Community-Driven Research on H. pylori infection: Making Microbiology Data Meaningful in Indigenous Arctic Communities

Background:

The Aklavik H. pylori Project aims to respond to urgent requests from the community, facilitated by BK and PE. The project examines Helicobacter pylori bacterial infection and related stomach diseases in Aklavik, NWT, to generate relevant community health care providers' findings, the Aklavik Health Committee (AHC), and University of Alberta (UA) researchers. This initiative, supported by the Hamlet council and local Indigenous governments, targets several First Nation and First Nations research priorities, with data sharing and knowledge translation being central to these aims.

Community members want to know more about the genetics of H. pylori bacteria and how the organism lives, and spreads. AHCS wants community participation in designing dissemination materials.

Aklavik’s microbiology results:

- 44% of stomach biopsies displayed severe inflammation of the stomach lining (gastritis)
- Yet many Aklavik residents reported no symptoms
- 25% of Aklavik H. pylori are resistant to standard therapy
- Need alternative treatment strategies
- Aklavik H. pylori are genotypically very similar to each other and very different from H. pylori from other parts of the world

Project timeline:

September 2012:

Researchers traveled to Aklavik

Amy Colquhoun (SC) coordinated program and activities for exchange program
- Organized travel, accommodation, and activities for researchers and Aklavik resident
- Studies communication between Aklavik residents and UA researchers to:
  - Assess effectiveness of the exchange activities
  - Identify barriers to communication and cooperation
  - Develop KT strategies for the CANHelp Working Group

Sally Carrarah (SC) introduced Monika Keelan (MK) to key people in Aklavik and organized venues for various community presentations to:
- Meet community members and organizations
- Recruit youth for the KT exchange
- Listen to community members’ concerns about H. pylori infection and research.

October 2012:

Aklavik residents traveled to Edmonton

Bonnie Lynn Koe (BK) and Prairie Dawn Edwards (PE) met with researchers and the microbiology lab to learn about H. pylori’s influence:
- Cultural-long-term biographies and identified
- Tested against various antibiotics to determine treatment
- Studied to identify and compare genetics components
- Met with AC, CANHelp epidemiologists and public health researchers
- Attended the clinic of CANHelp gastroenterologist Dr. Sander van Zanten to learn how patients with stomach or intestinal disease are examined and diagnosed
- Labeled how endoscopies are done in a simulation lab
- Toured college campuses in Edmonton

December 2012:

Aklavik residents present to community

BK and PE presented to community members on their trip to Edmonton, and what they have learned about H. pylori bacteria and the results of the Aklavik H. pylori Project microbiology research.

BK and PE are in attendance at the 2012 ArcticNet conference to present our findings with SC and to learn what other kinds of research are happening in the Arctic.

Making microbiology meaningful: Six key findings

1) Residents well informed about:
- H. pylori is a bacterium that lives in the stomach lining, and can cause health problems including nausea, vomiting, ulcers, and stomach cancer
- H. pylori can be treated by taking antibiotics
- Once treated, it is possible to get re-infected

2) Residents less informed about:
- H. pylori infection occurs in different populations all over the world, not just in the North
- Not everyone who has H. pylori will get sick
- Although people have heard of DNA and germs, basic knowledge of genetics and micro-organisms are unfamiliar to many residents
- When UA researchers are not present in Aklavik, that does not mean that research activities have stopped, or that the project is over
- Many people do not know what happens to their breath samples and stomach biopsies in Edmonton

3) Residents’ questions:
- Where does H. pylori come from? (Is there an environmental source like water?)
- Residents with drug-resistant strains and previous treatment failures want to know why some medicines do not work
- Residents want to be proactive, and often ask what they can do to avoid acquiring H. pylori infection (related to local concerns that there is a possible environmental source)
- When will UA researchers return to Aklavik?

4) Researchers’ questions:
- Why do Aklavik residents have concerns about environmental sources of H. pylori, even though previous KT activities have emphasized person-to-person transmission? (There is a need to learn more about local understandings of risk, and to continue to acknowledge and address community concerns.)
- How do the cultural beliefs and worldviews of northern residents influence their understanding of the microbiology data presented to them?

5) Benefits of KT exchange:
- Observing lab and clinical activities first-hand helps to show that research does not stop when researchers are not physically present in Aklavik
- Getting to see the microbiology lab allowed BK and PE to learn what H. pylori look like, and how samples are prepared for genetic and drug-susceptibility testing.
- BK and PE learned that treating H. pylori with antibiotics is one way to protect people from developing stomach complications in the future
- Visiting Dr. van Zanten’s clinic allowed BK and PE to understand more of the personal side of stomach diseases and what patients have to go through if they are diagnosed with stomach cancer

6) KT challenges:
- Long distance between Aklavik and Edmonton can make direct, face to face communication challenging
- Expense of travel and accommodation limits the total number of people we can put into direct contact with each other
- Researchers and community residents display different cultural norms surrounding daily work schedules and routines
- General education in Aklavik does not cover a lot of biology or genetics, making microbiology education difficult for residents to understand