Whose burden? A comprehensive approach to describing burden of disease by synthesizing evidence from diverse perspectives

by

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Abstract

Epidemiologists tasked with addressing public concerns about a specific health issue and developing effective public health strategies aimed at reducing related health risks must begin by describing the extent of the health threat in the target population. Typical approaches use quantitative measurement of pertinent epidemiologic indicators to assess the impact of the health threat. To ensure that public health strategies developed through the investigative process are relevant to the target population, however, public health researchers can gain valuable insights by also ascertaining how affected members of the target population view the health issue and related risks. While existing literature espouses the benefits of building collective knowledge to capture the depth and complexity of health and disease, there is limited information on the most effective ways to synthesize different forms of evidence to construct a comprehensive assessment of the burden of disease.

Indigenous communities in the Northwest Territories and Yukon concerned about their high prevalence of *Helicobacter pylori* infection and the associated risk of stomach cancer are currently guiding research that addresses their concerns. In this dissertation, I report research I conducted as part of this community-driven research program to characterize the self-described impact of disease by individuals at risk and describe disease burden using more conventional epidemiologic approaches. I then describe the similarities and differences in disease burden assessed using diverse forms of evidence and synthesize this information to provide a comprehensive description of disease burden among those impacted. My synthesis confirmed a disproportionate impact of *H. pylori* infection and associated diseases among northern Indigenous populations compared to other groups. However, academic, healthcare, and community research partners did not appear to have a shared understanding of *H. pylori* and its impacts; furthermore, the burden attributed to *H. pylori* infection by northern community members may be broader than the burden as described by academic scientists and healthcare providers.

In addition to these contributions, this dissertation provides examples of best practices when using epidemiologic approaches to describe disease burden, particularly when community concerns about a specific health issue trigger investigations. Using examples of community-academic collaborations that identify and implement reciprocal learning initiatives and incorporate the target population's characterizations of the health problem, this work highlights the importance of building shared knowledge about a health issue of interest. Ultimately, this dissertation illustrates the value of incorporating diverse perspectives when seeking effective public health solutions.

Preface

This thesis is an original work by Amy Colquhoun (AC). The research program, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Addressing Community Concerns about Risks from *H. pylori* Infection in the Circumpolar North”, No. Pro00007868, October 19, 2010. Between 2010 and 2018, ethics approvals were updated as required. Northwest Territories and Yukon research licenses were also issued yearly during data collection periods.

Some of the research conducted as part of this dissertation was the result of collaborations. Collaborators are: Dr. Karen J Goodman (KJG), Laura Aplin (LA), Dr. Janis Geary (JG), Dr. Juanita Hatcher (JH), Dr. Sally Carraher (SC), Dr. Monika Keelan (MK), Bonnie Lynn Koe (BLK), Prairie Dawn Edwards (PDE), Dr. Christopher Fletcher (CF), Richard Papik (RP), Mary Jane Moses (MJM), Johanna Edwards (JE), Rachel Munday (RM), Skye Russell (SR), Doug Dover (DD), Vidhi Desai (VD), Freya Hik (FH), Sateen Werner (SW), Dr. Cindy Jardine (CJ), Dr. Heather Hannah (HH), Dr. André Corriveau (ACor), Dr. Yan Yuan (YY), Dr. Melina Arnold (MA), Jacques Ferlay (JF), Dr. David Forman (DF), Dr. Isabelle Söerjomataram (IS), and Dr. Brendan Hanley (BH). Their contributions are outlined in detail below.

The introductory and concluding sections of every Chapter, and Chapters 1, 2, and 9 in full are the original, unpublished work of the author. AC conceptualized and wrote each of these sections with guidance from KG, and input from CJ and YY.

Chapter 3 of this thesis includes two works previously published by Taylor & Francis. Chapter 3.1 was published as: Colquhoun A, Aplin L, Geary J, Goodman KJ, and Hatcher J (2011) Challenges created by data dissemination and access restrictions when attempting to address community concerns: individual privacy versus public wellbeing. *International Journal of Circumpolar Health* doi: 10.3402/ijch.v71i0.18414. AC conceptualized the article with input from LA and JG under the supervision of KJG and JH. AC drafted the manuscript and all other authors provided critical review and revision of the manuscript.

Chapter 3.2 was published as: Colquhoun A, Geary J, and Goodman KJ (2013) Challenges in conducting community-driven research created by differing ways of talking and thinking about science: a researcher's perspective. *International Journal of Circumpolar Health* doi: 10.3402/ijch.v72i0.21232. AC conceptualized the article with input from JG under the supervision of KJG. AC drafted the manuscript; JG and KJG critically reviewed the manuscript.

Chapter 4.1 is original work in preparation for submission for peer-reviewed publication under the co-authorship of AC, SC, MK, BLK, PDE, CF, and KJG. As the Principal Investigator, AC received grant funding to support this work from the Canadian Institutes of Health Research. AC, SC, and MK conceptualized the work with input from BLK, PDE, and KJG. AC prepared the first draft of the manuscript with input from SC, MK, BLK, PDE, CF, and KJG.

Chapter 4.2 is original work in preparation for submission for peer-reviewed publication under the co-authorship of AC, RP, MJM, JE, RM, SR, and KJG. RM initiated the first logo contest in Aklavik; AC conceptualized the use of the drawings for the work presented here. RP, MJM, JE, drew the winning logos in Aklavik, Old Crow, and Fort McPherson, respectfully; they also contributed descriptions of their work for this manuscript. AC drafted the manuscript with input from SR who contributed to the literature review. KJG supervised this work, providing critical input and review throughout.

Chapter 5.1 is original work in preparation for submission for peer-reviewed publication under the co-authorship of AC and KJG. AC conceptualized the article with input from KJG. AC drafted the manuscript and KJG critically reviewed it.

Chapter 5.2 is original work in preparation for submission for peer-reviewed publication under the co-authorship of AC, DD, and KJG. AC conceptualized the article with input from DD under the supervision of KJG. AC drafted the manuscript; DD and KJG critically reviewed the manuscript.

Chapter 6.1 is original research in preparation for submission for peer-reviewed publication under the co-authorship of AC, VD, FH, CJ, and KJG. AC designed the study with input from CJ and KJG. AC collected the data and, along with VD and FH, analyzed and interpreted the data. AC drafted the manuscript, which was critically revised by CJ and KJG.

Chapter 6.2 is original research in preparation for submission for peer-reviewed publication under the co-authorship of AC, SW, CJ, KJG, and the CAN*Help* Working Group. AC designed the study with input from CJ and KJG. Research assistants with the CAN*Help* Working Group, including AC and SW, collected structured interview data. AC and SW collected semi-structured interview data. AC analyzed and interpreted the data and drafted the manuscript. CJ and KJG critically revised the manuscript.

Chapter 7.1 is original work in preparation for submission for peer-reviewed publication under the co-authorship of AC, HH, ACor, YY, and KJG. AC designed the study, with input from KJG. HH and ACor facilitated data acquisition from the Northwest Territories. AC analyzed and interpreted the data, and drafted the manuscript, with input from YY and KJG. YY, and KJG critically revised the manuscript.

Chapter 7.2 includes a version of research accepted for publication in *Gut*, 2015, following peer review. The Version of Record can be accessed online at http://dx.doi.org/10.1136/gutjnl-2014-308915. This work, titled "Global patterns of cardia and non-cardia gastric cancer incidence in 2012," is reused here pursuant to the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 (CC-BY_NC-ND 4.0) International licence. AC, MA, DF, and IS conceptualized, designed, and drafted the manuscript. AC, MA, JF, KJG, DF, and IS analyzed and interpreted the data. JF, KJG, DF, and IS critically revised the manuscript. DF and IS supervised the study.

Chapter 7.3 is original work in preparation for submission for peer-reviewed publication under the co-authorship of AC, HH, ACor, BH, YY, and KJG. AC designed the study, with input from KJG, and gathered data from the International Agency for Research on Cancer. HH and ACor facilitated data acquisition from the Northwest Territories. AC analyzed and interpreted the data, and drafted the manuscript, with input from YY and KJG. YY and KJG critically revised the manuscript.

Finally, Chapter 8 is original work in preparation for submission for peer-reviewed publication under the co-authorship of AC, CJ, and KJG. AC designed the study, analyzed and interpreted the data, and drafted the manuscript with input from CJ and KJG. AC, CJ, and KJG. CJ and KJG critically revised the manuscript.

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Chapter 1: Introduction

If the pursuit of a PhD could be described as a journey, I would like to begin my account of this voyage as most tales do: at the beginning. In 2010, I was working with the provincial cancer surveillance team of Alberta Health Services (formerly the Alberta Cancer Board). One of my major roles was the coordination of community cancer incidence investigations. Whenever an Albertan community member voiced concerns about cancer incidence, I worked with community members and with public health surveillance and healthcare professionals to address concerns. This typically involved an assessment of whether there was an 'actual' problem with cancer incidence in the community, determined by comparing cancer rates within the area of concern to those of a reference population. If there was no evidence of elevated rates of cancer in these communities, as was typically the case, I would implement a series of communication techniques to alleviate concerns.

It became apparent to me through these investigations that this process had limitations. Some of these were distinctly methodological; challenges with cluster investigation methods, such as the complex etiology of diseases like cancer and the in- and out-migration of the target population, have been outlined succinctly by Goodman et al. (2014). Some investigation challenges could be described as more philosophical in nature: are scientists able to adequately address community concerns when there may be conflicting perspectives? For example, questions being addressed at the beginning of these investigations are often different: community members voice concerns about a problem they have identified while scientists first aim to determine whether there is a problem as they define it. Furthermore, views of how the community is impacted might differ: a cancer case contributing to disease rates in an isolated rural community, for example, is likely to have a different burden on that community compared to a cancer case contributing to rates in a city centre.

Inspired by these experiences and driven by what I perceived to be opportunities for improved social justice and risk communication practices, I have endeavoured to understand more about the interface between what may be described as 'information producer' and 'knowledge beneficiary' or, more specifically, between public health scientists and target populations. That is, put crudely, how can academic experts and members of the public without academic training with different (indeed, sometimes opposing) worldviews work together to resolve public health problems? This question is the thread that ties together this dissertation. Of course, more questions arise. For example, should the perspectives of those impacted be considered alongside the results of scientific investigations conducted by trained public health professionals? Should these perspectives be given equal weight? I do not explore these additional questions in depth in this dissertation; rather, I outline why the consideration of multiple perspectives is valuable and proceed with the premise that working together to address public health concerns will produce more meaningful and effective public health solutions.

To explore these concepts further, in this dissertation I aim to identify challenges and plausible solutions to working in community-university partnerships that seek to describe burden of disease. While there are a variety of ways that disease burden may be defined, such as the economic or social impacts of disease, epidemiologic inquiry typically considers disease burden in terms of morbidity-based measures: Last (2007) defines burden of disease as "The amount of ill health from a given cause (disease, injury, cause of disease, or risk factor) in a population of interest" (p. 46). Here, I question the meaningfulness of typical epidemiologic approaches to the description of disease burden, particularly when addressing community concerns about a specific health condition. I further illustrate the value of incorporating multiple perspectives in characterizations of disease burden in order to comprehensively inform its description.

I begin by describing the foundational principles which inform my perspective (Chapter 2). This includes a description of key theories and paradigms and an explanation of how my worldview impacts the work that is described in latter sections of the dissertation. Following this description, I outline challenges that limit one's ability to effectively achieve public health goals as well as plausible solutions (Chapter 3). I then provide examples of these solutions in action: I begin with descriptions of two community-university projects that support public health goals (Chapters 4) and subsequently outline how the use of multiple forms of evidence to describe disease burden can support public health initiatives (Chapter 5). In the next three chapters, I apply the principles introduced in Chapter 5 to comprehensively assess the burden of *Helicobacter pylori* infection and associated diseases in Canadian Indigenous communities using diverse forms of evidence. This includes the characterization of self-described burden of disease by individuals at risk (Chapter 6), quantification of disease burden using epidemiologic measures (Chapter 7), and characterization of the similarities and differences in disease burden assessed using diverse forms of evidence (Chapter 8). Lastly, I provide a summary of key points and reflections from my dissertation and outline the ways in which I would like to pursue these concepts in the future (Chapter 9).

Reference

Goodman, M., LaKind, J. S., Fagliano, J. A., Lash, T. L., Wiemels, J. L., Winn, D. M., … Mattison, D. R. (2014). Cancer cluster investigations: review of the past and proposals for the future. *International Journal of Environmental Research and Public Health*, *11*(2), 1479–1499. https://doi.org/10.3390/ijerph110201479

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Chapter 2: Guiding principles

The Merriam-Webster dictionary defines *worldview* as, “a comprehensive conception or apprehension of the world especially from a specific standpoint” ("Worldview", n.d.). Educated in the biomedical laboratory sciences, I had not given much thought to how my worldview might impact my approach to research. I entered into any research endeavour focused solely on the research question at hand with the assumption that the methods I was implementing to address this question were the most valid. My experiences working and travelling abroad and working in public health partnerships with people from various backgrounds gave me pause: I am now mindful that my perspectives are shaped by my experiences and that these perspectives inform my work in science. The view that scientists’ perspectives impact research practices is consistent with Kuhn’s assertion that the scientific community determines the validity of theories (Rothman, Greenland, & Lash, 2012). An example of this was provided by Rothman et al. (2012) in their textbook, *Modern Epidemiology*: “…observing the moons of Jupiter through a telescope seems to us like a direct observation, but only because the theory of optics on which the telescope is based is so well accepted” (p. 21). These experiences, readings, and reflections taught me the utility of considering who I am and how I view the world and the research process when endeavouring to undertake research activities.

My desire to reflect on my perspectives in my approach to research has been fortified through exposure to various research fields that place a high value on how a researcher’s worldview informs their work. As Maria Mayan stated, a researcher’s worldview, or paradigm, is “the net that holds the researcher’s ontology, epistemology, and theoretical position/perspective” (Mayan, 2009, p.24). Fields that embrace this principle consider researchers and their worldview to be intertwined with the research itself; it is necessary, therefore, for researchers to consider what is driving us and how these perspectives might impact the research we conduct. Despite calls to understand more about the theoretical underpinnings of epidemiology (Krieger, 1994), outlining a philosophical or theoretical foundation is not typical for epidemiologic research practices. For this reason, I have chosen not to frame my dissertation within a particular philosophy or theory. Rather, I outline within each chapter how relevant methodological approaches will address a specific research question and contribute to the overarching aims of this work. In this chapter, I describe my perspectives on epidemiology and the guiding principles I value from this discipline to provide context for the work discussed in Chapters 3-9.

My views of epidemiology

The literal meaning of the term *epidemiology* is the study of what is upon the people: it is derived from the Greek *epi* ("upon, among"), *demos* ("people, district"), and *logos* ("study, word, discourse") ("Epidemiology," 2017). A variety of definitions have attempted to provide further clarity. These include, for example, epidemiology is "…the study of the distribution and determinants of disease frequency" or "…the study of the occurrence of illness" (Rothman, 2012, p.1). From definitions such as these, we might conclude that "what is upon the people" is disease, injury or perhaps the determinants or risk factors that contribute to these outcomes. Within this framework, epidemiologic research seeks to contribute to a body of scientific knowledge relating to disease frequency or distribution and factors that influence disease frequency or distribution. As a result, this kind of research may not necessarily be evaluated by how it influences public health more broadly nor its impacts on actionable events aimed at improving public health (Rothman, Adami, & Trichopoulos, 1998).

Other definitions of epidemiology have been broader. For example, epidemiology is "…the study of health and disease of population and groups in relation to their environment and ways of living" (Morris, 1957, p. 5) or "Epidemiology…is about measuring health…and intervening to improve health" (Webb, Bain, & Page, 2016, p. 1-2). From these definitions, we might conclude that epidemiology extends beyond descriptions of disease frequency and determinants to include the study of a spectrum of health states and, importantly, how we might effectively act to improve health. This concept resonates with me: I believe that socially responsible science must consider the greater good. Therefore, as the core scientific discipline of public health, epidemiology must consider, in Hill's words, "what flows from" (Hill, 1965, p. 300) research in how it might inform public health action. It is from these latter definitions of epidemiology that I frame my perspective. This is consistent with what has been described as "context sensitive science": rather than science for its own sake, research is driven by priorities identified by those impacted (Gibbons, 2000). While there are many things that contribute to an effective epidemiologic approach under this framework, I will focus on three elements that are key driving principles for me: pragmatism, collaboration, and justice. I will describe briefly how each of these informs my perspectives below.

Key driving principles

1) Pragmatism

In public health surveillance, effective ways to inform action are often influenced by what is expedient. As a result, data may be compiled and disseminated in ways that differ from more typical research approaches (Dover, 2017). For instance, data on a health outcome may, in some cases, be compiled without complete case reporting (Teutsch & Churchill, 2000). Furthermore, particularly when compiling information for knowledge beneficiaries with varying backgrounds, flexibility is important given issues such as time constraints, workloads, and limited resources. Having worked in public health surveillance for over 10 years, my perspectives on effective ways to address public health questions have been shaped by these adaptable practices. As a result, rather than a research approach that has the potential to be restrictive and unmalleable, I believe that meaningful success in research aimed at improving public health is achieved through a pragmatic approach where practical consequences of a concept inform its meaning (Creswell & Plano Clark, 2011). As Hill (1965) noted, "All scientific work is incomplete – whether it be observational or experimental…That does not confer upon us a freedom to ignore the knowledge we already have, or to postpone the action that it appears to demand at a given time" (p. 300). To me, approaching research through pragmatism permits the flexibility required to work with people of various backgrounds and perspectives. Focusing on what will have a practical end result also enhances the utility of the knowledge product and, ultimately, the impact of research on public health action.

2) Collaboration

Many of my friends and colleagues might be surprised to learn that I have always preferred to work alone. In addition to fueling my introverted disposition, I have felt that working alone supports pragmatic approaches by avoiding unnecessary complications that might inhibit efficient actions. Through my experiences working directly with knowledge beneficiaries such as community representatives concerned about health problems, I have witnessed the power of collaboration and have become aware that working alone is often at odds with finding the most effective solutions. Beyond my own experiences, literature espouses the benefits of collaborative approaches: working together through partnerships to address health problems is necessary for the success of these endeavours (much to the chagrin of my inner introvert). Benefits of collaborative approaches include improved knowledge exchange, a process by which information is shared between scientific researchers and the targeted beneficiaries of knowledge resulting from particular scientific research (Bowen, Martens, & The Need to Know Team, 2005; Jardine & Furgal, 2010; Wallerstein & Duran, 2010). Working in partnership also supports effective risk communication by bolstering mutually respectful and trusting relationships, thus promoting opportunities for meaningful discussions about potential hazards and risks to health (Fischhoff, 1995; Jardine, 2008). Based on my experiences and the multitude of documented benefits, I would now say that I am drawn to aspects of a participatory worldview: I value conducting research that aims to address issues through a collaborative process with those impacted (Creswell & Plano Clark, 2011). By working through collaborative partnerships when endeavouring to design, implement, and communicate epidemiologic research, partners are able to learn from one another about their respective views, build strong relationships that foster trust and reciprocity, and support meaningful and effective public health action.

