

The Meaning of Symptoms: Illness Narratives as a Means for Describing Self-Perceived Impacts of *H. pylori* Infection among Residents of an Arctic Community.

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INTRODUCTION

Helicobacter pylori Infection

- H. pylori* infection is a major cause of digestive diseases worldwide, although its occurrence is not evenly distributed across populations. Despite a relatively low prevalence of the infection in industrialized regions, Arctic communities in Canada are burdened with an elevated prevalence of this infection.



- In 2007, the Canadian North *Helicobacter pylori* (CANHelp) Working Group estimated the prevalence of *H. pylori* infection to be 58% in Aklavik, NT.

- As an important health disparity in the north, *H. pylori* also represents a significant public health concern given that many people with *H. pylori* infection remain asymptomatic. Thus, they do not seek medical care and their infection remains undetected and untreated.

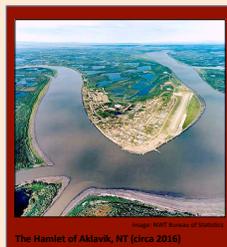
- High treatment failure in northern populations (potentially ranging as high as ~40% of patients treated in Aklavik, NT) reduce the effectiveness of interventions aimed at eliminating *H. pylori* infection as a means of preventing *H. pylori* associated diseases including: gastritis, stomach ulcers, and stomach cancer.

H. pylori and Community-Driven Research in the North

- Motivated by an invitation from community representatives to conduct research on the subject, the CANHelp Working Group has been engaging in community-driven research aimed at addressing *H. pylori* infection in Aklavik, NT for nearly a decade.

- In partnership with the Aklavik *H. pylori* Project Planning Committee, which is comprised of local community residents, this illness narrative pilot project has proceeded from the standpoint that given what is known about *H. pylori* infection in Arctic communities, it is evident that a conventional biomedical approach to managing this important health disparity is insufficient.

AKLAVIK, NT



- Aklavik is a small Arctic hamlet with a population of 668 residents according to the NT Bureau of Statistics data for 2015. The community is located on the west bank of the Mackenzie River Delta in the Northwest Territories, Canada.

- The community is multi-ethnic with the majority of residents identifying as either Gwich'in or Inuvialuit, but also including Métis people as well as individuals of European descent.

- Aklavik is 'remote': transport in and out of the community is limited to river traffic in the summer, travel by ice road in the winter months, or flying by air.

METHODOLOGY

- Interviewees for this pilot-project were recruited from among previous participants of the CANHelp Working Group's Aklavik *H. pylori* Project.

- Eligible participants included: adults (19 years of age or older, which is the age of majority in the Northwest Territories) who are current residents of Aklavik, NT.

- A target number of 10 interviews were conducted over the telephone from Edmonton using contact information previously collected by the CANHelp Working Group; audio recordings of interviews will be transcribed to facilitate qualitative content analysis.

- This pilot project is intended to test the interview tool developed for this research prior to expanding the project to a full-scale study to be conducted "on the ground" through in-person interviews in Aklavik later in 2016.

- A modified version of the McGill Illness Narrative Interview (MINI) tool was developed. This semi-structured interview tool was designed specifically to elicit illness narratives for qualitative research purposes.

- The MINI was selected since the open-ended responses that it yields have additional applications for cross-cultural health research that include broader studies of health in the Arctic in addition to facilitating *H. pylori* specific research goals.

Participant Recruitment Criteria	Number of Individuals
Number of Aklavik Residents (2015)	668
Previous participants of the Aklavik <i>H. Pylori</i> Project with contact information provided to the CANHelp Working Group	372
Previous participants of the Aklavik <i>H. Pylori</i> Project who provided a phone number with their contact information	251
Previous participants of the Aklavik <i>H. Pylori</i> Project who are of the legal age of majority in Aklavik (19 years or older)	215
Previous participants of the Aklavik <i>H. Pylori</i> Project who are not known to have died or to have left the community	202
Previous participants of the Aklavik <i>H. Pylori</i> Project who have not indicated a desire to project staff for no further communication regarding research projects	196
Previous participants of the Aklavik <i>H. Pylori</i> Project who are neither current nor former members of the Aklavik <i>H. pylori</i> Planning Committee, the CANHelp Working Group, or residents of their households.	188

PROJECT OVERVIEW

- The standard version of the MINI is traditionally used for assessing the social burden of chronic illnesses with clearly defined symptoms and a straightforward progression of the experience of the disease.

