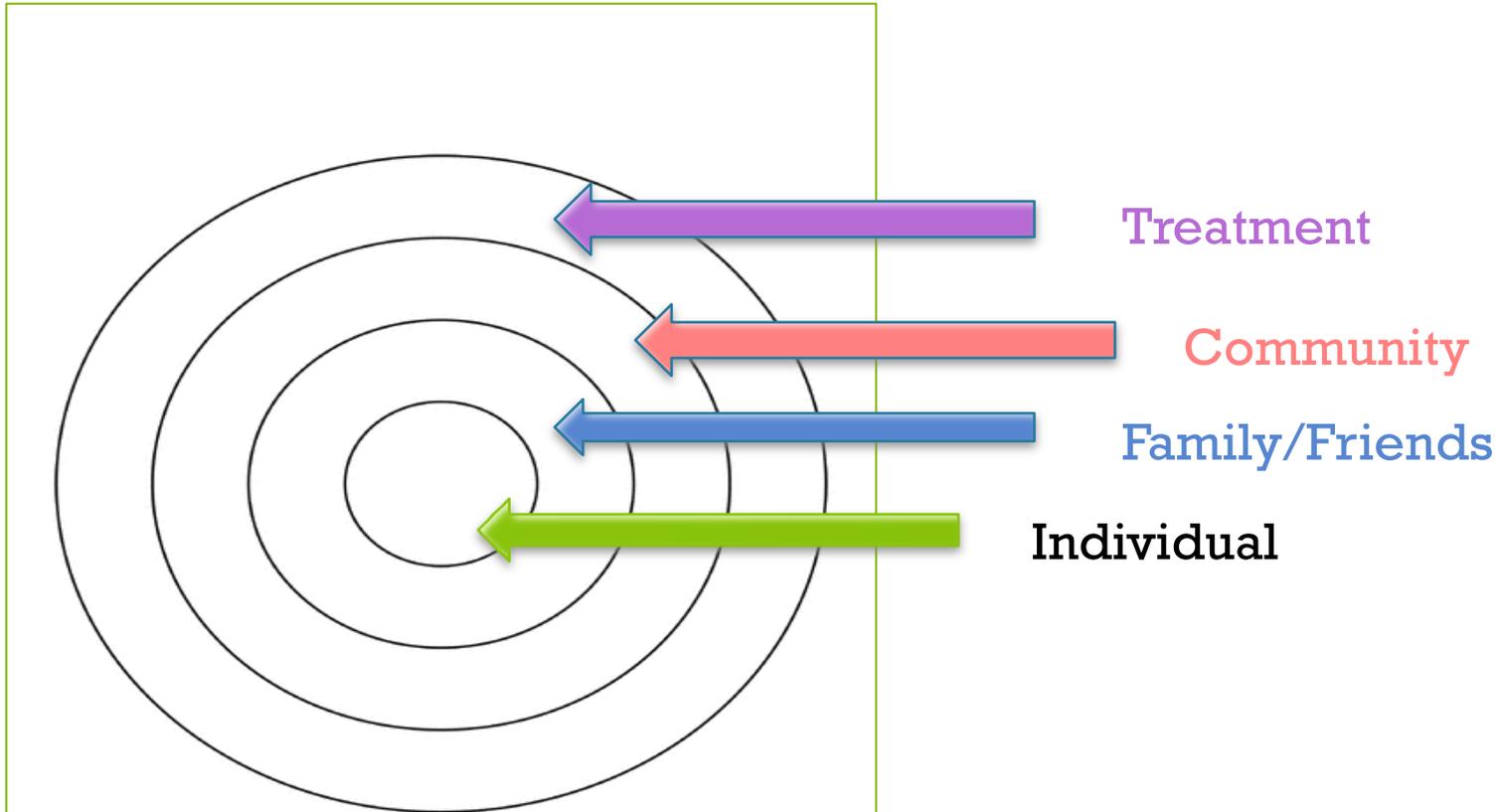
- Urban – is separated into (a) a small population centre (pop bw 1,000 and 29,999) (b) a medium population centre (pop bw 30,000 and 99,999) and (c) a large urban population centre (pop over 100,000). (Statistics Canada, 2011) Urban in this study included all three
- Non-Remote Reserve – is located under 350 km from an urban centre (Health Canada, 2012).