3) Justice

After spending time in low resourced countries and with socioeconomically marginalized communities in Canada, I often find myself struck by what I can only describe as the injustice of birth: had I been born anywhere else, to anyone else, at any other time in history, I may not have been granted the opportunities I have enjoyed. I have come to understand that this concept of justice – or lack thereof – is a strong motivator for me. As a result, I find myself inspired to bolster the voices of people typically unheard, and to challenge the status quo in an effort to seek more equitable landscapes. While this is a driving principle for me in life broadly, I am similarly motivated when pursuing epidemiologic inquiry that aims to inform public health action. I am excited about how epidemiology can help to describe health inequities across populations and identify targeted approaches to reduce these inequities. In this way, I am influenced by critical theory, an umbrella term for perspectives such as postmodernism and poststructuralism that focus on unequal relations of power (Mayan, 2009). In pursuit of equity, I am keen to work in partnership with target populations when attempting to describe their health and to identify ways to reduce health inequities through collaborative endeavours that dispute the status quo. This includes questioning the authenticity and meaningfulness of typical health indicators, as well as incorporating the voices of target populations when aiming to describe their health.

Summary

An in-depth articulation of how various philosophies and theories influence me might provide further insights into my perspectives as a researcher; however, the overarching aim of my dissertation is to inform epidemiologic practice when describing the health of a population, particularly in situations where there is community concern about a health problem. For this reason, I will outline in each chapter how each methodological approach will address a specific research question and contribute to the overarching aims of this dissertation. Based on my perspectives of epidemiology and its contributions to public health action, I believe that incorporating the target population in efforts to describe their health will contribute to important elements of public health action such as knowledge exchange and risk communication. Doing so through pragmatic approaches will support successful and meaningful outcomes. Furthermore, using collaborative and participatory methods when undertaking epidemiologic research will also contribute to elements of social justice by fostering equitable landscapes where the people impacted are included in descriptions about what is upon them.

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Chapter 3: Challenges and solutions in community-university research partnerships

3.0 Introduction

When I was contemplating pursuing a PhD, I sought opportunities to work within a research team that was compatible with my interests. My experiences working with communities concerned about health problems, and my desire to engage in collaborative community-based work, drew me to the Canadian North *Helicobacter pylori* (CAN*Help*) Working Group. This Working Group links academic researchers from a variety of disciplines with community members, health care professionals, and public health officials in the Northwest Territories and Yukon. Driven by northern community concerns about the health impacts of a stomach bacterium, this collaborative endeavour seeks to describe the disease burden associated with the bacterium and to develop strategies aimed at reducing health risks. Another important goal is the development of effective knowledge exchange and communication strategies intended to maximize the applied benefits of the research. The CAN*Help* Working Group research program is described in more detail within subsequent sections of Chapter 3.

Through work with this team, it became apparent that challenges exist when seeking to identify and implement public health strategies within community-university partnerships. To overcome these challenges, it is helpful to understand the nature and extent of existing barriers. While myriad challenges can present themselves – as is true in any research endeavour – I focused on describing two main issues that were striking to me through my experiences as part of this team: 1) challenges that result from data access and release restrictions (Chapter 3.1); and 2) those arising from different ways in which academic and community partners talk and think about science (Chapter 3.2). I, along with my co-authors, published peer-reviewed articles on both of these topics in the *International Journal of Circumpolar Health*. These articles are provided in Chapters 3.1 and 3.2 below: in addition to identifying and describing various challenges, these sub-chapters also outline plausible solutions to minimize the negative consequences of these obstacles.

3.1 Challenges created by data dissemination and access restrictions when attempting to address community concerns: individual privacy versus public wellbeing

Abstract

Background: Population health data are vital for the identification of public health problems and the development of public health strategies. Challenges arise when attempts are made to disseminate or access anonymised data that are deemed to be potentially identifiable. In these situations, there is debate about whether the protection of an individual's privacy outweighs potentially beneficial public health initiatives developed using potentially identifiable information. While these issues have an impact at planning and policy levels, they pose a particular dilemma when attempting to examine and address community concerns about a specific health problem.

Methods: Research currently underway in northern Canadian communities on the frequency of *Helicobacter pylori* infection and associated diseases, such as stomach cancer, is used in this article to illustrate the challenges that data controls create on the ability of researchers and health officials to address community concerns.

Results: Barriers are faced by public health professionals and researchers when endeavouring to address community concerns; specifically, provincial cancer surveillance departments and community-driven participatory research groups face challenges related to data release or access that inhibit their ability to effectively address community enquiries. The resulting consequences include a limited ability to address misinformation or to alleviate concerns when dealing with health problems in small communities.

Conclusions: The development of communication tools and building of trusting relationships are essential components of a successful investigation into community health concerns. It may also be important to consider that public wellbeing may outweigh the value of individual privacy in these situations. As such, a re-evaluation of data disclosure policies that are applicable in these circumstances should be considered.

Introduction

Community members regularly express concerns about perceived health threats, such as apparent higher rates of cancer in their community. In the United States alone, over 1,000 cancer cluster investigation requests are made annually to health authorities (Trumbo, 2000). Concerns about specific local health problems may also be reported to health practitioners, community champions, researchers, or the media. Once reported, health officials or researchers often undertake an investigative process to answer questions and address concerns (Centers for Disease Control and Prevention, 1990; Kingsley, Schmeichel, & Rubin, 2007). Through these examinations, investigators aim to determine whether there is evidence of an excessive rate of the perceived health problem and to establish if further investigation is required and feasible. These investigations involve both analytical and communication components: both are essential to effectively address community concerns.

Analyses are conducted that compare the frequency of disease in the concerned community to that of a reference population in another geographic area. These calculations may involve a comparison of community disease rates to those observed elsewhere, or a comparison of the number of disease outcomes observed in the community to the number of outcomes expected based on rates in a reference population. While analytical assessment provides evidence about whether there is a higher-than-expected number of outcomes, other aspects of the investigation are also vital to the success of the investigation. These include the building of relationships and the maintenance of open and bi-directional communication (Edwards, Elwyn, & Mulley, 2002; Frewer, 2004; Plowfield, Wheeler, & Raymond, 2005). It has been noted that successful investigations require an on-going collaborative relationship with the local community at the beginning stages of the investigation, and that the process and results must be transparent (Greenberg & Wartenberg, 1991; Thun & Sinks, 2004).

Many challenges arise when attempting to undergo such investigations. This article describes one of the challenges faced by investigators when attempting to address community concerns about a particular health problem; specifically, the obstacles created by data disclosure and data access restrictions. To illustrate these issues, we present a case study highlighting work done in northern Canada to address community concerns related to the frequency of *Helicobacter pylori* infection and stomach cancer. Also discussed are the consequences of data controls in such investigations and potential solutions that may reduce future challenges when addressing community concerns.

Obstacles

There are a variety of challenges that arise when undergoing investigations to address community concerns about a specific health problem. These include methodological issues, as well as problems resulting from miscommunication between investigators and concerned community members (Edwards et al., 2002; Jardine & Hrudey, 1997). Conducting the analyses required in these investigations can be difficult, particularly when investigations occur in small communities such as those located in the northern regions of Canada. These methodological issues may include an inability to capture cases of disease observed in people who have moved away from the community and were diagnosed elsewhere, or incomplete historical data for analytic purposes (Chen, 2009). Additionally, drawing conclusions from analytic results can be difficult. In many cases, a small number of outcomes within the community yields results with low statistical power, making results difficult to interpret and inhibiting the assessment of trends over time (Wartenberg & Greenberg, 1992).

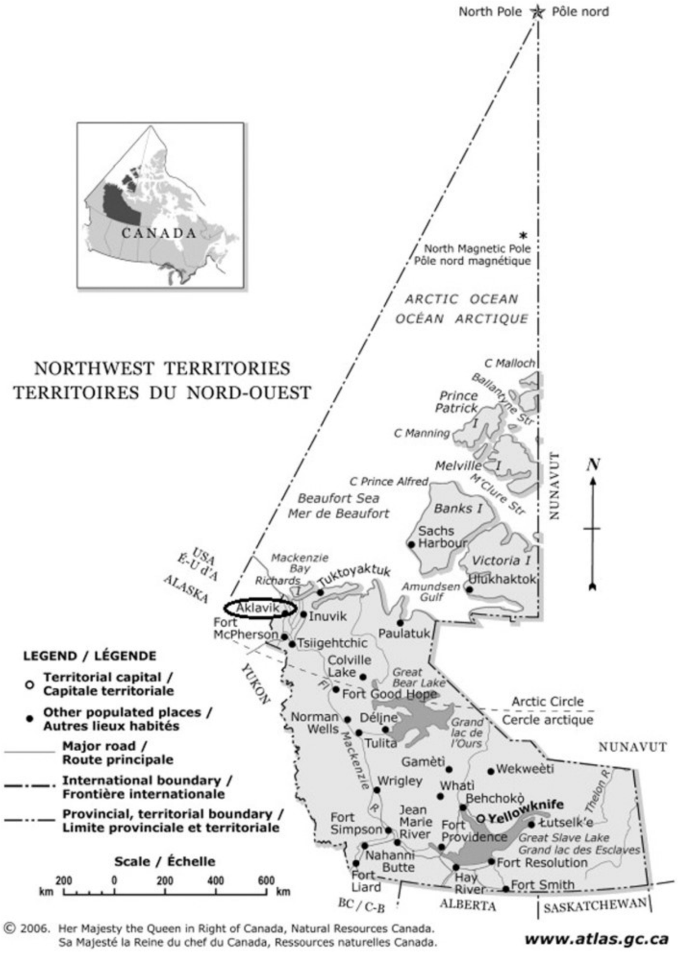
Other barriers to a successful investigation include fundamental differences between the questions posed by the concerned community and those answered by investigators: community members may *know* there is a problem and want to understand its cause, while investigators first attempt to determine *if* there is a problem. These misaligned perceptions can be exacerbated by other challenges with communication of the investigation results. Community members may differ on how they interpret scientific facts (Levy, Weinstein, Kidney, Scheld, & Guarnaccia, 2008) and cross-cultural differences in research interpretation (Estey, Kmetic, & Reading, 2008) may prevent a common conclusion about the meaning of the synthesized results. Furthermore, community members may differ in their perceptions of what constitutes a higher than expected number of disease outcomes and may be more likely to perceive a need for an in-depth investigation (Levy et al., 2008).

Another obstacle to the effective dissemination of investigation results is the inability of investigators to share some of the findings with community members due to data release controls (Statistics Canada, 2009; Statistics Canada, 2010). Concerns over confidentiality infringements prevent the release of identifiable data such as name, date of birth, and health care number by health officials and other custodians of health-related data. The importance of privacy has been widely acknowledged; Myers et al. stated that, "As a society, we place great value on individual rights and uphold the importance of protecting personal information…" (Myers, Frieden, Bherwani, & Henning, 2008, p. 793). Nass et al. (2009) stated that privacy is, "an essential component of human well-being," and highlighted that privacy is valuable because it promotes ideals such as "personal autonomy, individuality, respect, and dignity and worth as human beings" (Nass, Levit, Gostin, & Rule, 2009, p. 77). The importance of privacy has also been emphasized by the fact that release of individual health information may result in embarrassment, stigma, or discrimination (Gostin, 1997; Myers et al., 2008).

Data release restrictions designed to maintain confidentiality are not limited to overtly identifiable data; anonymised data may also be considered *potentially* identifiable and, therefore, withheld to uphold the privacy of an individual. This can occur when there are a small number of outcomes in a small population. In such situations, if cases are characterized by a small number of factors such as age and year of diagnosis, it may be possible for the identity of the individual to be inferred. The exact rules and regulations around what constitutes "small" varies by agency, political region, disease, and investigative situation. Typically, fewer than 5 outcomes are suppressed to prevent the release of information on *potentially* identifiable cases (Statistics Canada, 2009). For example, 2 cases of stomach cancer in a community of 1,000 people would be reported as fewer than 5 cases. These restrictions limit the amount of information that custodians of the data, such as cancer registries, are permitted to share with community members. Data controls also prevent the release of useful information to researchers who are conducting community-driven work in attempt to address concerns.

Case study: Aklavik *H. pylori* Project

The hamlet of Aklavik is a remote community located on the Peel Channel of the Mackenzie River Delta in the Northwest Territories (NWT), Canada (Figure 1). The community has a population of approximately 600 and is made up of primarily Gwich'in First Nations and Inuvialuit peoples; in the 2006 Canadian Census, 92% of Aklavik residents self-identified as Aboriginal (Statistics Canada, 2007). Throughout several years preceding 2006, Aklavik residents voiced concerns to local health professionals about a perceived increase in the number of stomach cancer cases diagnosed in the community. Many residents believed that this occurred due to a high frequency of *H. pylori*, a bacterium known to be a risk factor for stomach cancer. While the prevalence of *H. pylori* has decreased in developed countries, research suggests that northern Aboriginal populations have a disproportionately high prevalence of *H. pylori* infection and an increased frequency of *H. pylori*-associated diseases (Goodman, Jacobson, & van Zanten, 2008).



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Sa Majesté la Reine du chef du Canada, Ressources naturelles Canada.

www.atlas.gc.ca

Figure 1: Map of the Northwest Territories, Canada. Aklavik circled by authors (modified from The Atlas of Canada: Northwest Territories, Natural Resources Canada) (Natural Resources Canada, 2006)

In response to community concerns, the Canadian North *Helicobacter pylori* (CAN*Help*) Working Group was formed in 2006. The CAN*Help* Working Group is a collaborative research initiative that links community representatives, faculty from various disciplines at the University of Alberta in Canada, as well as Northwest Territories and Yukon health care practitioners and health authorities. The overall aims of the research program are to describe the burden of disease and risk factors associated with *H. pylori* infection, and to identify effective public health strategies for infection control (Cheung et al., 2008). Although originating in Aklavik, other communities in the NWT and Yukon Territory have since expressed interest in participating in this research; projects have been initiated in Old Crow, Yukon and Tuktoyaktuk, NWT. In each community, a planning committee comprising community representatives, researchers, and health professionals helps guide the research so that the work done is aligned with community priorities and interests.

Challenges have arisen when attempting to specifically address concerns over the perceived excess of stomach cancer cases. Unsubstantiated numbers of stomach cancer cases have been reported to and disseminated by the media, along with assertions of increased stomach cancer incidence. For example, the Edmonton Journal has reported that, “Between 1992 and 2000, the Northwest Territories government recorded 27 cases of stomach cancer, of which 8 were centred in Aklavik” (Sinnema, 2008), thus making the highly improbable attribution of 30% of the territory's stomach cancer cases to less than 1.5% of its population. Reader's Digest has stated that, “[Aklavik] has had exceptionally high stomach-cancer rates for years – men here develop it at about 3 times the national average” (Cornwall, 2010), applying a statistic reported for the territory's regional centres to one community for which no such statistics are estimated (Government of the Northwest Territories, 2003). Another popular news source has also reported that, “Residents have long suspected that a high number of *H. pylori* infections may explain why so many of their family members and other residents have died from stomach cancer. Exact numbers are not known, but 1 local family is said to have lost 5 relatives to the disease” (“High rates of stomach bacteria in Arctic hamlet,” n.d.).

Due to data disclosure restrictions, the territorial cancer registry has been unable to release information on the actual number of stomach cancer cases diagnosed in the community over recent time periods to clarify unsubstantiated information. This inhibits the research team from giving the community needed region-specific information to put their risk of stomach cancer in perspective. Furthermore, comparisons between the incidence of stomach cancer within northern communities expressing concern and incidence observed in other parts of Canada have not been possible. Attempts to address questions and concerns about cancer in the community, therefore, have had to be done indirectly; researchers have provided community members with broad educational information on *H. pylori* and what is known about the risk of developing stomach cancer. Unfortunately, without being able to directly address community-specific stomach cancer risk, anxiety over a perceived excess of cancer cases in the community persists.

Consequences

Data disclosure and data release restrictions inhibit the ability of investigators to effectively address community concerns. Data custodians, such as cancer registries or health surveillance departments, are unable to release to community members, or to researchers, data that are considered to be potentially identifiable. These data release restrictions hinder the ability of researchers to compare disease rates within a concerned community to disease rates in other reference populations, thereby preventing the assessment of disease risk associated with living in the area. Consequently, researchers are not able to gain perspective on the community health issue relative to other areas of Canada and are limited in their ability to undertake public health research (Wartenberg & Thompson, 2010), such as etiologic studies that would be warranted if an elevated disease frequency were documented.

In situations where analyses are feasible, data release controls prevent investigators from adequately communicating investigation results to community members, a vital component of the investigative process. Data controls prevent the release of certain investigation findings, which creates problems when investigators attempt to describe the results to community members and explain how the findings may be interpreted. For example, investigators may be able to explain that there is no evidence of higher rates of disease in the community compared to rates observed in other populations, but are unable to share how many cases have actually been observed. Community members may feel that they have been left out of the investigative process by not being allowed to evaluate the results for themselves. Because a sense of inclusion in the investigative process by the community is necessary for acceptance of the investigation results (McComas, Trumbo, & Besley, 2007), these restrictions therefore also create issues when discussing next steps. These communication challenges are exacerbated by the potential perception that the investigation lacks transparency. Because a transparent process is essential to the success of these investigations (Greenberg & Wartenberg, 1991), the perceived absence of this transparency limits trust in the investigative process, the acquired results, and the conclusions drawn. Furthermore, withholding information makes it difficult to maintain trusting relationships that are essential to the success of investigations into health problems in communities (Siegrist, Cvetkovich, & Gutscher, 2001).

Because of data disclosure restrictions, opportunities to decrease anxiety in the community are missed; misinformation or unsubstantiated information cannot be corrected, thereby perpetuating anxiety over the perceived health threat. In addition, without directly addressing concerns over the specific health problem, resources may be wasted or misaligned. Money, time, and energy may be spent on addressing specific concerns at the expense of other community health and social issues. Without the ability of data custodians to share data that are considered to be *potentially* identifiable, and without data access for researchers, investigative teams are unable to adequately address community concerns.

Solutions

Investigations that attempt to address community concerns about a specific health problem are filled with a variety of challenges. These challenges include data disclosure and data access restrictions that inhibit the ability of investigators to disseminate information to community members. This may be overcome through the development of risk communication and knowledge translation tools, acknowledgement of the importance of relationship-building, and a re-evaluation of data disclosure policies.

The development of risk communication strategies and knowledge translation tools that are specific to health investigations initiated through community concern will support communication between investigators and community members throughout the investigative process. Enhancing effective communication will foster a mutual understanding of one another's perceptions and ultimately help to build strong relationships that are vital to the success of these investigations. This may involve an assessment of the prevalence and degree of concern amongst community members (Morgan, Fischhoff, Bostrom, Lave, & Atman, 1992), and whether a common language is used when discussing investigation components (Edwards et al., 2002; Jardine & Hrudey, 1997). The identification and development of effective communication tools can also support increased knowledge amongst all investigation participants about the research methods, results, and interpretation, thereby enhancing understanding of the investigative process and the limitations imposed by data restrictions (Thun & Sinks, 2004). For example, an evaluation of which communication medium, such as community presentations or newsletters, would best facilitate discussions amongst investigation participants could help to foster participation and enhance successful communication (Greenberg & Wartenberg, 1991; McComas et al., 2007). Furthermore, knowledge translation tools may provide insights into how the results of these investigations can be effectively communicated in a way that is meaningful to community members and decision-makers.