- Adapting the MINI for use in capturing people's experience with *H. pylori* infection proved challenging given that the disease is often asymptomatic.

- Preliminary review of the data highlights participants' healthcare experiences, as one interviewee noted that although she had had persistent heartburn, it was not until she received testing through the Aklavik *H. pylori* Project that it occurred to her that her symptoms might be caused by *H. pylori* infection.

- Overall attitudes regarding testing and treatment were characterized by a general sentiment that people feel *H. pylori* to be "an ongoing concern" in their community and that opportunities for knowledge translation regarding *H. pylori* remains an important community priority.

- This research employs an ethnographic approach to capture social and cultural dimensions of ill-health stemming from *H. pylori* infection in Arctic Canada. Interviews are directed at revealing the social implications of sickness, illness, and disease stemming from the bacterium, which represent the separate but interrelated perspectives of society, the patient, and the physician respectively.

- Given that a particular cause of ill-health cannot be meaningfully understood apart from its social and cultural context, each interview produces an illness narrative, which constitutes a person's story about their experiences surrounding *H. pylori* as a sickness, and illness, and a disease. Each of these in turn carry significant implications for individual patient outcomes, for managing the local disease burden from *H. pylori* infection, and for addressing the cost-effectiveness of health care provided for testing and treatment in the region.

'There is no culture-free way to think about disease'

RESULTS

- This pilot project has highlighted considerations for the development of future ethnographic projects in Arctic communities as well as indicating additional revisions to the modified MINI tool that should be undertaken in preparation for the full-scale study.

- Conducting interviews by telephone, while not ideal for ethnographic research, was nevertheless decided upon as a means of balancing the high cost of travel to Aklavik, NT with the fact that this is a small-scale pilot project intended to test the methodology prior to commencing the full-scale study that will entail travel to the Arctic community 'field site'.

Three challenges were encountered as a result of this approach:

- 1) The telephone was a highly unreliable means of contacting people for this project. Many people in Aklavik do not have home telephone service, and rely on messages being conveyed through friends and family.
- 2) Population mobility. Many people leave Aklavik temporarily or permanently to pursue education or work opportunities, to engage in traditional cultural or subsistence activities, or to travel for personal or health related trips.
- 3) A high failure rate to reach people via the telephone. Many people were not home or opted to not answer their telephone for unknown reasons. Many of the people telephoned also did not have answering machines, necessitating numerous attempts to reach a given individual at different times of day and on different days of the week.

- This pilot project has shown the adapted version of the MINI developed for this pilot project to be an effective tool for soliciting information about sickness, illness, and disease surrounding *H. pylori* infection in Aklavik.

- While the MINI promises to provide pertinent insights, it is evident based on the outcomes of this pilot project that even in its adapted form, the MINI is not well-suited to telephone interviews. Given the impersonal nature of the exchange, establishing rapport with interviewees is exceedingly difficult over the telephone, which undoubtedly limits the information that participants are willing to share in this context.

- Moving forward, further revisions will increase the opportunities for subjective, open-ended discourse as the structure of the tool, as it was employed in this project, occasionally forced the conversation along rather than allowing the discussion to develop organically.

- This has also highlighted the need for conducting this type of research "on the ground" in the community in order to allow the researcher to establish and build rapport with participants.

CONCLUSIONS

- This research provided insight into social and cultural dimensions of *H. pylori* infection and associated diseases among residents of Aklavik.

- This project could be expanded to incorporate other CANHelp Working Group partner communities in northern Canada. Broadening both the scope and depth of this research is important given that people, cultures, communities, and environments of Arctic Canada are not homogenous.

- The chronologically structured narratives that will result from each interview will provide important insights for better managing the health disparity characterized by *H. pylori* infection and associated diseases.

- Considered alongside biomedical frameworks, illness narratives constitute a powerful tool for solidifying multiple perspectives and ways of knowing about health and disease.

"I think that it help[s] lots of people...you know, to ask questions, and things like that."

Interviewee, asked if she would like to share anything else

(Female, age 66)