Remote/Isolated Reserve

- Remote Reserve –over 350 km from the nearest service centre and has year-round road access” (Health Canada (2012) p.28).
- Isolated – has scheduled flights and good telephone services, however it is without year-round road access” (Health Canada, 2012, p.27)



+ An ecological model



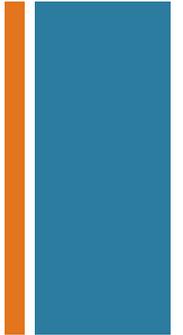
RQ: How does community setting (i.e., urban/no-remote and remote/isolated) influence the TB experience at the individual, family, community and treatment levels?



In Relation to the Tipping Point:

Community

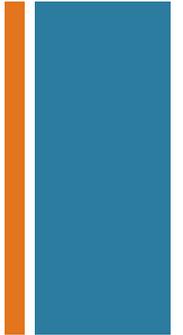
- Experience with health care provision
 - **Urban/Non-remote** group did not have a family doctor and frequented walk in clinics and emergency rooms in some of the best hospitals in their province, yet were consistently met with negative perceptions and misdiagnoses.
 - **Isolated/Remote** accessed nursing stations and community health centres, had relationships with the nurses, and were most times tested “immediately”.





■ The nurse came over to my house and they asked me “how you feeling?” “Feeling sick.” Well I went to the nursing station but you guys gave me this Tylenol but it doesn’t seem to help. I started feeling my chest, I thought I was short of breath. They said, “you have to come with us” you know. I said “okay” and I started walking outside and went to the truck like I was having a hard time breathing you and they said, “how is your chest?” And I just told them how is it and they gave oxygen you know, breathing. That’s when they just told me “you have to go” so at 7 o’clock at night and I stayed downstairs for 15 minutes and they just flew me to Saskatoon. (Saskatchewan, Isolated Reserve)

■ Individuals are still really sick, but it is possible that the Tipping point only happens once if health care provider diagnoses TB when individuals actually present with it.



Urban/Non-remote

Isolated/Remote

Tuberculosis Knowledge in the Community

Both had very little TB Knowledge

Reported annual community TB testing and TB events which *may* turn back tipping point

Family/Friend Encouragement to Seek Treatment

Both needed this to “push” them to seek treatment

who lacked social connections (e.g., some homeless), delayed “tipping point”

Urban/Non-remote

Isolated/Remote

Guilt about Family

Both felt guilt regarding possibly infecting their families and creating a burden for them

Talked about it in context of being isolated, flown out for treatment, making visits and communication very difficult . This was expressed in AB and MB interviews due to policy regarding isolation. Possible delay in “tipping point” as individuals are aware they will be removed from the community”?

Treatment Feelings of Loneliness and Being Punished

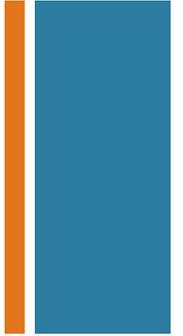
Both felt lonely and both in AB and MB felt like they were being punished

Again, *may* affect tipping point for participants in AB and MB because they are aware of the isolation experience.



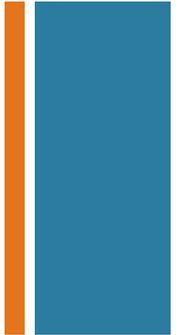
Conclusion

- The everyday 'usual' that people are comparing their feelings against differs in different populations for various and complex reasons
- Feelings that could be interpreted as TB Symptoms are easily masked/ explained away
- So, people "keep going"
- Out of fear of previous/historical experiences with the health care system, fear of losing work, and other fears
- If seeking care, often diagnosed with pneumonia, the flu...





Conclusion



- The point at which people seek care for TB disease under the circumstances described above is known as the “*tipping point*”. Family, friends were identified as important in identifying illness and need to be part of the effort to shifting the tipping point back so that those who contract TB are treated earlier and the concomitant cycle of transmission is interrupted.
- It is also important to consider the differences in health care for urban/non-reserve individuals and isolated/remote reserve individuals, and how effective a consistent health care provider can be, one that can identify changes in an individuals health and who has a relationship with the patient. Further, we need to appreciate how isolation policy disrupts relationships and feels punitive and the role of these emotions in the healing process.



Thanks