Another way that these investigations can be supported is through investment in trust and bi-directional relationship-building. Relationship- and trust-development between investigators and community members will increase the likelihood that these investigations will be considered successful (Christopher, Watts, McCormick, & Young, 2008; McComas et al., 2007; Plowfield et al., 2005; Siegrist et al., 2001). Because of large distances between remote communities and research centres, particularly in the northern regions of Canada, communication is often accomplished over email or by telephone. It should be noted, however, that successful relationship-building takes time, and that the development and maintenance of trust in community-based work is typically more successful and fulfilling when done in person (Bowen, Martens, & The Need to Know Team, 2005; Christopher et al., 2008; Plowfield et al., 2005). As such, researchers conducting work to address community concerns should allow for multiple in-person discussions when planning and budgeting for these research initiatives. Funding agencies that support these researchers should also recognize the necessity of strong relationships to the success of community-driven work, as well as the resources required to support these initiatives. Likewise, resource support from government agencies that employ health professionals who take part in these investigations is necessary to promote the development of meaningful relationships.

While the development of communication tools and trusting relationships are essential components to the success of investigations into community health concerns, they do not deal directly with the challenges posed by data disclosure controls. These data restrictions are in place to protect the right of individuals to privacy and apply to both directly identifiable data and anonymised data that are considered to be *potentially* identifiable. In situations where there is extreme community alarm over a perceived health threat, it may be important to consider that these data are only *potentially* identifiable, and that public wellbeing may outweigh the value of individual privacy. In these circumstances, exceptions to data release restrictions should be considered; that is, data custodians should consider releasing *potentially* identifiable and anonymised data to promote effective and direct communication with concerned community members, and to facilitate the ability of researchers to directly evaluate community risk in these circumstances. If applicable, data custodians might also consider contacting individuals who may be impacted by the public release of these anonymised data. As Bayer and Fairchild stated, "…there are occasions when those whose privacy will be compromised view [data sharing] not as a burden but as serving their interests" (Bayer & Fairchild, 2002, p. 29). If these individuals are members of a concerned community, they may encourage the public release of anonymised data to support community goals, despite the potential breach of their privacy.

In summary, challenges created by data disclosure and data access restrictions inhibit the ability of investigators to disseminate information to community members when attempting to address community concerns about a health problem. The development of communication tools, acknowledgement of the importance of relationship-building, and the re-evaluation of data disclosure policies that are applicable in these circumstances will help support the effective and successful investigation of community health threats, and foster the ability of investigators to adequately answer community questions and address concerns.

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3.2 Challenges in conducting community-driven research created by differing ways of talking and thinking about science: a researcher's perspective

Abstract

Increasingly, health scientists are becoming aware that research collaborations that include community partnerships can be an effective way to broaden the scope and enhance the impact of research aimed at improving public health. Such collaborations extend the reach of academic scientists by integrating a variety of perspectives and thus strengthening the applicability of the research. Communication challenges can arise, however, when attempting to address specific research questions in these collaborations. In particular, inconsistencies can exist between scientists and community members in the use and interpretation of words and other language features, particularly when conducting research with a biomedical component.

Additional challenges arise from differing perceptions of the investigative process. There may be divergent perceptions about how research questions should and can be answered, and in expectations about requirements of research institutions and research timelines. From these differences, misunderstandings can occur about how the results will ultimately impact the community. These communication issues are particularly challenging when scientists and community members are from different ethnic and linguistic backgrounds that may widen the gap between ways of talking and thinking about science, further complicating the interactions and exchanges that are essential for effective joint research efforts.

Community-driven research that aims to describe the burden of disease associated with *Helicobacter pylori* infection is currently underway in northern Aboriginal communities located in the Yukon and Northwest Territories, Canada, with the goal of identifying effective public health strategies for reducing health risks from this infection. This research links community representatives, faculty from various disciplines at the University of Alberta, as well as territorial health care practitioners and officials. This highly collaborative work will be used to illustrate, from a researcher's perspective, some of the challenges of conducting public health research in teams comprising members with varying backgrounds. The consequences of these challenges will be outlined and potential solutions will be offered.

Introduction

Scientists attempt to gain new knowledge by applying their expertise to learn more about the world around them. Historically, with the exception of necessary practical requirements such as funding applications and access to data, this work was typically done in isolation: scientists from universities conducted research and worked to publish their results in scientific journals. This process required little interaction between the scientists producing research results and the community members or stakeholders who made use of this information. In recent years, it has become widely recognized that there are limits to the utility of research conducted in isolation. Instead, it is preferable to build "context-sensitive" knowledge through the pursuit of research that will have a real-world impact; this process will help to grow knowledge in a meaningful way (Gibbons, 2000) and is particularly relevant for public health research.

One way that scientists build context-sensitive knowledge is by developing research collaborations that include community partnerships. Such collaborations have been shown to produce a variety of benefits (Baum, 2000; Saven, 2004; Stanton, 2008). These benefits include access to communities, individuals, or datasets that may be optimal for addressing specific research questions. Researcher-community partnerships are also a means to create other benefits such as building capacity, generation of new research questions, and broadening understanding and knowledge amongst all partners: community members are able to learn about the scientific process and researchers are able to gain insights into community perspectives and other forms of knowledge creation (Stanton, 2008).

Community-university collaborations have become common in the field of public health and have been found to be an effective way to broaden the scope and enhance the impact of public health research. Such collaborations extend the reach of academic scientists by integrating a variety of perspectives and thus strengthening the applicability of the research (Baum, 2000; Gibbons, 2000; Stanton, 2008). Comprehensive collaborations between researchers and community members throughout the design and conduct of research can work to "enrich knowledge, address and help solve critical societal issues, and contribute to the public good" (Stanton, 2008). Ensuring that community members and end-users are participants in the research process from the beginning increases the chance that research results will be meaningful and useful for all stakeholders.

Despite the benefits to participating in collaborative research, there are some challenges. Communication challenges can arise when attempting to address specific research questions in these collaborations. This article describes some of the challenges that occur when there are inconsistencies in the use of language and definitions, and when scientists and community members have differing perceptions of the investigative process, particularly when the research includes biomedical frameworks. To illustrate these issues, we present a case study highlighting a collaborative public health research program conducted in northern Canada to address community concerns related to health risks from chronic *Helicobacter pylori* infection and, in particular, its most serious disease consequence—stomach cancer. Finally, we discuss potential consequences of these communication challenges and suggest potential solutions that may reduce future challenges when working in collaborative researcher-community settings. In highlighting distinctions between researchers and community members in what follows, we are not implying that either group lacks similar internal communication challenges due to within-group differences in education, culture, language, and general life experience, but rather are attempting to characterize the ways in which the larger between-group differences may compromise collaboration.

Common challenges in community-university collaborations

Language and literacy

Communication challenges can arise when attempting to address specific research questions in researcher-community collaborations. In particular, inconsistencies can exist between scientists and community members in the use of language and definitions. These challenges are most apparent when spoken and written languages differ; for example, Canadian researchers generally communicate in English or French while community members may communicate in a variety of other languages. Communication challenges may still arise, however, even if a common language is used: the choice of vocabulary or phrases can determine how something is communicated and may differ between researchers and community members, particularly when conducting research with a strong biomedical component. These differences can result from diverse education and experience, and they are particularly challenging when scientists and community members are from different cultural and linguistic backgrounds (Cochran et al., 2008; Estey, Kmetic, & Reading, 2008; Jardine & Furgal, 2010; Laveaux & Christopher, 2009). In these instances, the gap between ways of talking and thinking about science may be widened, further complicating the interactions and exchanges that are essential for effective collaboration.

Scientists frequently use specialty-specific language. This may include the use of terms or acronyms that are part of a scientist's regular vernacular, or biomedical terms such as "endoscopy", that may be unfamiliar to researchers in other fields or the general public. Less obviously, specialty-specific language can include familiar words and phrases that are used with a more restricted meaning; for example, the statistical meaning of the word "significant". Even if specialty-specific language is avoided, scientists may unintentionally speak or write from a certain perspective and with an assumed foundation of knowledge that makes the message inaccessible to community partners. For instance, if researchers are discussing the impact of a bacterium on a population, it may be assumed that there is shared knowledge about what bacteria are. Similarly, confusion may result from differing literacy levels. This may occur through differences in general literacy, subject-specific literacy, or through differences in numerical or statistical literacy which is particularly problematic in public health research where statistics are often used to investigate hypotheses (Gigerenzer, Gaissmaier, Kurz-Milcke, Schwartz, & Woloshin, 2008).

Community members may also use terms unknown to academic researchers. For example, in an ethnographic study, Cassady (2009) found that Alaskan Inupiat peoples referred to "bad-blood" as a precursor to, and a product of, cancer. The term "bad-blood" may not be widely understood and could be interpreted in a variety of ways. Community members may also refer to geographic landmarks, the names of local people, organizations, or practices that are unfamiliar to researchers. For instance, community members in northern Canada may use the term "living on the land" to describe spending time in handmade cabins outside community limits. To others, this phrase could describe traditional hunting practices, surviving outside of towns or cities, or building shelters from materials available in the natural environment. Similarly, daily life practices in rural communities may not be familiar to researchers. For example, the use of the last four digits of 7-digit phone numbers is understood among residents of small communities where the first three digits of all phone numbers are the same and thus known to everyone. For researchers, this may not be immediately obvious and may create confusion.

Difficulties may also arise from the inconsistent use of familiar language, where the meaning of commonly used words or phrases may vary. For instance, the term "bug" can be used to describe an insect, a germ, a pest, or an illness such as cold or flu, or even cancer. Every day phrasing may also be disparate. For example, researchers may use the phrase, "What is that?" while community members may state, "What that is?" to ask the same question. Although the meanings may be equivalent, the thought process required to interpret each slightly unfamiliar phrase may make communication disjointed and uncomfortable. The process by which this communication occurs may also be challenging: health scientists may prefer text that provides detailed explanations, and community members may prefer visual diagrams or verbal communication (Houts, Doak, Doak, & Loscalzo, 2006).

Research and expectations

Additional challenges arise from differing perceptions of the investigative process. The term "research" may be defined in a variety of ways, resulting in disparate conceptions about the purpose of research and the process by which it is conducted. Research may be broadly defined by community members as any process of gathering data, information, or facts to form knowledge about a specific topic (Schnarch, 2004). This may be accomplished through the gathering of information from libraries, news sources, conversations, or other sources, with or without using reproducible protocols for gathering data or applying methods of analysis believed by experts to yield scientifically valid results. Conversely, biomedical or public health scientists typically view research as a rule-governed process that uses systematic observations to test, screen, or form hypotheses. In addition to different perspectives about the definition of research, differences may also exist in perceptions about the purpose of research. Community members may view research as a means to address their concerns and to immediately identify solutions. Alternately, scientists generally view research as a systematic exploration of evidence to address specific research questions.

Divergent definitions and perspectives about research can lead to contrasting expectations about research timelines. Biomedical or public health scientists typically proceed slowly and systematically in putting together pieces of information to support and build knowledge, whereas community members who may be unaware of the time required for many scientific processes may expect research results to be available rapidly. Expectations about research funding requirements may also differ. Biomedical and public health researchers are typically required to adhere to institutional and professional guidelines. These include writing reports and publishing findings in a timely fashion. These demands do not always match the requirements of communities that may wish to evaluate and comment on each data analysis according to their own timelines before results are made public (Schnarch, 2004).

Case study: community-driven research on *H. pylori* in Northern Canada

Helicobacter pylori is a bacterium known to persist long term in the stomach, where it causes chronic gastritis, peptic ulcers, and stomach cancer. In northern Aboriginal communities, there is a disproportionately high frequency of *H. pylori* infection and associated diseases, and relatively low success of treatment aimed at eliminating the bacterium (Goodman, Jacobson, & van Zanten, 2008). Community-driven research is currently underway in northern Aboriginal communities located in the Yukon and Northwest Territories (NWT), Canada (Figure 2) that aims to describe the burden of disease and risk factors associated with *H. pylori* infection, and seeks to identify effective public health strategies for reducing associated health risks.

Figure 2: Map of the territories, Canada; Yukon and Northwest territories circled by authors (modified from The Atlas of Canada: the territories, Natural Resources Canada) (National Resources Canada, 2006)

This research links community representatives with faculty from various disciplines such as epidemiology, anthropology, gastroenterology, and microbiology at the University of Alberta, as well as territorial health care practitioners and officials. As of 2012, four communities were a part of this research program: Old Crow, Yukon and Aklavik, Tuktoyaktuk, and Fort McPherson, NWT. Each of these communities is located in a remote area north of the Arctic Circle with populations ranging from approximately 250 to 900, primarily Gwich'in First Nations and Inuvialuit peoples; in the 2006 Canadian Census, over 84% of the residents of each of these communities self-identified as Aboriginal (Statistics Canada, 2007). In each case, community representatives invited researchers to work with the community to address concerns related to *H. pylori*. At the beginning of each community research project, and throughout the process, collaborations between researchers and community representatives occur through local planning committees where decisions about research components and implementation are made jointly. This collaborative decision making process is essential to the success of this research as it ensures that the work done fits with community interests and goals, and that optimal scientific processes are upheld.

Despite our success in these collaborations, communication challenges have arisen. There have been inconsistencies in language used to describe certain terms amongst researchers and community members, including members of the local planning committee, general members of the community, and local health care practitioners, as well as news reporters who disseminate information about the research in the local media. For example, regional news reports about our community projects often describe *H. pylori* as a virus. Some community members speak about *H. pylori* as an environmental cancer-causing agent, while others have referred to it as a “worm” in their stomach or as “bad stomach”, raising questions about whether there is a common understanding of the bacterium. Likewise, community members have also referred to the research as work on “HPV” or “H1N1”. It is not clear whether use of these similar acronyms for distinct infectious disease agents are slips of the tongue, whether they reflect differential understandings about the *H. pylori* bacterium, or whether the research itself is not widely understood despite the ongoing knowledge exchange activities that are a fundamental component of our community-based, participatory research approach.

There have also been differing views on the purpose of the research. For example, some community members have described the focus of the research as on water quality (Stokell, 2011) or on pinpointing the source of *H. pylori* in order to eliminate it from the environment. Furthermore, some community members describe the main goal of the research in health care terms as immediate treatment of *H. pylori* infection for all community members found to be infected. Similarly, differences have been apparent in expectations about the research process. Community members have stated that they expected the research to be finished quickly and to receive answers to their questions soon thereafter. This differs from the perspective of biomedical or public health researchers who view research as a process that takes time and yields uncertain results, and thus requires many pieces of a puzzle to come together before generating adequate evidence on which to base solutions to complex problems.

In these community-based *H. pylori* research projects, researchers have worked to alleviate these issues through on-going engagement with community partners via local planning committees, and by developing project-specific research agreements to document a shared understanding of the research process and expectations. Researchers and community partners have also worked to promote bi-directional communication that supports the production of meaningful results, aiming to effectively move the knowledge created through research into implementation by users such as community members and healthcare providers, a process known as knowledge translation. In this setting, effective communication between scientists and non-scientists has been a major priority of the collaborative research endeavor because different understandings of language, terminology and expectations of the research process and goals have the potential to negatively impact the relationships that have been built between partners involved in this community-based, participatory health research. In the next section, we will discuss potential consequences to not resolving communication challenges, and present solutions in progress.

Common consequences of communication challenges in community-university collaborations

Communication challenges resulting from differences in language and differing perspectives about research may lead to misunderstandings between researchers and community members that can jeopardize the research process and damage essential partnerships. At the very least, communication challenges slow the research process: addressing misunderstandings as they arise takes time away from the main research goals. Similarly, it takes time to decipher carefully the meanings of words and expressions used by others so that miscommunication may be avoided and so that the research can move forward with all partners on common ground (Jardine & Furgal, 2010; Suarez-Balcazar, Harper, & Lewis, 2005).

Furthermore, without a shared understanding of language and process, the success of a joint research endeavour may be in jeopardy. Researchers may misunderstand or misinterpret the issues raised by community members and may inadvertently work to answer research questions that are not those posed by the community. Even with agreement about the main purpose of the research, the implementation of this work may not be mutually understood. If so, the work conducted may not incorporate the community context, or may be culturally insensitive (Cochran et al., 2008; Laveaux & Christopher, 2009; Smylie et al., 2004). Consequently, research results may not be meaningful or accepted by community members. If the knowledge gained through the research process is not employed by end-users such as community members, the opportunity for a successful collaboration is lost, as is the time and the resources required to carry out these research endeavours.

Differing definitions and expectations of the research process may also strain relationships and create conflict. Misunderstandings about how the results will ultimately impact the community can occur. For example, community members may believe that for research to be considered successful, it should have recognizable benefits available quickly to the community, whereas scientists may view small gains that contribute to larger bodies of evidence as successes, even if they do not provide solutions immediately. Likewise, divergent definitions or expectations about the partnership itself may create conflict. For instance, a common view among Canadian First Nations communities is that the community has collective ownership of any data collected as part of research collaborations (Schnarch, 2004). Similarly, partners may disagree on the appropriate custody and allotment of research funds. Conflicts may then occur between researchers bound by institutional and professional expectations, if they do not coincide with the expectations of collaborating communities (Cochran et al., 2008).

Solutions to common communication challenges in community-university collaborations

Research collaborations that include community partnerships can offer a variety of benefits, but challenges can occur when partners are not communicating effectively. Communication challenges may be overcome through the development of knowledge translation and communication strategies and tools, acknowledgement of the importance of trust and reciprocity in these relationships, and through the development of project-specific research agreements that are drafted jointly by researchers and their community partners.

The development of effective knowledge translation and communication tools for research involving scientist-community partnerships will support collaborations throughout the entire research process (Bowen, Martens, & The Need to Know Team, 2005; Van de Ven & Johnson, 2006). Enhancing effective communication will foster a mutual understanding of one another's perspectives and ultimately help to build strong relationships that are vital to the success of these research endeavours. This may involve an evaluation of whether a common language is used when discussing research components (Suarez-Balcazar et al., 2005), development of a common language between researchers and community members (Minkler & Wallerstein, 2010), or an assessment of the levels of literacy amongst collaborators and end-users (Nutbeam, 2008). Engagement of local professionals working in the community, such as health care providers and teachers, who can help facilitate understanding between outsider scientists and local residents, is essential to this effort. The identification and development of effective communication tools can also foster a mutual understanding about the research process, methods, results, and interpretation amongst all research partners and participants. For example, an evaluation of which communication medium, such as community presentations or newsletters, would best facilitate research dissemination could help to enhance successful communication (Smylie et al., 2004; Suarez-Balcazar et al., 2005). Identifying best methods for the dissemination of research results that include statistics may be particularly important: evidence suggests that statistical literacy is low amongst members of the general public (Gigerenzer et al., 2008; Lipkus, Samsa, & Rimer, 2001). Presenting statistical results in a way that increases accessibility and transparency could help prevent miscommunication and promote mutual understanding (Gigerenzer et al., 2008). Effective knowledge translation and communication tools will help collaborators identify which results are most meaningful, as well as the most effective ways in which they may be communicated to end-users.

