Addressing Arctic Health Concerns through Participatory and Collaborative Research

THE CANADIAN NORTH Helicobacter pylori (CANHelp) WORKING GROUP


13th Annual Arctic Health Sciences Seminar, Anchorage, Alaska, April 4, 2014
The CANHelp Working Group

Canadian North Helicobacter pylori Working Group

- A team of community leaders, practitioners, regional health officials, and scientific researchers:
  - Epidemiology
  - Microbiology
  - Gastroenterology
  - Pathology
  - Anthropology
  - Health Policy

- Established in 2006 to:
  - Address community concerns about the health risks related to H. pylori infection
  - Improve management of H. pylori infection
  - Gather evidence to inform regional health policy related to H. pylori management
Working with Aboriginal communities

- The Aklavik *H. pylori* Project (AHPP) is the CANHelp Working Group’s pilot project

- Meaningful knowledge translation (KT) is **crucial!**

- Informs our research process at all stages from initial planning to data collection, analysis, reporting of results, and healthcare action

**The Aklavik Health Committee (2012)**

Helicobacter pylori

- Bacteria that infect the human stomach lining

- Known health risks:
  - **Gastritis** (almost 100% of infected people)
    - Can be mild and asymptomatic, or severe
  - **Peptic ulcer disease** (~10% of infected people)
  - **Stomach cancer** (<1% of infected people)
Aklavik is a NWT community of ~625. Many residents are Inuvialuit or Gwich’in Aboriginal. Aklavik is not on a road system.

- **Community concerns**
  - Many people with *H. pylori* infection
  - Frequent *H. pylori* treatment failure
  - Community reports of stomach cancer – contemporary and in recent family histories

Background
Background

- **H. pylori infection = 60% across participating communities in Yukon and NWT**
  - **Aklavik 58% (194/332)**
  - **Old Crow 68% (126/186)**
  - **Tuktoyatuk 57% (58/102)**
  - **Fort McPherson 59% (117/199)**

<table>
<thead>
<tr>
<th>Place</th>
<th>Population</th>
<th>Age</th>
<th>n</th>
<th>HP+ %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chutkotka, Russia</td>
<td>Reshetnikov 1998</td>
<td>Native coastal village, males</td>
<td>Mean = 32</td>
<td>34</td>
</tr>
<tr>
<td>Nuuk, Greenland</td>
<td>Milman 2003</td>
<td>Population survey</td>
<td>22-76</td>
<td>71</td>
</tr>
<tr>
<td>Sismiut, Greenland</td>
<td>Koch 2005</td>
<td>Population-based sample</td>
<td>15-87</td>
<td>68</td>
</tr>
<tr>
<td>Norton Sound, Alaska</td>
<td>Zhu 2006</td>
<td>Regional Alaska Native villages</td>
<td>All ages</td>
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Background

Aklavik Microbiology results

- 44% of stomach biopsies displayed severe gastritis
  - 194 Aklavik endoscopies

- Yet many Aklavik residents reported no symptoms

- 25% of Aklavik *H. pylori* are resistant to standard therapy

- Aklavik *H. pylori* are genetically very similar to each other but very different from *H. pylori* strains from other parts of the world
Funded through the ArcticNet

Aklavik residents work together with university researchers to develop materials and media for reporting microbiology study results back to the community

• In appropriate social contexts
• In ways that make sense and will be most meaningful to community members

“Making Microbiology Meaningful”

The 2012 Aklavik KT team
Researchers travel to Aklavik

- Amy Colquhoun coordinated program and activities in Edmonton
- Sally Carraher introduced Monika Keelan to key people in Aklavik and organized activities in Aklavik
- Keelan gave community presentations to:
  - Health centre staff
  - Grade 10 science students
  - Elders at Joe Greenland Centre

Aklavik residents travel to Edmonton

- Bonnie Lynn Koe and Prairie Dawn Edwards met with the microbiology research staff to learn:
  - How \textit{H. pylori} is cultured from biopsies
  - Tested for antibiotic susceptibility
  - How \textit{H. pylori} genetics is studied
Aklavik residents present to scientific and Arctic communities

• Koe and Edwards attended the 2012 ArcticNet conference to present our findings and to learn what other kinds of research is happening in the Arctic

• Koe and Edwards presented to Aklavik residents 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
RESULTS

Residents well informed:
• *H. pylori* is a bacterium that lives in the stomach lining, and can cause health problems
• *H. pylori* can be treated by taking antibiotics
• Once treated, it is possible to get re-infected

Residents less informed:
• *H. pylori* infection occurs in different parts of the world
• Not everyone who has *H. pylori* will get sick
• DNA, micro-organisms
• What happens to biological samples

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
• Builds scientific understanding and local research capacity
• Lab researchers have a better understanding of community life and local priorities in the Arctic

KT challenges:
• Long distance and expense
• Differing cultural norms surrounding daily work schedules and routines
It’s bigger than just “different worldviews”

• Cultural perceptions of humans, microbes, health risks, and environment are not static

• Scientific knowledge is not monolithic
  • *Neither is community knowledge!

• Different communication practices and learning-needs must be considered

• Build deeper understandings on all sides of research questions, capacities, and possibilities

• Economic considerations

• Make research and knowledge translation fit with people’s other social priorities
Conclusions

• Knowledge exchange programs using collaborative teams and participatory approaches may greatly improve cross-cultural understandings and facilitate meaningful KT in all directions.

• Knowledge gaps and diverse cultural perceptions have been identified as areas of opportunity for future collaboration and engagement.
Next steps

- We’ve been awarded a renewal of our ArcticNet funding for this coming year

- Colquhoun, Carraher, Koe, Edwards, Goodman, and Keelan are devising strategies for:
  - Launching additional exchange projects
  - Building capacity for Koe and Edwards to recruit and mentor other Arctic residents through future exchange projects
  - Community data dissemination plans
  - Publication and presentation
Quyanainni!  Thank you!  Mahsi cho!

- Aklavik Health Committee
- Velma Illasiak
- Moose Kerr School
- Aurora College
- Joe Greenland Centre
- Aklavik Elders: Wilbur Papik, Sadie Whitbread, Ellen Arey