Another way that these research collaborations can be supported is through recognition of the importance of trust and reciprocity to relationship-building (Christopher, Watts, McCormick, & Young, 2008; Suarez-Balcazar et al., 2005). Trust and reciprocity between researchers and community members will promote meaningful engagement and increase the likelihood that the research will be considered successful (Christopher et al., 2008; Cochran et al., 2008). Funding agencies that support these collaborations should recognize the need for resources required for the development of strong community-researcher relationships (Jardine & Furgal, 2010; Suarez-Balcazar et al., 2005). The need for financial support for costs of relationship-building is particularly crucial for collaborative research endeavours involving long-distance partnerships where communication is often accomplished over email or by telephone. Successful relationship-building takes time, and the development and maintenance of trust in community-based work is typically more successful and fulfilling when done in person (Bowen, Martens, & The Need to Know Team, 2005; Christopher et al., 2008; Suarez-Balcazar et al., 2005). As such, researchers conducting work involving community collaborations should allow for multiple in-person discussions when planning and budgeting. Researchers and funders should also consider that the respect and reciprocity that are necessary for strong and meaningful relationships require a mutual exchange of privileges; a balanced distribution of resources and power is imperative (Cochran et al., 2008; Laveaux & Christopher, 2009; Maiter, Simich, Jacobson, & Wise, 2008; Schnarch, 2004).

Communication challenges may also be overcome through the collaborative development of research agreements. The process of developing a research agreement requires collaborative partners to begin developing shared language and expectations before the research is started (Government of Canada, 2010). Research partners should discuss the overall goals of the collaboration and include a statement of objectives at the beginning of the agreement; this provides context for interpreting the agreement (Steinbock, 2007). The parties should also discuss their expectations of the research (including benefits, contributions and timelines), and ensure that provisions of the agreement are consistent with a shared-understanding of expectations. The agreement should include a list of definitions used in the document (Gold & Bubela, 2007). This process will help open communication about a variety of issues that may not have otherwise been discussed, and help prevent communication challenges later on by providing written documentation that partners can consult over time.

Important consideration

The challenges outlined and solutions suggested in this article come from the perspective of researchers involved in community-driven health research with a substantial biomedical component. It is expected that researchers from different disciplines would have a different perspective and consider different solutions. Likewise, community partners participating in research initiatives, such as those involved in the case study outlined here, likely have different views on the challenges that exist in addressing their concerns, and on the potential ways to improve communication and research partnerships.

Conclusions

Communication challenges may arise when community members and researchers work together to answer community health research questions using biomedical or public health methods of inquiry. From a health researcher's perspective, these challenges include inconsistencies in the use of language, as well as differences in values and expectations about the research process. These result, in part, from differences in ways of thinking about science and are deepened by differences in culture and language. If research partners do not address different understandings of language and the research process, partners may risk damaging their relationships and slowing down progress on research questions which have the potential to impact real-world problems. When conducting public health research with a strong biomedical component, effective engagement and relationship-building, reinforced by formal research agreements between collaborators, as well as development of knowledge translation and communication tools may all work to increase shared understanding and ultimate success in collaborations between scientists and community members.

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3.3 Reflections and summary

In the previous sub-chapters, my coauthors and I outlined challenges and plausible solutions to community-university partnerships aimed at addressing a public health problem. These included challenges arising from data dissemination and access restrictions, as well as those created by differing ways that community and university partners talk and think about science. Taken together, these papers identified some common challenges: for instance, accessible information or research results may be interpreted differently by project partners, thus preventing a shared conclusion about the meaning or relevance of synthesized evidence. Without effective communication among research partners, differing viewpoints may cause harm to community-university relationships and can negatively impact any actions aimed at improving public health. These articles also revealed common plausible solutions. For example, investing in opportunities to learn from one another can foster trust and reciprocity that bolster mutually beneficial relationships. Furthermore, working together to develop effective knowledge translation and communication strategies can help minimize miscommunications and support the movement of knowledge gained through the research into practice.

These kinds of challenges and solutions may be particularly relevant when working in collaborative research programs, such as the CAN*Help* Working Group, that involve highly technical fields of research with components unfamiliar to non-experts. Biomedical research activities, for example, may involve medical procedures that require physician expertise or laboratory work that may be foreign to partners without related experience. Similarly, the methods, results, interpretations, and implications of typical epidemiologic inquiry might not be clear to all research partners. As a result, to ultimately address public health questions aimed at improving public health, it is also valuable to determine if there is a shared understanding of research components: that is, whether the evidence being compiled to inform action is relevant and meaningful to all knowledge beneficiaries. Applied examples of how proposed solutions can be practiced are explored in following chapters of this dissertation.

Chapter 4: Solutions in action 1: co-creating reciprocal learning opportunities

4.0 Introduction

In the previous chapter, I outlined examples of challenges that can occur when working through collaborative community-university partnerships aimed at improving public health. I also discussed solutions: these included working together to develop effective knowledge translation and communication strategies. These kinds of strategies can enhance the effectiveness of community-university research programs by facilitating understanding among research partners about one another's perspectives. This in turn contributes to the successful communication of knowledge generated through the research to knowledge beneficiaries (Bowen, Martens, & The Need to Know Team, 2005; Campbell, 2010). Learning from one another through processes that respect differences in culture, language, and education promotes reciprocity and supports equitable landscapes that strengthen collaborative research environments (Wallerstein & Duran, 2010). While the benefits of these learning partnerships are abundant (Stanton, 2008; Wallerstein & Duran, 2010), it is often unclear how to identify and implement projects that support bi-directional learning processes essential for the success of these endeavours, particularly when conducting research with a biomedical component.

Here, I describe two collaboratively developed and implemented community-university projects that contribute to knowledge sharing across research partners. In the first (Chapter 4.1), community and university partners co-developed a knowledge exchange program involving two youth from Aklavik, Northwest Territories (NT). In this collaboration, university scientists visited the community of Aklavik to share results from the research program and to learn about life in the community. To support reciprocal learning opportunities, two Aklavik youth then spent time at the University of Alberta where they had hands on experiences with biomedical research components conducted in Edmonton before returning to the community to share their experiences.

In the second example (Chapter 4.2), contests were held across participating communities to identify a visual image, drawn by a community member, which would be used to represent the community-specific research project. Researchers spoke with community members about the collaborative research program and the bacterium. Dozens of drawings were subsequently submitted, each showcasing the community and research program through the eyes of the artist. Through a community-identified process, the ‘winning’ image was selected and was then digitized: the resulting digital image of the ‘winning’ drawing is used as a logo that represents the community-specific research. In the following sub-chapters I, along with my co-authors, describe these two knowledge exchange collaborations in detail. We outline the methods used to develop and implement each strategy and provide in-depth reflections on the key results and lessons learned from each collaborative endeavour.

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4.1 Learning from one another: a knowledge exchange collaboration between an Arctic Aboriginal community and academic researchers in Alberta, Canada

Abstract

To address community concerns about a high frequency of *Helicobacter pylori* infection in northern Canadian Aboriginal communities, the community-driven Canadian North *Helicobacter pylori* (CAN*Help*) research program brings together community members, scientists, and healthcare providers. A vital component of this work is the exchange of knowledge between community members and academic researchers. In Aklavik (Northwest Territories, Canada), community representatives and scientists worked to develop a knowledge exchange project on *H. pylori* and human health. As part of this initiative, academic partners traveled to Aklavik to deepen their understanding of community knowledge and information dynamics. Mirroring the community-based learning, two young community partners recruited with the guidance of community leadership made a reciprocal visit to observe and participate in laboratory research at the University of Alberta, in Edmonton, Canada. Upon returning to Aklavik, the community partners presented what they learned to other members of the community. This circular form of knowledge exchange encourages knowledge to flow from community members to scientists and from scientists to community members. Extending knowledge exchange into the knowledge production process enhances the relevance and effectiveness of collaborative research and supports the meaningful dissemination of research results while responding to concerns and educational needs arising from the community.

Introduction

At its core, scientific research is a social process in which data collection, knowledge production, and the dissemination of results are dependent on relationships between scientific researchers and different publics. The direct movement of information between scientific researchers and the targeted beneficiaries of knowledge resulting from particular scientific research, which we call here knowledge exchange (KE), is inherently a type of social exchange (Trostle, 2005). Translating scientific research results into beneficial impacts is influenced by many factors including social distance, historical inequity, and language and cultural differences between the scientific research community and the populations studied. It is widely accepted among Canadian public health scientists that effective communication between scientists and targeted beneficiaries throughout the research process is vital for successful public health research (Davis et al., 2003; Graham et al., 2006; Straus, Tetroe, & Graham, 2009), particularly when academic researchers and the communities they work with come from different cultural, ethnic, or socio-economic backgrounds (Estey, Kmetic, & Reading, 2008; Jardine & Furgal, 2010; Smylie et al., 2004, 2009). In recent years, KE practices used in research involving Aboriginal Canadians have come under particular scrutiny (Smylie et al., 2004). By framing and describing a KE project resulting from a partnership between academic scientists and residents of an Aboriginal Arctic community, this article seeks to contribute to the literature that addresses the gap between knowledge gained from scientific research aimed at improving health and how this knowledge can be implemented as actions that lead to improved health.

Without meaningful movement of health research findings into practice, members of targeted populations may not receive the best possible health services and limited resources may be wasted (Straus et al., 2009; Woolf, 2008). Additionally, those who participate in research may not see a benefit of their contribution and, as a result, they may rightly question the value of participating in research however participatory its conduct. KE has been identified as an essential component of health research and critical for the improvement of health and health services (Canadian Institutes of Health Research, 2009; Davis et al., 2003; Graham et al., 2006; Straus et al., 2009; Woolf, 2008). However, evidence-based knowledge of KE best practice is an under-developed field of inquiry, particularly in health research with Aboriginal communities in Canada (Canadian Institutes of Health Research, 2009; Estey et al., 2008; Glasgow & Emmons, 2007; Smylie et al., 2004). A comparative study of three settlements in Ontario found that while some KE concepts crosscut Aboriginal communities, other factors such as local information sources, community-level decision-making processes, and locally-relevant concepts of health vary across communities, demonstrating that there is no one-size-fits-all approach for KE (Smylie, Kaplan-Myrth, McShane, & Métis Nation of Ontario-Ottawa Council Pikwakanagan First Nation Tungasuvvingat Inuit Family Resource Centre, 2009).

Previous work has established that community participation in the research process, relationship development, and building of trust are essential elements of community-based research (Bowen, Martens, & The Need to Know Team, 2005; Canadian Institutes of Health Research, 2010; Fletcher, 2003; Jardine & Furgal, 2010), defined here as scientific research aimed at supporting community-identified research goals. The development of KE processes based on community goals provides grounding for community, academic, and health professional partners working in collaboration to effectively implement scientifically derived solutions and to better understand remaining challenges for reducing health risks (Bowen et al., 2005). As part of a community-driven health research program seeking to address concerns about the *H. pylori* stomach bacterium in northern Canadian Aboriginal communities, academic scientists and community representatives in Aklavik, Northwest Territories (NT), worked together to develop a KE project that would foster a greater understanding amongst scientists of the social context of the community and their views and questions about the research conducted, while also contributing to knowledge within the community about scientific research processes and the value and limitations of research results. Aklavik is a remote hamlet located on the Peel Channel of the Mackenzie River Delta with approximately 600 residents drawn primarily from Gwich'in (Athabaskan) First Nations and Inuvialuit (western Canadian Inuit) peoples; in the 2006 Canadian Census, 92% of Aklavik residents self-identified as Aboriginal (Statistics Canada, 2007). Although the term 'Indigenous' is often used to refer to First Nations and Inuit populations, we acknowledge the preference of our Aklavik-based coauthor (BLK) and respectfully use the term Aboriginal here. This paper describes this unique collaborative KE project.

Context

Community-driven research program

Helicobacter pylori is a bacterium that was estimated to infect approximately 40% of the population of the developed world and 70% of the population of developing countries in 2000 (Brown, 2000). It has been identified as a major cause of peptic ulcer disease, chronic gastritis, and stomach cancer. Northern Aboriginal populations have a disproportionately high prevalence of *H. pylori* infection (Goodman, Jacobson, & van

Zanten, 2008) and an increased frequency of *H. pylori*-associated diseases, including stomach cancer (Goodman et al., 2008; Young, Kelly, Friborg, Soininen, & Wong, 2016).

Health issues related to *H. pylori* came to the attention of people in Aklavik seeking to understand a perceived increase in the number of stomach cancer cases diagnosed in the community. Concerns voiced by Aklavik residents about *H. pylori* infection led to the creation of a community-university research program in 2007. Subsequently, several other Aboriginal communities across the NT and Yukon have participated in this collaborative research program, conducted by the Canadian North *Helicobacter pylori* (CAN*Help*) Working Group, which links scientists from various disciplines including epidemiology, gastroenterology, microbiology, anthropology and public policy sciences, with healthcare practitioners, health officials, Aboriginal organizations, and community representatives. The aims of the program are to address community concerns through research that describes the burden of disease associated with *H. pylori* infection, ascertains factors that influence this burden, and identifies effective public health and knowledge exchange strategies for infection control.

Activities within the CAN*Help* research program include screening for *H. pylori* infection, structured interviews that ascertain socio-environmental exposures, and antibiotic treatment for those who test positive for *H. pylori* infection. Another component involves the physical examination of participants by gastroenterologists; they assess the stomach health of participants through endoscopy, which permits the visual inspection of the stomach through images taken through a scope inserted down the throat. Biopsies of the stomach lining are taken as part of this procedure: resulting tissue samples are assessed by a pathologist for *H. pylori* density and tissue-level injury, and cultured in a microbiology laboratory to isolate *H. pylori* organisms and assess their characteristics.

While the overarching research program aims to address issues faced across Canadian Arctic populations, the implementation of this research occurs through community-specific collaborations with the guidance of a local planning committee comprising community representatives, local health professionals, and scientists. Together, team members work closely to identify research questions, implement the research, and disseminate results in a culturally-appropriate and meaningful way, mindful that inter-cultural knowledge translation has proven difficult in other northern Canadian situations (Estey et al., 2008; Myers & Furgal, 2009; Smylie et al., 2004, 2009) and subtle attention to meaning, language and history is required to effectively communicate between scientific and non-scientific communities.

Knowledge exchange projects methods

Aklavik residents on the project planning committee advocated for meaningful KE strategies so that CAN*Help* Working Group research results could be disseminated in a way that makes sense to the community. Additionally, they sought learning opportunities for community youth; in particular, the planning committee proposed that the dissemination of results be integrated into local school activities. To support these goals, community representatives and scientists collaborated to develop a KE project. To acknowledge the collaborative nature of this project, scientist and community member KE project participants are referred to here as academic and community partners, respectively.

Knowledge exchange activities: Aklavik

In September 2012, two CAN*Help* Working Group academic partners, a microbiologist (MK) and an anthropologist (SC), travelled to Aklavik to meet with community partners, share research results related to a microbiology component of the research program, and participate in daily life and activities in the community. While there, they met with planning committee members, staff at the school and other community members, attended social functions, and listened to community members' concerns and views about *H. pylori* infection. The two academic partners also aimed to deepen their understanding of the social context and information dynamics within the community to support effective communication of research processes and results.

The academic partners and members of the planning committee worked together to develop a KE plan: two community partners would travel to Edmonton, Alberta, Canada, a metropolitan area of approximately 1,000,000 people located 2,000 kilometres south of Aklavik and home of the academic partners of the research team, to learn about the project components that are conducted at the University of Alberta. The two community partners would return to Aklavik and share their experiences with other residents of the community. Members of the planning committee felt that this would be an excellent opportunity for youth to learn and share what they learned with the community. Two young women (BLK and PDE), who were then under 20 years old, were identified and invited to participate as partners in this community-designed KE project. The idea was to create opportunities for academic partners to deepen their understanding of community knowledge and for community partners to engage in the entire research process rather than merely receiving results after the work was done. With this project, we attempted to expand the horizons of research dissemination by identifying and addressing barriers to effective communication and by opening the doors for the community to experience the complex processes involved in scientific research.

Knowledge exchange activities: Edmonton

In October 2012, the two community partners traveled to Edmonton where the KE project coordinator (AC) met them at the airport, took them to their hotel and gave them a package that included an itinerary and other items that might be useful for their stay: bus tickets, phone cards, a list of important phone numbers, a city map, and spending money for food. The next morning, a CAN*Help* staff member took them to the University of Alberta campus where they met with the lead microbiologist (MK) and her laboratory team for an orientation. As planned during the community visit, the main goal of their visit to Edmonton was to learn about the CAN*Help* Working Group research and to take back what they learned to share with the community. They received a camera and video recorder and were encouraged to record the aspects of their visit they felt were appropriate for fulfilling the KE project goals.

Over their week-long visit, the community partners learned about a variety of microbiology methods used to study the *H. pylori* bacterium, and they learned how to interpret the data. The emphasis was on direct observation and participation. The community partners also met with CAN*Help* public health scientists who provided an overview of how *H. pylori*–associated disease is studied in human populations. They observed clinical appointments of the lead CAN*Help* gastroenterologist, Sander Veldhuyzen van Zanten, to learn how patients with symptoms of digestive disease are examined and diagnosed. Furthermore, the community partners participated in a variety of tours and exercises to foster a greater understanding of healthcare processes: they learned about upper and lower gastrointestinal endoscopies in a simulation lab where they were able to practice conducting the procedures themselves on a life-like dummy; they toured the Cross Cancer Institute, a cancer care center where people from the NT are often referred if diagnosed with cancer; and they toured college campuses in Edmonton to learn about opportunities for higher education. In effect, the approach described here was intended to invert the normal relations of community members and researchers, preparing the community partners to be educators of scientific practice.

Knowledge exchange activities: follow-up

At the end of the week-long visit, the community partners designed and delivered a PowerPoint presentation to CAN*Help* Working Group academic partners about their trip to Edmonton, highlighting what they had learned about the *H. pylori* bacterium, the scientific research process, and the microbiology research results of the Aklavik *H. pylori* project. Upon returning to Aklavik, they edited their presentation to communicate the same information in ways consistent with community communication patterns, to make it accessible to Aklavik residents of all ages. They gave this presentation several times to community groups, with a focus on junior high and high school students. During these presentations, they distributed evaluations that they designed themselves to get feedback on the presentation and to evaluate what their audience had learned.

In December 2012, along with CAN*Help* Working Group academic partners, the community partners attended a national scientific research conference in Vancouver, Canada: the 2012 ArcticNet Annual Scientific Meeting. There, they shared their perspectives on life in the North with participating scientists and learned about other kinds of scientific research happening in the Arctic. They also co-presented a poster that described the KE project with graduate student lead authors (AC and SC), which won first prize in the ArcticNet student poster competition (Carraher et al., 2012).

In March 2014, community partners returned to Edmonton to share their experiences as educators in the community with researchers and students at the University of Alberta. They gave two formal presentations: one hosted by the Circumpolar Students' Association and the other hosted by the School of Public Health.

They presented their experiences with the KE project, and taught academic researchers about life in their community (for example, the scope of the science curriculum in the local school) and about community perspectives on scientific research (for example, how community members talk about *H. pylori*). During this visit, CAN*Help* Working Group academic partners interviewed the community partners, asking them to provide feedback on the positive and negative aspects of the KE project. Both community partners continue to act in an advisory capacity for other CAN*Help* Working Group KE projects.

Reflections and lessons learned

Through an ongoing process of collective reflection, including informal interviews with KE participants, we identified key outcomes and valuable lessons of the KE project. In the following sections, we outline the benefits and challenges of KE evidenced through our collaborative approach.

Benefits of the knowledge exchange process

The benefits of integrating KE in research are numerous. Here we have highlighted a selection of benefits that were particularly prominent features of our project.

Fosters mutual understanding which builds strong community-university partnerships

Strong community-university partnerships foster the meaningful development of scientific research that supports desired societal change (Gibbons, 2000). However, historical, as well as cultural differences in the personal backgrounds of people working together can impact the ways in which community-university partnerships are developed and maintained (Jardine & Furgal, 2010; Smylie et al., 2004). Unfamiliarity with the social context and normal expectations on either side of such a partnership make conducting collaborative research a challenge. Community members may never have the opportunity to witness specific research processes first-hand. This is particularly evident when research involves a biomedical component that requires intensive laboratory work. Conversely, laboratory scientists may not have an adequate understanding of the sociocultural context of the community from which laboratory samples are taken. Thus, in this kind of work, each group in a research partnership may have a crucial knowledge deficit regarding the other group.

For the academic partners in our team, particularly those who rarely work outside the university setting, spending time in the community and having in-depth conversations with community partners allowed them to learn about life in the community; the insights they gained included a greater understanding of some of the challenges and strengths of living in a remote Arctic community. Academic partners also deepened their understanding of how community members view *H. pylori* infection, what they hope to gain from the research, and their preferred learning approaches. Similarly, community partners had the opportunity to learn about the sociocultural context of the University of Alberta through first-hand experiences; in particular, they were able to witness the educational programs and life of university students, and observe the work-lives of academic researchers. This KE project permitted the exchange of information—both research-related and community-related—which fostered a greater mutual understanding amongst all parties. As a result, KE initiatives such as these reinforce strong university-community partnerships that enhance the relevance and effectiveness of collaborative research and promote the effective implementation of scientifically derived solutions.

Promotes a common understanding of research and research processes

By spending time in the community and with the community partners in Edmonton, the academic partners deepened their understanding of community knowledge about scientific research processes. Community-driven research with a biomedical component can be challenging to conduct collaboratively because of differing perspectives about research (Colquhoun, Geary, & Goodman, 2013). In the CAN*Help* Working Group research program, it has been observed, for example, that community members may not be aware that work continues when researchers are not within the community; moreover, the methods and extent of analysis undertaken outside the community in the university are not readily apparent. Observing lab and clinical activities helped show the community partners that research is still ongoing when researchers are not physically present in Aklavik. Importantly, seeing the microbiology lab allowed the community partners to make sense of the new information they were receiving. Among other things, they learned about bacteria in general, and specifically what *H. pylori* look like; they witnessed how tissue samples are processed, how bacteria are grown in a laboratory and how they are prepared for genetic analyses and antimicrobial drug susceptibility testing. Following these experiences, one of the community partners noted, “We got to make some *H. pylori* babies, Lol!” The other stated, “I learned that all the scientific work that is done in [the lab] really has more to do with everyday life than we think.” The experiential learning that comes from visiting the research labs and university supported the objective of informing people in Aklavik about the full extent of the research process. The community partners returned home and shared stories with the community helping to answer community questions about how long it takes for results to be generated, and what happens with people’s biological samples after they are taken from the community. Learning about one another’s perspectives promotes a common understanding of research and research processes; thus, KE projects such as these bolster the effective and meaningful communication of research-related information and strengthen collaborative research endeavours.

Builds knowledge about the health issue

People learn by incorporating new information into their existing culturally formed knowledge. For this reason, strategies aimed at building knowledge must take initial understandings and perspectives into account (Morgan, Fischhoff, Bostrom, Lave, & Atman, 1992). Our KE project allowed both academic partners and community partners to gain insight into differing perspectives on the health burden of *H. pylori* infection. By spending time in the community and discussing the topic at length with community partners, academic partners gained insights into how Aklavik residents view the bacterium and related health risks. They also learned how community members understand the microbiology data presented to them. For example, northern residents often ask academic partners questions about bacteria being present in water, in caribou or other subsistence resources in their local environment, or whether events such as climate change and pollution can influence the health risks from *H. pylori* infection. Their concerns and the way these are framed reflect the importance of engagement with the land and environment from which people in the community derive much of their livelihood. Questions like these are important to northern residents and convey insights into local ways of integrating scientific information which tends to be abstract and removed from local experience. Equally important, our KE program allowed the community partners to better understand how biomedical treatment can reduce health risks, which is particularly important given that treating *H. pylori* infection with antibiotics is a way to protect people from developing stomach problems in the future. Likewise, visiting the gastroenterology clinic at the University of Alberta allowed the community partners to understand more about the healthcare aspects of the research program. As one community partner noted, “We understand more of the personal side of stomach diseases and what patients have to go through if they are diagnosed with stomach cancer”. Another reported: “My favorite part of the trip was where we did the endoscopy on the fake dummy, [and] we got to sit in on the appointments with Dr. van Zanten. It was so nice of the patients and him to let us do that, to get a better understanding.” Creating opportunities for academic and community partners to experience one another’s environment and culture helps broaden each partner’s understanding of a health issue, enhancing the relevance and effectiveness of collaborative research and strengthening the meaningful dissemination of research results.

Promotes bi-directional capacity building

This KE project also provided opportunities to build research and education capacity, as well as communication skills amongst participants. For example, the science curriculum at the community school does not cover much biology, particularly cell biology or genetics. There are few opportunities in a remote community school to learn about science topics directly using laboratory equipment and experiments, as is more common in southern Canadian schools. In working collaboratively on this project, the academic partners were able to contribute opportunities for hands-on experience in a scientific research laboratory. Furthermore, the community partners also developed their presentation skills: they had several opportunities to do so, in different forums, aimed at varied audiences. These included the presentation of project results at a national research forum, at various university events, to CAN*Help* Working Group academic partners, and to community members back home.

Academic partners also had the opportunity to develop communication skills through the instruction elements of the KE initiative. Other valuable skills that graduate student researchers, in particular, learned throughout this process included program planning and project management in a northern and Aboriginal context. The scheduling, organization, and implementation of the KE project required time management and other key project management skills as a result of the language, geographic and social distance between the university and the community. Each of these skills was augmented by understanding the social context and locally-available facilities and resources that had to be considered when collaborating on KE activities in Aklavik. Academic partners learned which elements of the research program were important to focus on when communicating about the research or disseminating research results. In this sense, capacity building has been a two-way process in which local realities in the north and the south have been shared and queried by all participants; this dimension of the KE project underscores the value of framing the endeavor as the exchange of knowledge between academic researchers and community collaborators who have a stake in the research. Expanding competencies amongst research partners through collaborative initiatives like these bolster community and academic partners' abilities to effectively communicate research results.

Facilitates shared power in research environments

There are many examples in history of how research has been damaging to Aboriginal communities (Smith, 2012): in many cases, Aboriginal communities were the subjects of research without the chance to play a role in establishing their own research priorities or to collaborate on research that was meaningful and beneficial to their communities and societies. Given this history, it is imperative that current research efforts are community-driven and collaborative. To support this, many Aboriginal communities and governance organizations have come to develop and adopt community-directed research ethics processes, and collaborations. Many projects now include consideration of the OCAP (Ownership, Control, Access, and Possession) principles pertaining to the collection, use, and dissemination of research data and results (Schnarch, 2004). Similar guiding principles have been generated by academic networks, such as the Association of Canadian Universities for Northern Studies (Association of Canadian Universities for Northern Studies, 2003) and research funding agencies, such as the Canadian Institutes of Health Research (CIHR) Institute of Aboriginal Peoples' Health (Canadian Institutes of Health Research, 2005). Adhering to such principles can be facilitated through research that is both community-based and participatory, where community-university partnerships are established and research questions are posed and pursued through collaborative endeavours. In such partnerships, communities negotiate what research will be conducted in their communities, how it will be implemented, and how resulting data will be used. Guiding principles for collaborative community-driven research require that the design of community health research starts with relationship building that allows for genuine and equitable participation. Given the diversity of Aboriginal communities across the country and beyond, there is a necessity in all research to allocate the time and resources required to move beyond good will and into community-relevant, concerted, sustainable action.

Our overarching collaborative research team, the CAN*Help* Working Group, follows guiding principles described in a Statement on the Stewardship and Dissemination of Knowledge Generated Collaboratively (CAN*Help* Working Group, 2016b). These principles include the establishment of community-specific planning committees that are made up of community representatives. Also required is the development of a written research agreement (CAN*Help* Working Group, 2016a) that outlines how community values and priorities will be safeguarded and responsible stewardship of data ensured while simultaneously supporting academic researchers' obligations to adhere to academic standards and research funding agency requirements. The CAN*Help* Working Group approach incorporates input from partners throughout all phases of research, from beginning to end. The CIHR refer to this approach as "integrated knowledge translation" (Canadian Institutes of Health Research, 2015); this approach aims to ensure that research is collaborative and that work done is meaningful to the intended beneficiaries. Methods such as these are particularly relevant in populations with restricted exposure to academic science, including Canadian Aboriginal populations:

as noted by Smylie et al. (2004), because of differences in academic scientific and Aboriginal knowledge systems, “knowledge translation methods for health science research need to be developed and evaluated in the context of Aboriginal communities” (p. 142).

Our KE project exemplifies a community-driven, collaborative approach. In addition to supporting an equitable community-university research partnership, the individual benefits of this approach are demonstrated in participants’ description of their experience: when asked how they felt about bringing this information back to their community the youth responded that they felt proud. Other community members also expressed pride, such as the community school principal: “we are proud of these girls as they have done a great job with their involvement and representations [throughout] the initiative…”. Collaborative processes such as our KE project foster a participatory approach to the development of a research plan; in particular, the collaborative dissemination of research results promotes a more equitable research landscape by developing shared authority and ownership over the research process, interpretation of results, and communication of research findings. In engaging together around complex scientific and community issues, the latent power dynamics of the research process are acknowledged and steps taken to move beyond the culturally defined roles of researcher and subject.

Challenges of the knowledge exchange process

While the benefits of KE are significant, it is important to be mindful that this strategy requires energy and resources to be effective. Each project will have its own dynamic and here we signal a number of issues that qualify as challenges to our KE project processes.

Logistics of long-distance relationships

The physical and conceptual distances between the remote Arctic community of Aklavik and the University of Alberta in Edmonton, a large urban centre located 2,000 kilometres to the south, are important features of our working relationships. Travel time makes the trips burdensome: during the winter months, there are no flights to the community; an hour and a half drive on the ice road is necessary to and from Inuvik, NT, with flights between Inuvik and Edmonton typically requiring two stops and taking five to six hours. Distance was a barrier to effective communication amongst people in different locations and impacted the planning, coordinating, and executing of aspects of the KE project: most discussions needed to take place over the phone or via email rather than in person.

The expense of travel and accommodation in Arctic communities also placed a heavy burden on research resources and limited the number of KE project participants. Given the personal benefits of the hands-on experiences, it would have been ideal if other members of the academic research team could have visited Aklavik and if other members of the community could have participated in the visit to the university. In particular, while we focused efforts here on the participation of youth at the request of the community planning committee, we wonder what other insights would have arisen had elders also been invited to the university. Despite the myriad KE project benefits, it would be costly and timing-consuming to implement our KE project model for each line of inquiry within the CAN*Help* Working Group research program.

Differing cultural and educational norms and expectations

When KE activities are organized by academic partners, differences in cultural norms surrounding daily work schedules and routines may lead to overly challenging demands on community partners from settings where daily routines are slower-paced. In small Arctic communities, for example, large fluctuations in daylight hours, seasonal and regional events, and other environmental and sociocultural factors lead to daily schedules that differ from a typical university research setting and are not always amenable to advanced planning. When academic partners traveled to Aklavik, they learned that community time frames tend to be more flexible and responsive to local events; as a result, arranging KE project activities held there required flexibility. Conversely, the community partners stated that the 9-5 workdays planned for them in Edmonton were stressful and tiring: they learned that university time frames and scheduling reflect a frenetic work environment that tends to be very rigid. The community partners said they would have valued a longer visit with shorter work days. In retrospect, it would have worked better to stretch the week-long educational period to two weeks to provide more time for reflection and synthesis and for producing the culminating PowerPoint presentation. The intensity of this work week was exacerbated by the excitement of a location with activities not available in their home community. Furthermore, additional time would have been useful to enhance the background knowledge required to maximize learning in the lab setting. The need for background knowledge was not fully understood by the academic partners in advance who were not aware that the high school curriculum in Aklavik does not cover biology to the same degree as is typically the case in southern Canadian schools. This posed challenges for the implementation of lab exercises and was a valuable lesson for academic partners about the educational disparities across many northern and southern communities.

Timing of apparent benefits

The academic partners who coordinated the KE project expected that some of the benefits for the community partners would be immediately apparent; they anticipated that, following their time at the university, the community partners would return to Aklavik filled with new knowledge about *H. pylori* and the research program. Some of the challenges outlined above gave an initial impression that KE efforts may not have been as successful as anticipated. In retrospect, the community partners spoke about the experience with great pride. They were eager to share their experiences and became skilled at presenting what they had learned in effective ways to various audiences. They were also eager to provide feedback and guidance to CAN*Help* Working Group academic partners on how these KE activities might be improved in the future. Similarly, the knowledge gained by academic partners was not immediately apparent; upon reflection, however, it became clear to participating scientists that they had gained insights into community knowledge through this initiative. The full extent of benefits was not immediately obvious; it took time for the individual- and community-level benefits to be observed through on-going discussions and interactions between KE project participants.

Breadth of apparent benefits

While community and academic partners expressed a strong satisfaction with the KE project, it is not clear precisely how many individuals benefited from this initiative or the extent to which understanding was increased among the partners because we opted against formal evaluations that are often applied in university settings. These simply do not reflect local ways of learning and are awkward impositions. Nevertheless, community partners were able to share their perspectives and hear from the academic partners in various settings. Similarly, scientists from various disciplines had the opportunity to deepen their understanding of community knowledge and information dynamics. In Aklavik, the community partners presented several times at the local school and, while open to other community members, the main audience was junior and senior high school students: about 30 people attended these presentations in total. The collaborative and flexible nature of the KE project required being open about who was participating and how they would participate. Consequently, the success and impact of the KE project was determined through a process of collective reflection and informal feedback. These efforts suggest the project touched a large number of community youth and academic researchers more broadly. For example, following a series of presentations at the local school, the community partners conducted a survey using a questionnaire they developed to determine if attendees had a good understanding of the bacterium and to see if there were any suggestions on how to improve their presentation. The majority of attendees reported that they knew more about the bacterium after the presentation than they did previously. Similarly, academic partners participating in the KE project and those attending the community partners' presentations reported an increased understanding of how community members view the bacterium, about existing barriers to the communication of biomedical science topics, and about community members' preferred learning approaches. Consequently, we can affirm that the overall goal of knowledge exchange between community and academic partners has been achieved.

Data collection as a process of social exchange

Both the benefits and challenges identified through our KE project highlight the ways in which data collection can be improved when treated as a type of social exchange, where relationships are developed through reciprocal transactions. Ultimately, instances where community partners and academic partners developed mutual understandings are those where social exchange was most effectively managed and appropriately tailored to the particular facilities, resources, and social contexts in Aklavik and the university setting. Challenges occurred when social exchange was hindered either by physical distance (preventing face-to-face-personal communication and rapport-building) or by social distance (unequal educational backgrounds in biology, limited knowledge of appropriate social norms for daily routines and work schedules). KE is an important strategy for trying to reduce the conceptual and cultural distances apparent in the community-university interactions around scientific research process. This project shows how a flexible and bi-directional exchange across all parties involved can help bridge the apparent divides. Conceptualizing and implementing this KE project based on a two-way model of knowledge exchange empowered the community partners as observers of university practice and the dynamic became one of mutual learning rather than the typical translation from scientists to the public. We believe this exchange makes a crucial contribution to long-term and sustainable impacts of the community-university research relationships. The greatest benefits, such as expressions of pride amongst community partners and other members of their community, only became apparent some months after the immediate project activities in Aklavik and Edmonton were completed.

Conclusion and future work

We developed and implemented our KE project as a community-university collaboration that was part of a community-driven research program seeking to address concerns about a stomach bacterium and its health effects. Through first-hand experiences, the project supported the flow of knowledge from community partners to academic partners about their views on the bacterium and scientific research, and their preferred learning approaches. It also fostered a way to clarify scientific research and opportunities for community partners to understand and disseminate health research results to other members of their community in a meaningful, culturally appropriate way. The project favoured a shared knowledge and exploration approach in which community partners became observers of academic culture and practice in the same way that academic partners observed human health issues and social context in the community. The project strengthened community and researcher knowledge about a variety of topics and benefitted from the openness and mutual respect this approach demonstrated.

The apparent success of this endeavour highlights the need for greater KE opportunities, particularly when conducting community-driven research aimed at addressing a specific health problem. Including community partners directly in research processes promotes their engagement in the research being conducted; strengthens the skills, competencies, and abilities of both community and academic partners; supports effective communication of research results and their translation into beneficial actions; and promotes efforts towards an equitable distribution of power. It also empowers academic partners to be more cognizant and fluent in community knowledge dynamics and social processes related to health.

This on-going collaborative work fosters a strong community-university partnership in which knowledge is shared between community and academic partners, who learn from one another to address health problems together. Guided by KE project participants about which aspects were successful and where there may be room for improvement, this KE work will inform future collaborative research methodologies and will be used as a framework for future knowledge exchange initiatives with other communities.

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4.2 Community-driven research in northern Canada: local visual representations of a health research project

Abstract

Northern Indigenous populations in Canada have a disproportionately high frequency of *Helicobacter pylori* infection and associated diseases. To address concerns, a multidisciplinary community-driven research program aims to describe disease burden and risk factors associated with *H. pylori* infection, and identify effective public health and knowledge translation strategies to reduce associated health risks.

Research implementation occurs through community-specific *H. pylori* projects guided by planning committees comprising various local representatives and research staff. Committee members work together to achieve community-specific goals and to uphold the integrity of the research. In three participating communities, during the project launch, community members developed a visual symbol, or logo, representing the community project. In each case, through community guidance, contests were held to solicit entries and select ‘the best’ *H. pylori* project logo.

This initiative opened discussions about the project, the bacterium and its health effects, and resulted in dozens of submissions from various community members. In each community, the planning committee determined how the ‘winning’ design was selected. A digitized version of each winning drawing was created. Each of the three graphically designed images is now used to represent the respective community project. We describe, in the artist’s own words, each of the official community project logos and describe the value of logo art in community health research projects.

These images capture the imagination and innovation of community members, visually conceptualizing the community-based research and the bacterium from their perspectives. These figures also promote and represent a strong community-researcher partnership where questions are posed and solutions to health problems are discovered together.

Introduction

Scientific research seeks to contribute to a body of knowledge about a particular phenomenon. Research aiming to yield real-world impacts helps scientific knowledge grow in ways that are socially meaningful for particular settings (Gibbons, 2000). These "context sensitive" research pursuits are particularly relevant for public health research where the ultimate goal of new knowledge is to bring about beneficial change for the health of populations. One way to enhance the impact of public health research is through community-university partnerships; such collaborations extend the reach of academic scientists by integrating a variety of perspectives, thus strengthening the applicability of the research to particular social settings (Baum, 2000; Minkler, 2005; Stanton, 2008; Wallerstein & Duran, 2010). In addition to producing benefits such as the generation of new research questions, community-university partnerships are also a means to create other benefits such as skill development and increased access to research components that optimize the climate for addressing context-specific research questions (Minkler, 2005; Stanton, 2008; Wallerstein & Duran, 2010). Furthermore, these partnerships can help broaden understanding and knowledge amongst all partners: community members may learn about scientific process and researchers may gain insights into community perspectives and other socially useful forms of knowledge creation (Minkler, 2005; Wallerstein & Duran, 2010).

Comprehensive collaborations between community members and scientists throughout the design and conduct of research is particularly relevant in research involving Indigenous populations (Estey, Kmetic, & Reading, 2008; Jardine & Furgal, 2010; Smylie et al., 2004). Because it is necessary to build on Indigenous approaches to knowledge sharing when aiming to meaningfully communicate knowledge generated through scientific research (Smylie, Olding, & Ziegler, 2014), activities supporting these communications must be done in partnership and tailored to the communities involved (Smylie, Kaplan-Myrth, McShane, & Métis Nation of Ontario-Ottawa Council Pikwakanagan First Nation Tungasuvvingat Inuit Family Resource Centre, 2009). Here, we describe a collaboratively developed and implemented activity conducted as part of a community-university partnership that aims to address northern community health concerns about a stomach bacterium. To support community goals and promote conversations about the health research partnership, participants in three community projects developed a visual symbol, or logo, representing the project taking place in their community. We outline the community-specific processes undertaken, showcase these images, and highlight how they contribute to the overarching community-university research goals.

Context

Helicobacter pylori is a bacterium identified as a major cause of chronic gastritis, peptic ulcer disease, and stomach cancer. In 2000, an estimated 70% of the developing world was infected with the bacterium (Brown, 2000). Although the prevalence of *H. pylori* is lower in developed countries (40% in 2000), research shows that northern Indigenous populations have a disproportionately high frequency of *H. pylori* infection and associated diseases (Goodman, Jacobson, & van Zanten, 2008; Young, Kelly, Friborg, Soininen, & Wong, 2016). To address concerns voiced by affected communities, a community-driven research program carried out by the Canadian North *Helicobacter pylori* (CAN*Help*) Working Group has engaged several Indigenous communities in northern Canada. This research program is a collaborative initiative that links community representatives, faculty from various disciplines at the University of Alberta, as well as Northwest Territories (NT) and Yukon (YT) health care practitioners and health officials. The overall aims of the program are to describe the burden of disease and risk factors associated with *H. pylori* infection, to identify effective public health strategies for infection control, and to develop knowledge translation strategies that help build understanding of health risks as well as solutions and unsolved challenges for reducing these risks.

While the overarching research program aims to address issues faced across the territories, the implementation of this research occurs through close community-specific collaborations. To achieve this, community planning committees comprising various local representatives and research staff are established in each community. These teams work together to achieve community-specific goals and to uphold the integrity of the research. These community-specific projects are being conducted in several communities across the territories: three participating communities are Aklavik and Fort McPherson, NT, and Old Crow, YT (with 2011 census populations of 633, 792, and 245, respectively) (Statistics Canada, 2012). Each of these communities is located north of the Arctic Circle and is primarily comprised of Indigenous peoples: according to the 2006 Canadian

Census, over 85% of residents in these communities identified as Indigenous (Statistics Canada, 2007a, 2007b, 2007c). In Aklavik, 55% of the Indigenous population in private households in 2011 identified as Inuvialuit, a term used to describe Inuit people residing in northwestern Canada; 41% identified as First Nations and another 3% as Métis (Statistics Canada, 2013a). In Fort McPherson and Old Crow, the majority of the Indigenous population in private households identified as First Nations (93% and 98%, respectively) (Statistics Canada, 2013b, 2013c). The majority of First Nations in these three communities are Gwich'in: the Gwich'in First Nation may be described as Indigenous people of the northwestern part of North America belonging to the Athabaskan language family and include tribes such as the Vuntut and Teetl'it Gwich'in peoples ("Fort McPherson - About Us," n.d.; "Gwich'in," 2016; "Old Crow - History," n.d.). We respectfully use the term Indigenous to refer to Métis, First Nations, and Inuit populations unless other terms are preferred by our coauthors.

Methods

To distinguish the work that is being conducted locally from the overarching research program, community members in three participating communities developed a visual symbol, or logo, to represent the community-specific project. To accomplish this, through guidance from respective community planning committees, contests were held for 'the best' *H. pylori* community project logo. Community representatives determined the process for selecting the 'winning' design: the successful artist won a prize, and a digitized version of the drawing was created. The ways in which these contests were conducted and the process used to select the 'winning' logo were different for each community.

For both Aklavik and Old Crow, the contest was open to the whole community, advertised by word-of-mouth, flyers, and local radio stations; submissions were accepted from anyone who was interested in participating. In Aklavik, there were fewer than 10 submissions in total, all from adult residents. At the time of the contest, we did not anticipate displaying or analyzing contest submissions and, as a result, did not receive permission from contest participants to use non-digitized images for purposes other than the contest. Unfortunately, many logo contest participants have since left Aklavik making follow-up and the use of these images for any other purpose impossible. In Old Crow, there was only one submission and it was selected as the Old Crow *H. pylori* Project logo.

In Fort McPherson, the logo contest was implemented differently than in Aklavik and Old Crow. At the suggestion of the Fort McPherson *H. pylori* Project planning committee, the logo contest was limited to school-aged children. Two visiting university researchers were asked to present on the project and the logo competition to each class in the local school. Students were instructed to draw something that represented the project and their community, and to submit their drawings to project staff within a week's time—the top three submissions would receive a prize. Based on feedback from the project planning committee, the process for selecting the 'winning' drawings involved a blinded assessment of entries conducted by five people without historical family ties to the community: two university researchers, two nurses, and one police officer. Each drawing was evaluated on pre-determined inclusion elements such as apparent portrayal of the bacterium and of the community; the submissions were then ranked based on their composite score.

Results

This initiative fostered interest and awareness about the collaborative research endeavour amongst community members in three participating communities. It created opportunities for engagement and education: the initiative opened discussions about the project, the bacterium and its health effects, and resulted in dozens of submissions from community members. Here, we provide further information about the winning drawing submissions. We include summaries about the artists and their self-described meanings for the images. We also provide details on how these images have been used since their creation.

Aklavik, Northwest Territories

The drawing that was selected for graphic design to represent the Aklavik *H. pylori* Project was drawn in 2007 by Richard Papik (Figure 3). Through correspondences with university researchers, Mr. Papik expressed pride in his participation with the research program and being selected as the ‘winner’ of the logo context. The CAN*Help* Working Group was deeply saddened to hear of his death in 2012 and commented in a northern newspaper article about Mr. Papik’s contributions to the research program (Puglia, 2014). To support on-going discussions about the Aklavik *H. pylori* Project logo, Mr. Papik provided text about himself and his drawing:

> Richard Papik was born, raised and played in Aklavik at a time when Aklavik was the ‘Muskrat Capital’ of the world. Richard prefers [sic] to Arts & Crafts as a hobby and can put together beaded moccasins, mukluks, hats, mitts, parkas, cover-parkas but decided to enter this ‘logo contest’ and low and behold…won…
>
> The Logo has three cultures living in unity; a house, representing the Whiteman; the Drum, representing the Inuvialuit; and the teepee, representing the Gwich’in and the dreaded *H. pylori* that will inhabit anyone regardless of race.

Figure 3: Digitized image of Aklavik *H. pylori* Project logo drawn by Richard Papik in Aklavik, Northwest Territories, 2007

Old Crow, Yukon

In 2010, Mary Jane Moses completed the drawing that is used to symbolize the Old Crow *H. pylori* Project at 61 years of age (Figure 4). Through email, Ms. Moses was asked by university researchers to describe herself and the drawing: what the drawing meant to her and why she included the symbols that she did. She began by writing in Gwich'in, which is followed by a translation and further descriptions in English. Here are her written responses:

> Drin gwiinzii thak ts'o' - Shoozri Mary Jane Moses vaazhii. Shiiyuuwhan Wm & Mary Vitrekwaa. Old Crow niizhuk ti'ich'uu, 1979 gwats'at gah taihee Tetl'it Zheh gwats'at ihłii. Tetl'it Gwich'in ihłii, geenjit shoh ihłii. Good day everyone. My name is Mary Jane Moses. My parents were the late William & Mary Vittrekwa. I have lived in Old Crow for a long time, since 1979 but I come from Fort McPherson, Northwest Territories. I am a proud Tetl'it Gwich'in, for which I am happy.
>
> I have lived in Old Crow for almost 34 years now. I enjoy my life there. It keeps me connected to my Gwich'in way of life and culture within the Vuntut Gwitchin traditional homelands. I practice the traditional teachings that I was raised with. I had good teachers in my upbringing. I am employed with the Vuntut Gwitchin as Heritage Researcher and my work involves the language, culture and heritage aspects of Vuntut Gwitchin. I keep closely connected to my Gwich'in culture and language. I have a strong cultural background and use the teachings taught to me by my parents and others and pass them onto future generations. I have 5 grandchildren. I am also a film maker, I have produced about 7 films to date, most of which are about the culture and traditions of the Gwich'in. My films are named in my Gwich'in language and the last 3 films are in full Gwich'in narration. I'm very proud of my progress in film making. Mahsi'

I drew the logo for the Old Crow H Pylori [sic] Project because for me this was a very important project that our community members needed to get involved with. They needed to get themselves checked out for this “bug” in our stomachs that most northern communities were becoming alarmed, concerned about. When I found out the project was coming to Old Crow, I was excited. “Now, maybe they will find out how come many of us in the community always have stomach problems” and it could be related to our way of life so that is what is represented on the logo.

1. The landscape image you see is Crow Mountain with snow on top in back of Old Crow, that is our strong hold, our lifeline, that is where the caribou walk, we are caribou people, we live off the land and animals. We go to Crow Mountain in summer to pick blueberries, black berries and salmon berries and in falltime [sic], we pick the cranberries. The mountains also represent water, all water flows from mountains. The sun is important in our lives here and everywhere, the sun makes us happy. We have 24 hour daylight from about May to July. The green, rich landscape, the land is our provider, the berries that grow on it, the lichen that the caribou feed on, the caribou is our life. It’s our main food source. We are healthy because of the ways we live, connected to the land and animals. The teepee represents the caches where we store and or cook our food from the land in the summer months. The house, shelter, is what we live in town, modern life tied in with the traditional life. The blue river full of fish, here it is salmon, another food source for the Vuntut Gwitchin, We live seasonally off of the land, the land provides for us when we take care of the land and animals, fish. The Hpylori [sic] bug you see at the bottom is us wanting to find out how all this, if it is connected to our way of life on the land, to the waters, to the animals, fish we eat. Is there a connection to why the bug is in our systems and for how long has it been with us?

> 2. The border flowers the white is the white yarrow, the Labrador tea plant flowers or the salmon berry flowers, both plants that grow here. Yarrow is a plant with many uses one of which is boiling it for a tea to drink for colds. Salmon berry flower turns into a fruit, the nakàl, salmonberry which is rich in Vitamin C. The Labrador tea flower turns to a leafy plant we make teas out of or add a pinch to our teapots to give it a flavor and it has other medicinal uses. The red flower is just for the color, red is energy, life-giving. The yellow flower is the buttercup, symbol of beauty and strength. The green leaves are growth, newness of life every spring for everyone, humans and animals, plants etc. This is a seasonal cycle of life on earth.

Figure 4: Digitized image of Old Crow *H. pylori* Project logo, drawn by Mary Jane Moses in Old Crow, Yukon, 2010

Fort McPherson, Northwest Territories

The drawing selected in Fort McPherson was drawn in 2012 by Johanna Edwards who was 11 years old and in grade 5 at the time (Figure 5). Following the selection process, Ms. Edwards was interviewed by a university researcher and asked to provide details about herself and what she had in mind when creating the drawing. The researcher summarized their conversation and sent the drafted text to Ms. Edwards and her family for review and confirmation. The following is a summary of how she described herself, her artistic methods, and the image symbolism.

> Johanna Edwards knew she wanted to be an artist when she was 5 years old. Since then, she's been working on improving her drawings and getting her own flare. To do this, she visualizes the image in her head, then starts with drawing the frame, then the drawing itself, and then adds colour. Johanna got the idea for this piece from a big sign that used to say, "Welcome to Fort McPherson." On the front of this sign was a big moose which she thought represented Fort McPherson pretty well. She wanted to add her own flare, so put a moose with dandelions in the background, as well as big *H. pylori* in the clouds. When she looked up *H. pylori* on the computer, she saw many different colours like blue and pink but thought the green popped out. The landscape in the drawing includes mountains and fields because Aboriginal people used to be all over the place when there weren't cities.

Figure 5: Digitized image of Fort McPherson *H. pylori* Project logo drawn by Johanna Edwards in Fort McPherson, Northwest Territories, 2012

Each of these logos continue to be used to identify community-specific *H. pylori* research projects. For example, they are included in paperwork that relates to a community project, such as questionnaires that are used in interviewer-administered surveys. They are also used on the CAN*Help* Working Group website to identify the community project (" CAN*Help* Working Group - Aklavik *H.pylori* Project," n.d.; "CAN*Help* Working Group - Fort McPherson Project," n.d.; "CAN*Help* Working Group - Old Crow *H.pylori* Project," n.d.). In addition to their use as part of community-specific work, there has also been a great deal of interest from people outside the research program with varied backgrounds. For example, these graphically designed images and dozens of submitted drawings from children in Fort McPherson (see Appendix I) have been presented at several local and international *H. pylori*- and gastrointestinal-related conferences ("Alberta Digestive Disease Summit 2013," 2013; European *Helicobacter* Study Group, 2013), offering researchers such as microbiologists and gastroenterologists the opportunity to witness how community members depict the bacterium. The artwork has also been showcased as part of an international art exhibit titled Insight2: Engaging the Health Humanities ("Exhibitors - InSight 2: Engaging the Health Humanities," n.d.) and subsequently displayed in a University of Alberta building as a permanent installation. Through collaborative initiatives between communities and university researchers, the drawings will continue to be analyzed to learn more about how their content provides insights into how community members view the bacterium, the research project, and their community.

Reflections and discussion

The logos created by northern residents showcase the community-driven research on *H. pylori* in three participating communities: Aklavik and Fort McPherson, NT and Old Crow, YT. Each drawing provides insight into individual and community perspectives on the *H. pylori* research program taking place; they reflect how community members view the bacterium, the research, and their community. These images also reflect strong community-university partnerships where questions are posed and solutions to health problems are pursued together.

These visual representations provide insights into how individuals view the *H. pylori* bacterium. As described by contest winners in each of the three participating communities, co-authors Papik, Moses, and Edwards, the bacterium is indiscriminate and ubiquitous. Papik's drawing, for example, depicts the bacterium stretching across a house, drum, and teepee; he notes that the bacterium impacts everyone, "regardless of race". Similarly, Moses' and Edwards' drawings also suggest that *H. pylori* is pervasive. In particular, Edwards' drawing includes representations of the bacterium within the sky, as part of animals, and across the landscape. Perhaps because of these views of the bacterium, the language used to describe *H. pylori* by each of these artists invokes a sense of fear—Papik labels it as "dreaded" and Moses describes the communities as alarmed or concerned about the "bug". Despite this, Moses also offers a sense of hope: she suggests that answers to why many people have "stomach problems" might be possible through the research projects, proposing that the answer may lie in the way of life for people in the community.

Ways of life and other aspects of the land and cultural practices of these communities are also reflected in these images. For example, the eclectic background of community members in Aklavik was represented by Papik through the drum, teepee, and house which he describes as signifying Inuvialuit, First Nations, and non-Indigenous people, respectively. Through these drawings and their descriptions, Papik and the other artists also share their strong connections to cultural activities: beading moccasins, mukluks, and other items; bonds to local language and generational teachings; and connections to local wildlife. In particular, through detailed descriptions of each element included in the drawing, Moses offers a glimpse into life and culture in Old Crow, YT. She describes how they live off of the land and animals, highlighting the importance of various natural elements including the sun, water, animals, fish, and berries. Moses also provides a description of the health benefits of the flowers that she included in the drawing. Furthermore, Moses identifies an element of her drawing that is a reflection of "modern life": the house or shelter they live in when staying in the community of Old Crow. A reference to traditional ways of living was also made by Edwards who included mountains and fields in her drawing because, as she describes, "Aboriginal people used to be all over the place when there weren't cities." The elements included within these visual representations reflect how individuals view their respective communities. These themes are also evidenced in the dozens of drawings submitted in Fort McPherson by school-aged children in the community. As with the graphically designed logos, these drawings provide insights into how children within the community view the bacterium, the research program, and their community. Drawings have previously been used as a means of understanding children's perspectives. The World Health Organization, for instance, published a report in 2001 titled, "Through Children's Eyes" where they showcase how children view mental illness as depicted in drawings (World Health Organization, 2001). In other examples, drawings and other visual depictions (such as photographs) have been used to understand how children view health and illness (Piko & Bak, 2006), their ideas about technology (Rennie & Jarvis, 1995), and to understand children's views on tobacco use (Jardine & James, 2012) and food security (Genuis, Willows, & Jardine, 2015). Given their rich storytelling potential, it is anticipated that the submitted images will be analyzed further to learn more about how children in Fort McPherson understand the bacterium and its relationship to their community.

In addition to learning more about community members' views, this work also strengthened various aspects of the health research program itself and helped to open dialogue about the bacterium and its health effects. To execute the logo competitions, community members and researchers engaged in discussions about the bacterium and the research. Through these dialogues, participants and researchers expanded their knowledge about the health issue, gaining insight into one another's perspectives on the bacterium and research program. This work also strengthened community-university partnerships: collaborative processes, such as the design and implementation of logo contests, are imperative as they bolster a participatory approach to research (Minkler, 2005; Wallerstein & Duran, 2010). In particular, the involvement of community members as partners promotes an equitable research landscape as a means to address inequalities in power structures (Baum, MacDougall, & Smith, 2006; Castleden, Morgan, & Lamb, 2012; Wallerstein & Duran, 2010). Moreover, these kinds of collaborative endeavours cultivate strong university-community partnerships that foster meaningful research that supports societal change (Gibbons, 2000). By collaboratively developing and implementing this logo initiative, this work ultimately supported the community-university partnerships necessary for the success of the *H. pylori* research program in these communities.

Conclusions

These images capture the imagination and innovation of community members, visually conceptualizing, from their perspectives, the bacterium and community-based research aimed at promoting health and well-being in their communities. While each image is unique in its representation of individual and community, the logos also incorporate common themes amongst communities involved: ties to the land and to rich Indigenous cultures. In addition to illustrating community perspectives, these figures also promote and represent a strong community-university partnership where questions are posed and solutions to health problems are discovered together.

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4.3 Reflections and summary

In the previous sub-chapters, my co-authors and I described two community-university projects that created reciprocal learning opportunities as part of an overarching research program with a strong biomedical component. This included a knowledge exchange collaboration between university scientists and two youth from Aklavik, NT. In the second example, community-specific *H. pylori* project logos were identified through local contests where community members submitted drawings that characterized the bacterium, the research program, and their community. Common benefits of these initiatives were apparent across both knowledge sharing approaches: they supported community goals by connecting community youth with project activities, created opportunities for capacity building amongst community and university partners, and supported equitable landscapes that bolstered research partnerships. Together, these works provide examples of how community-university partners can co-create reciprocal learning opportunities that support collaborative research endeavours aimed at improving health.

By exemplifying the co-development and co-implementation of reciprocal learning initiatives, in addition to the benefits highlighted above, these projects also facilitated understanding among research partners about one another's perspectives. As a result, these projects contributed to overarching research program goals: they supported the effective communication of research processes and results and promoted the exchange of knowledge among partners. These initiatives, therefore, provided opportunities to strengthen understandings of health risks associated with *H. pylori* infection and of challenges encountered in research aimed at reducing these risks. They also created opportunities to support the movement of knowledge gained through the research into practice, bolstering attempts to maximize applied benefits.

Creating opportunities to gain insights into the perspectives of community members about the health issue can also contribute directly to efforts aimed at describing the health of the population: learning about the views of the target population can help inform the characterization of health among those impacted. In subsequent chapters, I describe the importance of incorporating the perspectives of those impacted into descriptions of population health and provide an applied example of how this might be achieved.

Chapter 5: Solutions in action 2: incorporating the views of the target population in descriptions of their health

5.0 Introduction

In Chapter 2, I outlined the key principles that guide my work in epidemiologic inquiry: pragmatism, collaboration, and justice. In the subsequent two chapters, my co-authors and I outlined some of the challenges and solutions to working in university-community partnerships that aim to improve the health of a population (Chapter 3). We also provided examples of applied solutions where reciprocal learning environments foster equitable spaces so that solutions to health problems may be pursued together (Chapter 4). These works provide valuable examples of how research with an epidemiologic focus can be bolstered through collaborative community-university partnerships. The co-development and co-implementation of initiatives aimed at the exchange of knowledge among partners supports the movement of knowledge gained through the research into practice, strengthening attempts to maximize applied benefits. These efforts also facilitate learning among research partners about one another's perspectives and provide opportunities to strengthen understandings of health risks.

Creating opportunities to gain insights into the perspectives of community members about their health can also contribute directly to efforts aimed at describing the health of the population. In the next sub-sections, driven by my underlying principles of pragmatism, collaboration, and justice, my co-authors and I outline in depth why it is informative to consider different perspectives when attempting to describe the health of a population. In Chapter 5.1, we outline why it is useful to question typical epidemiologic methods when compiling information aimed at informing meaningful and effective action. In Chapter 5.2, we apply a practical perspective to these same concepts: we briefly reiterate why the perspectives of the target population are valuable and provide a plausible way in which these voices may be captured in the context of public health surveillance or in research programs that aim to describe disease burden. We also outline key considerations for effective incorporation of qualitative inquiry in public health surveillance practice.

5.1 Between the lines: the stories behind epidemiologic data

Abstract

Data compiled through scientific inquiry are powerful in how they tell a story. However, they do not tell stories alone. Our worldview and values as researchers shape the work that we do – in the questions we ask, how we conduct research, and the ways in which we interpret research results. In epidemiology, the main science of public health, the stories told by the data can have real world impacts on public health action. While there are many positive contributions to public health made by epidemiologic science, there are also limitations that inhibit its ability to fully describe the health of a population and to effectively inform initiatives aimed at improving public health. This is due, in part, to restrictions inherent within typical epidemiologic methods which prevent a full understanding of the context or lens through which the data is compiled. Missing from these data stories is the context that contributed to their formation and the voices of the target population about whom the data tell a story and for whom public health action is aimed. Here, we outline some criticisms of typical epidemiologic approaches and their consequences. We also provide examples of some proposed solutions and outline how an expansion of the methods used in epidemiologic inquiry might contribute to a more comprehensive description of the health of a population.

Introduction

When contemplating the value of data, one might consider the common view that "data tell stories" (Cofiño, Prieto, Suárez, & Malecki, 2014; Walter & Andersen, 2013). It is important to be mindful, however, that this view might be misleading: it gives the impression that data have merely revealed themselves, displayed as symbols on a page waiting to be read. It also implies, if the analogy is continued, that the stories are static, modified solely by the ways in which they might be read: in tone of voice if read aloud, for example. In reality, the data stories that we tell are shaped by much more than the arrangements of symbols on a page or by the intonations of the story teller. Storytelling must also consider the elements of the story that have been included, as well as those excluded, who is listening, the language it is told in, and its ultimate goal (Walter & Andersen, 2013). Walter and Andersen (2013) noted that data do not tell a story in themselves: quoting from Zuberi and Bonilla-Silva (2008) they state that, “we use data to craft a story that comports with our understanding of the world” (Walter & Andersen, 2013, p. 34). This notion extends into scientific inquiry where data derived through research endeavours inform knowledge. Furthermore, Wing (1998) stated that, “All scientific knowledge is shaped by the social history of its production” (p. 241). Thus, the data stories that shape our understanding of a particular phenomenon are crafted and told through the influence of the historical, social, cultural, and environmental contexts from which they were derived.

The construction of stories using data has important implications on how the data might be used, particularly when aiming to impact public health. Epidemiology, the basic science of public health, uses data ‘stories’ to inform decision-makers about public health strategies (Cofiño et al., 2014), priority setting, and resource allocation aimed at improving the health of a population. However, it is not always clear whether the data stories used to support these efforts tell a complete story that will lead to effective action. That is, it is unclear whether the questions asked through epidemiologic inquiry and the ways in which these questions are answered will adequately tell stories that contribute to relevant or culturally-sensitive public health solutions that will benefit those impacted. Furthermore, in addition to their impact on public health action, the data stories told through epidemiologic inquiry also have important implications for who is impacted and how. Here, we explore some of these concepts further. We outline some criticisms of typical epidemiologic approaches and their consequences. We also provide examples of some plausible solutions and outline how an expansion of the methods typically used in epidemiologic inquiry might be beneficial in the comprehensive description of the health of a population.

Storytelling using typical epidemiologic methods

Questions posed

With recognition that data are not merely laying around waiting to be harvested, the compilation of data stories can be thought of as a complex crafting, beginning with the questions that drive their compilation. These questions – the driving force behind any data compilation – are not conjured in isolation; rather, they are driven by the perspectives of those inquiring. As Little (1998) notes, "The nature of the study is determined by the needs and aspirations of the people commissioning and doing the study" (p. 1137). Similarly, Walter and Andersen (2013) remind us that "…the questions we ask and research are not spontaneous. They emerge from somewhere…" (p. 50). Thus, when academic researchers engage in scientific inquiry, they bring with them their historically, socially, culturally, and environmentally informed perspectives. This has important implications in epidemiologic inquiry aimed at informing public health action. Because the values and perspectives of those contributing to epidemiologic data compilation drive the formation of epidemiologic questions they also, ultimately, determine what data stories are available to inform action. Descriptions of disease burden, and the solutions derived through the use of these data, therefore, may not be relevant to those for whom public health action is targeted if the values that drove the research questions differ from those held by the target population.

In addition to values and perspectives, the formation of questions may also be driven by convenience. For example, epidemiologic questions may be shaped by what is considered measurable rather than by what might best inform a comprehensive description of public health or effective public health action. In 1996, Susser and Susser described traditional epidemiology as operating in a "black box" where only those attributes that can be readily observed are introduced into analysis (Susser & Susser, 1996a, 1996b). Similarly, Murphy (2014) noted that "whatever can be readily measured becomes the focus of attention, while any other source of knowledge is ignored" (p. 66). Moreover, questions may be focused on short term processes and driven by consistency across jurisdictions (McMichael, 1999). As an example, in Elizabeth Pisani's popular book, *The Wisdom of Whores,* the HIV/AIDs epidemiologist noted that, "Sometimes, we ask the wrong questions simply because we are trying to collect information for some 'global' indicator fixed upon by some committee in Geneva" (Pisani, 2008, p.97). She notes that pursing the wrong questions might inevitably lead to the compilation of data that provides the wrong information to inform action; that is, decision-makers might plan the wrong HIV prevention programs. External forces might constrain research questions to be pursued, which may result in public health action that is ineffective or even harmful.

Methods: what is measured

In addition to the questions asked, the methods used to pursue research questions are also driven by the perspectives of those implementing the work. As noted by Walter and Andersen (2013), for example, methodology "contains the cultural, social, and consequently, political meanings of research process and practice" (p. 65). In conventional epidemiology, methods have typically been framed with a biomedical emphasis where studies focus on aspects of exposures and diseases that can be measured in individuals, rather than addressing the societal context in which disease occurs (Shy, 1997; Susser & Susser, 1996a; Trostle, 2005; Walter & Andersen, 2013; Wing, 1998). However, as Rose (1985) points out, "To find the determinants of prevalence and incidence rates, we need to study characteristics of populations, not characteristics of individuals" (p. 34). Focusing on the impacts of individual choices on disease outcomes, such as physical activity levels and smoking behaviours, may serve a biomedical model by providing insights into risk factors presumed to be under the control of individuals, but it does not indicate how society can act to promote health and prevent disease (Shy, 1997; Wing, 1994). It also ignores broader social, economic, environmental or cultural determinants of public health (McMichael, 1999; Shy, 1997; Susser & Susser, 1996a; Wing, 1994). As a result, epidemiologic research has been limited by the ways in which questions related to public health are typically addressed.

In addition to the questions asked and methodological framing of the research process, specific methodological choices contribute to particular narratives that can have a negative impact at both an individual and population level. For instance, when considering the classifications that are used to identify risk factors to analyze patterns of health and disease for populations, there are inherent limitations created by the use of proxies that may have unintended negative consequences (Plant & Rushworth, 1998). These consequences might include, for instance, classification of high risk groups that perpetuate stereotypes. For example, historically, the designation used for men at high risk of HIV/AIDS was 'homosexual' rather than a classification based on behaviour (Plant & Rushworth, 1998). Plant and Rushworth (1998) offer another example with 'Aboriginal status', used to classify individuals with Indigenous ancestry. It may not be ethnic or cultural status per se that increases risk of a particular outcome (Plant &

Rushworth, 1998); rather, the true causal factors might include aspects of colonialism, racism, or bigotry that inflict deprivation or injury on individuals. In epidemiologic studies, classifications based on aspects of personal identity are proxies for actual causes of health outcomes. The use of such proxies may be damaging at the individual level: the sense of health among members of a particular group may be influenced by the narratives created through these representations. Conversely, if an individual does not see themselves as belonging to a particular category they may not feel that the risk attributed to that category applies to them (for example, a heterosexual man who has sex with men). Proxies can also impact populations by propagating deficit-based narratives that perpetuate negative stereotypes (Plant & Rushworth, 1998; Walter & Andersen, 2013), and imply that poor health results from unhealthy choices. Contributing to stigmatizing stories about certain populations might steer the focus away from actual modifiable causes that may have an ultimately greater positive public health impact.

Methods: what isn't measured

Despite being the "basic science of public health" (Shy, 1997, p. 479), epidemiologic research may not pursue or address public health questions that inevitably lead to public health action. This may occur because the context that is required to implement effective change may not be acknowledged or may even be purposely ignored. As Wing (1994) noted, in epidemiologic research, "historical context is a nuisance to be avoided by design or controlled by analysis" (p. 78). Similarly, Shy (1997) stated that in epidemiologic inquiry, "…the societal context in which disease occurs has been either disregarded or deliberately abstracted from consideration" (p. 479). Missing context is an inherent problem with conventional epidemiologic descriptions of association and can ultimately lead to limited public health applications (Murphy, 2014; Shy, 1997; Wing, 1994). For example, both Wing (1994) and Shy (1997) described the impact of epidemiologic investigations that identified cigarette smoking as a risk factor for lung cancer (Shy, 1997; Wing, 1994). They noted that this work led, in many cases, to smoking prevention and cessation programs that were targeted at individual behaviours. While typically impacting educated and resource rich populations, these public health initiatives led to a decrease in cigarette smoking among some populations but, in the most populous places globally, the prevalence of smoking increased. As Wing (1994) pointed out, "in the three decades following epidemiology's major success, more people are exposed to and made sick from the disease agent than ever before" (p. 80).

Wing attributes these kinds of public health failures, in part, to gaps in the information that might inform action: typical epidemiologic approaches ignore other contextual factors that might have a larger impact on public health. In the case of tobacco, for example, broader public health impact might have occurred if epidemiologic inquiry had included investigations into the impact of organized production of tobacco beyond individual consumption, such as the regulations that control cigarette production and distribution (Pearce, 1996; Wing, 1994). Epidemiology that has an equitable impact on public health requires an extension of focus beyond individual behaviours to include the pursuit of research that explores and evaluates the impact of context on public health and on the individual exposures that determine disease outcomes (Krieger, 1994). Some efforts to acknowledge contextual factors often merely increase the number of variables in analyses without accounting for how the target population "perceive[s] their environment, evaluate[s] their health, or decide[s] to pursue help" (Murphy, 2014, p. 67). As a result, descriptions of the health of a population and identification of interventions aimed at improving public health are limited.

Methods: communication of results

Following a process of scientific inquiry, the results generated may be disseminated to people identified as knowledge beneficiaries. These communications are vital in shaping how those informed will be able to use the information garnered through scientific inquiry. However, this communication takes places through the communicators' lens, which necessarily limits which knowledge is conveyed and the methods through which communication is achieved (Little, 1998; Walter & Andersen, 2013). As Little (1998) notes, "The social backgrounds and the training of those who do the study will determine the type of language used in the report, and the style and content of its explanatory methods and power" (p. 1137).

In addition to how the information is portrayed by those telling the story, how the data stories are understood is also dependent upon who receives the information. This is particularly true when communicating information garnered through epidemiologic inquiry given that “the complexity of medicine and health means that it is possible for one interest group to derive knowledge and assign meaning to data in ways which have very little meaning for other groups” (Little, 1998, p. 1136). Diverse actors in a position to learn about and use the stories told with epidemiologic data, such as policy makers, healthcare providers, and the general public may all understand the information differently (Hajizadeh et al., 2017). Therefore, it is necessary to acknowledge that the results of epidemiologic inquiry may tell different data stories depending on who is producing and who is receiving the information. This, ultimately, may impact the kinds of public health actions identified and pursued.

Storytelling: whose stories are told and how

The stories told from data by those not impacted by the data can lead to restricted perspectives and narratives that that overlook the values of the target population. When describing the health and wellbeing of Indigenous populations, for example, most health information is framed only in the context of how they compare to other populations (Walter & Andersen, 2013). Walter and Andersen (2013) state that “…it is within Western settler quantitative methodological frames that the continuing authorization of our Indigenous peoples as the “other” occurs” (p. 65). Furthermore, these narratives have typically “created a “deficit-based visage of Indigeneity”” (Walter & Andersen, 2013, p. 65) where the questions asked, methods used, and results disseminated perpetuate a negative view of Indigenous people. This framing can limit the kinds of data stories that are told and can funnel policies aimed at improving public health through a lens of what is abnormal rather than through a frame of resiliency and population assets.

In addition to creating or perpetuating harm, when data stories are told from a lens that exists outside of those impacted, they may also fail to incorporate the socially, culturally, and environmentally informed views that determine how populations define health and disease. For example, epilepsy is a condition whose explanations and consequences can differ across cultures (Trostle, 2005). Trostle (2005) notes that, “The cultural meanings of epilepsy have affected whether and how it becomes visible to epidemiologists and what this means for estimates of its incidence, prevalence, causes, and outcomes" (p. 9). Cultural differences in the perceptions of health and illness can impact how diseases are reported and addressed, modifying the epidemiologic definitions of outcomes of interest across cultures (Trostle, 2005). As a result, data stories told only through an academic scientist's lens may not be relevant to the questions and priorities of the people the data describe. This also has implications for the impact of any proposed initiative aimed at improving public health. Because public health interventions typically require individuals to act, their perspectives are relevant to how they identify health issues in need of solutions and how they respond to public health initiatives (Murphy, 2014). The choice to act depends on more than just information about disease and how to prevent it: whether members of a target population are compelled to act – for example, to be screened for disease or seek treatment – depends on "how health and illness are perceived and evaluated" (Murphy, 2014, p. 71). Data stories that aim to inform public health action, therefore, must account for the perspectives of the populations they seek to influence.

Proposed solutions

Acknowledgement of the value of considering different perspectives in scientific inquiry is not new. There are a variety of examples of how diverse views have been incorporated into inquiry. Indeed, in fields of research such as anthropology, the perspectives of the populations studied are a foundational aspect of the research. Similarly, research that acknowledges Indigenous and non-Indigenous worldviews has been used to incorporate various perspectives in diverse research processes. Guiding principles such as Two-Eyed Seeing by Elder Albert Marshall of the Mi'kmaw Nation (Bartlett, Marshall, & Marshall, 2012) and Parallel Worldviews by Elder Reg Crowshoe of the Piikani Nation (Crowshoe, 2014), have offered frameworks for research that acknowledge multiple worldviews and ways of knowing for a greater benefit. Similarly, some health research has also incorporated concepts relating to the inclusion of multiple perspectives. These include, for example, patient-centred research approaches that incorporate the perspectives of patients engaged in the health system as part of descriptions of health care utilization patterns (Hajizadeh et al., 2017).

This kind of thinking is also not new to the field of epidemiology. Epidemiologist Steve Wing called for a democratic approach to epidemiologic inquiry: “the perspectives and interests of most people, not just those who control the economic, academic, and information institutions, must be recognized and included” (Wing, 1998, p. 250). Similarly, various epidemiologists have agreed that a shift in how epidemiologic inquiry is framed and implemented is necessary for meaningful impacts on public health (Krieger, 1994; Shy, 1997; Susser, 2004; Wing, 1998). As Wing stated in 1994, “An epidemiology oriented towards massive and equitable public health improvement requires reconstructing the connections between disease agent and their contexts” (p. 84). More recently, a ‘new epidemiology’ has been described where broader perspectives are used to study populations, particularly when there is a community-health focus (Murphy, 2014; Tulchinsky & Varavikova, 2010). Furthermore, new methods have been proposed that attempt to counter the status quo: participatory epidemiology, for example, has been used to describe participatory research approaches that are applied to epidemiologic investigations (Allepuz, de Balogh, Aguanno, Heilmann, & Beltran-Alcrudo, 2017; Bach, Jordan, Hartung, Santos-Hövener, & Wright, 2017; Catley, Alders, & Wood, 2012). These include, for example, the engagement of target populations throughout the research process.

As these works exemplify, exploring epidemiologic approaches that fall outside of typical processes can offer effective solutions to existing challenges. Solutions constrained to conventional epidemiologic study designs are unlikely to solve the inherent limitations of objective measurement aimed at breaking down information into quantifiable pieces (Little, 1998; Susser, 2004; Wing, 1998). As Little (1998) noted, “[epidemiology] moves so definitely in the computational domain, while the values that justify it originate in the cultural and value-laden domain which is expressed in language rather than numbers” (p. 1141). As a result, Little (1998) suggests that “…epidemiology may need to review and revise its present preoccupation with objective measurement…” (p. 1135). Exclusive focus on quantitative methods may be at odds with epidemiologic goals that aim to describe the health of populations. After all, as noted by Murphy (2014), “How persons make decisions about their health are brought alive in a manner that extends beyond probability” (p. 71). Similarly, Little (1998) points out that “Numerical data does not cope well with abstractions like fear, anxiety and suffering" (p. 1141). The inclusion of other forms of inquiry within epidemiology, such as personal narratives, may contribute to the information required to tell a more complete story about the health of a population.

Inclusion of qualitative inquiry in epidemiologic approaches to inform descriptions of disease burden might provide a means to move beyond the limits inherent in quantitative inquiry (Jack, 2006). The Leeds Declaration, as quoted by Shy (1997), suggested that the development of an appropriate knowledge base for public health action requires "a broadening of the methods of epidemiologic research to include qualitative and participatory research methods" and "integrating lay knowledge with scientific knowledge, to take account of the richness and complexity of community life" (Shy, 1997, p. 482). Similarly, in order to effectively inform public health action, Little (1998) suggested that "Epidemiological methodology needs to respect both reductionism and narrative accounts of truth" (p. 1135). Because many strategies aimed at improving public health require individuals to act, approaches that teach us about the perspectives of those impacted are indispensable. The collection of personal narratives is a valuable approach: "…the tales these persons tell about themselves hold the key to understanding their constructed reality" (Murphy, 2014, p. 70). Therefore, data stories that incorporate narratives from the target population will help inform the development and implementation of meaningful and effective public health initiatives.

Summary

Data compiled through scientific inquiry do not tell stories in isolation: the stories told are shaped by our perspectives and how they inform the questions we ask, the methods we apply, and the results we communicate. Empirical data compiled through typical epidemiologic inquiry can provide valuable information and should not be dismissed; however, it should also be acknowledged that the factors that contribute to disease are more complex than typical epidemiologic data can reveal. This has implications for the kinds of data stories told and the subsequent identification and implementation of actions aimed at improving public health. There have been a variety of health science fields, including subfields within epidemiology, which recognize the value of context in describing public health, particularly in community-based practice. Embracing these concepts may require expanding epidemiologic methods beyond reductionist approaches, to include narrative descriptions. Doing so may facilitate a more complete 'public health story' told through the lenses of those who are impacted. By incorporating their perspectives and contexts – the stories behind the data – a fuller picture of the health of a population that informs effective public health action could be achieved.

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5.2 Whose health is it anyway? A call for qualitative inquiry in public health surveillance

Abstract

To develop effective public health strategies, set priorities, and allocate resources, it is necessary to characterize the health of relevant target populations. Public health surveillance contributes to these characterizations by compiling information on risk factors, health outcomes, and the health care service use of populations, typically using quantitative measurement of pertinent epidemiologic and economic indicators. To ensure that public health strategies developed through these processes are relevant to a target population of interest, however, valuable insights can be gained by ascertaining how affected community members and their health care providers view relevant health-related factors. In fact, information regarding public perspectives and quantitative assessments of health indicators are both essential so that resulting solutions are culturally-sensitive and cost-effective for the target population. While existing literature espouses the benefits of building collective knowledge to capture the depth and complexity of health and disease, public health surveillance activities do not regularly incorporate various forms of evidence to construct a comprehensive assessment of the burden of disease. Here, we outline the value of incorporating multiple perspectives in characterizations of disease burden, particularly when attempting to address public health concerns. To illustrate these concepts, we briefly present several examples, including work in northern Canada that aims to address community concerns related to the frequency of *Helicobacter pylori* infection and stomach cancer. We also outline how a more complete characterization of disease burden may be achieved by incorporating the voices of the target population through qualitative inquiry.

Introduction

Public health surveillance is an essential tool to protect and promote the health of populations (Chambers, Ehrlich, O’Connor, Edwards, & Hockin, 2006; Choi, 2012). It can be defined as the “on-going systematic collection, analysis, interpretation and dissemination of health data for the planning, implementation and evaluation of public health action” (Choi, 2012, p. 1). Public health surveillance may be used for a variety of purposes: these include the detection of emerging health problems, and the assessment of the impact and trends of emerging and existing health outcomes and their risk factors. It is an important tool for supporting public health research initiatives, bolstering the planning, implementation, and evaluation of health services and policies, and developing effective public health strategies, setting priorities, and allocating resources. Each of these surveillance purposes facilitates effective evidence-based decision-making aimed at protecting and promoting the health of populations.

To accomplish public health surveillance goals, there are a variety of activities undertaken by public health agencies. These include the collection of pertinent health and population data, as well as the analysis and interpretation of these data. These analyses might involve assessments of the magnitude and trends of risk factors, health outcomes, and interventions or healthcare utilization, typically involving the quantitative measurement of epidemiologic indicators that describe public health (Brownson, Baker, Left, Gillespie, & True, 2010; Brownson, Gurney, & Land, 1999). These kinds of activities are useful for monitoring activities; they are also useful for other surveillance functions such as the characterization of disease burden across populations and over time. These assessments permit the development of a health picture where priorities and targeted health promotion and disease/injury prevention strategies can be identified and implemented.

Public health assessments may also be necessary when addressing community concerns about a health problem. In these situations, the public health surveillance response typically involves a quantitative assessment of disease burden that compares the frequency of disease in the target population where concerns arise with the frequency observed in a reference population. These comparisons are typically used to determine if there is a detectable elevation in disease occurrence. Other relevant information may include data on the prevalence of related symptoms, treatment effectiveness, as well as health care costs (Brownson et al., 2010, 1999). When addressing the impact of a specific health problem, measures of disease burden can help elucidate the extent of the problem and aid in assessing its significance relative to other health concerns (Lopez, Mathers, Ezzati, Jamison, & Murray, 2006).

While public health surveillance activities typically involve quantitative assessments of epidemiologic indicators, it is also useful, in addition to quantitative health assessments, to consider how affected populations and responsible health professionals understand health factors of relevance (Chambers et al., 2006; Jardine, 2008; Morgan, Fischhoff, Bostrom, Lave, & Atman, 1992). This is particularly true when responding to community concerns about a specific health condition to ensure that the concerns are adequately addressed and solutions developed through the investigative process are relevant to those impacted. Here, we provide an overview of typical public health descriptions currently conducted in public health surveillance. We outline the limitations of this approach and discuss the kinds of additional information that may be useful to provide comprehensive public health descriptions for public health surveillance goals. To illustrate these issues, we describe several examples, including work done in northern Canada to address community concerns related to the frequency of *Helicobacter pylori* infection and stomach cancer. Finally, we share some thoughts on anticipated challenges and potential solutions of our proposed approach.

Current situation

How is population health typically described?

There are a variety of ways to measure the health of a population. These include, for example, a quantitative assessment of pertinent epidemiologic indicators such as prevalence proportions and incidence rates, as well as other measures such as health care costs for a particular disease (Etches, Frank, Di Ruggiero, & Manuel, 2006; Lopez et al., 2006). In addition to measures relating to health status and health costs, other contextual components, such as non-biomedical determinants of health like sociocultural factors, permit further understanding of the elements that contribute to the health of a population (Etches et al., 2006; Saunders, Mathers, Parry, & Stevens, 2001).

To incorporate these and other factors, methods have been developed for measuring a variety of indicators that permit a deeper understanding of a particular health issue (Gore et al., 2011; Hyder, Puvanachandra, & Morrow, 2012; Murray, Lopez, & Wibulpolprasert, 2004). These indicators include, for example, disability adjusted life years, which may be used to estimate the average years of life lost or lived with disability among people with a specific health condition (Lopez, Mathers, Ezzati, Jamison, & Murray, 2006; Weinstein, Torrance, & McGuire, 2009). Quantitative indicators that are measured using consistent definitions and methodology are valuable because they permit comparisons between populations and across time (Murray et al., 2004).

Data to support these assessments may be obtained from a variety of sources. These include data classified as vital statistics, such as births and deaths. In most Canadian jurisdictions, other data are also available. Some of these additional data sources include those classified as 'administrative', where data are tracked for administrative purposes but may be used to compile information on disease outcomes and healthcare utilization patterns (Svenson, 2015). Disease registry data are also available; in these cases, data are collected strictly for the purposes of tracking disease. For example, cancer registries available in each jurisdiction throughout Canada house information about anyone who has been diagnosed or has died from cancer in the province or territory. Furthermore, survey data is also available from a variety of sources including Statistics Canada country-wide surveys such as the Canadian Community Health Survey and the National Household Survey (Statistics Canada, n.d.).

What are the limitations of typical descriptions of population health?

Despite the benefits of standard quantitative measures, academic scientists have raised questions about the extent of their utility. For example, experts have noted that, because there are values and assumptions intrinsic to these quantitative measures, they possess a degree of inherent subjectivity (Reidpath, Allotey, Kouame, & Cummins, 2003; Nygaard, 2000; Walter & Andersen, 2013). This is evidenced, for example, by differences in rank order of disease burden depending on the definitions and categorizations of disease, and on the measures selected (Brundage, Johnson, Lange, & Rubertone, 2006; Gold & Muennig, 2002; Thacker et al., 2006). In Alberta, for instance, cancer is considered the leading cause of death in the province if heart disease and cerebrovascular disease are grouped separately (Cancer Surveillance, 2009); however, cancer drops to the second leading cause of death if the latter two are grouped together as circulatory system diseases (Cancer Surveillance, 2012). In another example, Gold and Muennig (2002) estimated the burden of five different diseases in the US using three different measures. They found that the rank order of diseases depended on the measures used. For this reason, questions exist about how well these measures reflect the impact of disease as experienced by a given population, and the extent to which these measures are able to capture the context necessary to adequately inform policy and promote effective action (Reidpath, Allotey, Kouame, & Cummins, 2003; Thacker et al., 2006).

Moreover, others have described disease burden as a social construction and inherently subjective (Jones & Williams, 2004; Jones, Podolsky, & Greene, 2012; Trostle, 2005). Jones and Williams (2004) noted that, "...sociocultural factors, such as social organization, culturally defined social roles, and cultural beliefs about disease, all play an important role in the observed variability in the disease burden" (p. 157). One example of how social mores impact disease descriptions was evidenced in the 1970s when homosexuality was declassified as a mental disorder ("Homosexuality and psychology," n.d.). Changes in societal views have also impacted the kinds of data collected and how they are interpreted: in Alberta in 2017, for example, legislation was passed that permits a third vital statistics category that offers an alternative to the binary of 'male' and 'female' when reporting gender (Alberta Human Rights Amendment Act, 2017, 2017). This may ultimately change how differences across gender categories are characterized in public health surveillance analyses. Because there are potential differences across populations in their interpretations of disease, attempts to measure the health of the population are limited if they do not incorporate considerations of how health is experienced by those impacted.

Future potential

What are the benefits of additional information to describe population health?

Learning how health is characterized by those impacted can contribute to a rich description of a given health topic and better illuminate how a disease is described and experienced (Jones & Williams, 2004; Sofaer, 1999; Trostle, 2005). This kind of information can help inform quantitative research questions by identifying population characteristics or disease consequences that may further impact public health and well-being (Barbour, 1999; Johnson & Onwuegbuzie, 2004; Trostle, 2005). It can also help to explain the results obtained through quantitative inquiry by providing contextual information (Barbour, 1999; Johnson & Onwuegbuzie, 2004) .

In addition to these benefits, information on public perspectives can support effective communication about a health problem (Jardine, 2008; Morgan et al., 1992): because individuals learn new information within the context of their existing knowledge and beliefs (Morgan et al., 1992), the development of effective knowledge translation and risk communication strategies requires an understanding of existing internal representations. Likewise, understanding the perspectives of those impacted will inform public health strategies so that meaningful and effective interventions can be implemented (Brownson, Chriqui, & Stamatakis, 2009; Jones & Williams, 2004; Jones et al., 2012). Importantly, acknowledgement and incorporation of public perspectives will also foster the inclusion of public values and, in this way, support ethical practice in decision-making (Brownson et al., 2009).

How might this additional information be obtained?

In public health surveillance practice, information relating to risk factors and disease frequency and distribution are typically garnered through quantitative inquiry. Data describing the health of populations are compiled from a variety of sources; they are analyzed, interpreted, and disseminated to inform public health action. Similarly, surveillance activities may also use quantitative methods to gather information related to the perspectives of a target population of interest. This might occur, for example, through the use of surveys with questions that explore participants' views on their health or on their experiences when seeking care in the health care system. In many cases, these survey questions might be posed along with a list of possible replies or a ranking such as a Likert scale (Hartley, 2014) used to quantify responses. In other cases, questions may be open-ended, permitting the respondent to answer broadly; an analyst then identifies what is most relevant and creates categories to support quantification. Because health is a complex phenomenon and structured surveys are reductionist in their approach, in that they are designed to ascertain quantifiable bits of information, the quantification of results misses the complexity of meanings behind the data (Little, 1998; Murphy, 2014;

Trostle, 2005). As a result, these forms of inquiry are limited in how they characterize the perspective of individuals about their health (Little, 1998; Murphy, 2014; Trostle, 2005).

Another way to capture how health and related concepts are perceived by those impacted is through qualitative inquiry, where there are numerous methods that could be employed. This might include, for example, semi-structured interviews that permit an exploration of concepts that extend beyond open-ended questions in structured surveys aimed at reaping a richer description of the phenomenon in question (Jack, 2006). Similarly, focus groups or other qualitative approaches may permit a deeper understanding of how populations understand health and disease, and how they might experience health care (Jack, 2006; Little, 1998; Murphy, 2014). As a result, these tools may be able to offer more in-depth information about how populations understand their health, how they are experiencing disease, and what are the positive and negative aspects of health care that might impact their choices. Researchers who aim to develop a fuller characterization of the experiences of a population will often use elements of these approaches to gain insights into a phenomenon; however, despite an alignment of goals, similar approaches are not typically applied in public health surveillance.

Examples

Despite the potential benefits of incorporating information obtained through qualitative inquiry into public health assessments, its use is not standard practice in public health surveillance. For example, when describing vaccination uptake patterns across populations, surveillance staff might analyze the characteristics of populations using quantitative methods in an attempt to understand why some populations choose to vaccinate and others do not (Bell, Simmonds, & MacDonald, 2015). To develop an in-depth understanding about why particular populations have low vaccination rates, a more effective strategy might be to implement qualitative assessments that aim to characterize more fully attitudes and potential barriers to vaccination; such assessments can yield information that would not emerge from quantitative approaches yet may be crucial for designing public health actions that increase vaccination rates.

Similarly, qualitative inquiry may shed light on factors that contribute to disease burden that might be difficult to capture through other means. Among First Nations people in Alberta, for example, an in-depth exploration of cancer treatment pathways through focus groups revealed that one of the barriers to cancer treatment access is the medical transport vans that typically bring cancer patients to city centres for care (Voyageur, Letendre, & Healy, 2015). Because these vans transport multiple community members seeking care for a variety of health conditions at once, they are often not safe spaces for those who are immunologically compromised, such as persons undergoing chemotherapy. As a result, people seeking cancer treatment are not comfortable using these services and may struggle finding alternative forms of transportation to access care. Without guidance arising from cancer patients' descriptions of their experience in seeking care, analysis of cancer treatment data alone may not have discovered this key barrier that cancer patients were experiencing.

Other work has used participatory approaches to pursue epidemiologic questions; in some cases, these approaches have incorporated both qualitative and quantitative forms of inquiry in assessments of population health. For example, the Canadian North *Helicobacter pylori* (CAN*Help*) Working Group was established in 2006-2008 to address concerns about *H. pylori* and associated diseases voiced by residents of northern Canadian communities and their health care providers (Cheung et al., 2008). Although described broadly as a research program, this team works in partnership with territorial surveillance teams and employs activities used within public health surveillance such as epidemiologic assessment of *H. pylori* infection and associated diseases to understand the extent of the problem across northern populations. In addition to quantitative public health assessments, a key goal is to characterize how the communities impacted by associated diseases understand risks arising from *H. pylori* infection in order to support the identification of effective solutions (Bowen, Martens, & The Need to Know Team, 2005; Jardine, 2008; Morgan et al., 1992). There are a variety of ways to achieve this; however, an in-depth description of community perspectives around the bacterium, risks, and impact is achieved most effectively through qualitative approaches. These assessments, added to quantitative characterizations of disease burden, provide a comprehensive description of the impact of *H. pylori* infection and associated diseases in the communities seeking solutions to their concerns.

Anticipated challenges and potential solutions

In scientific inquiry, it is imperative to consider the quality or rigor of the work conducted. In particular, how an assessment or study will promote the reliability, validity, and generalizability of the generated data, analysis results, and interpretation. What constitutes each of these concepts in the context of study quality and the ways in which they may be assessed differs in quantitative and qualitative forms of inquiry (Mayan, 2009). Moreover, in qualitative inquiry, assessing rigor in terms of reliability and validity can be contentious, with some qualitative scholars arguing against the use of these concepts in qualitative approaches (Mayan, 2009). Instead, rigor in qualitative inquiry is often described more broadly as 'trustworthiness' (Given & Saumure, 2008); the elements of which include concepts such as credibility, transferability, dependability, and confirmability as outlined by Lincoln and Guba (1985) (restated in (Mayan, 2009)).

Given problematic issues in assessments of rigor in qualitative inquiry, if public health surveillance activities incorporate qualitative inquiry in practice, it is necessary to consider how the quality of the work would be promoted and assessed. Here, we briefly explore the concepts of reliability, validity, and generalizability, as they may be defined using both quantitative and qualitative lenses. Furthermore, because it may be challenging to use multiple forms of evidence to establish a succinct message, it is also important to consider the potential synthesis of evidence derived using methods based on different paradigms. These concepts are discussed further below.

Reliability, Validity, and Generalizability

Reliability: For quantitative measures, reliability "refers to the degree to which the results obtained by a measurement procedure can be replicated" (Last, 2001, p.156). Given the purposeful lack of standardization in qualitative inquiry, the work is typically not assessed by its reproducibility. However, there are ways in which qualitative work is assessed for the credibility of its results. For example, audit trails may provide an opportunity to examine the methods, data, and interpretation of results. Furthermore, in qualitative inquiry, reproducibility is often considered internally in a particular study; for example, in repetition within the dataset itself. This is often achieved by examining how frequently participants report common experiences in the data collection process (Mayan, 2009; Morse, Barrett, Mayan, Olson, & Spiers, 2002).

Validity: In quantitative research, validity has been defined in diverse manners, but a useful standard definition for epidemiology is "[a]n expression of the degree to which a given measurement measures what it purports to measure" (Last, 2001, p. 184). As described by Dellinger and Leech (2007),

> Quantitative research starts with a supposition that a specific construct or entity exists. The construct is traditionally explicitly defined so that a measure (e.g., a test, survey items, observations, performance assessment) can be developed that is capable of capturing the essence of the defined construct…Once a measuring device is created, strict criteria are used to determine if…the scores are valid reflections of the defined construct. (p. 318–319)

Alternatively, most qualitative inquiry is grounded within paradigms that acknowledge multiple and subjective truths where there is no benchmark upon which to validate research components. However, as Maria Mayan (2009) notes, "…we are concerned with whether the story, the description we give of the phenomenon, etc. are found in the data" (p. 106); that is, whether the findings make sense and are an accurate representation of the data. This may be achieved by employing strategies such as checking results with participants to ensure adequate representation (Mayan, 2009; Morse, Barrett, Mayan, Olson, & Spiers, 2002).

Generalizability: Sometimes referred to as 'external validity', generalizability of quantitative results may be assessed by the degree to which they "produce unbiased inferences regarding a target population (beyond the subjects in the study)" (Last, 2001, p. 185). That is, whether the results may be interpreted as describing broader or distinct populations beyond the study population. Such an assessment requires judgement based on subject-matter expertise. Generalizability cannot be verified quantitatively without collecting data from the target populations of interest. In qualitative inquiry, a range of participant experiences may be considered to develop a theory or understand a phenomenon; as a result, the knowledge generated through qualitative inquiry may be considered transferable to a similar population with similar circumstances (Mayan, 2009). In the same way as occurs for quantitative inquiry, evaluations of the extent to which the findings might be applicable to other settings can be achieved by considering the setting and participants upon which the results were based along with the subject-matter factors that would influence applicability to other target populations.

A public health surveillance model that incorporates both quantitative and qualitative evidence must incorporate ways to ensure and evaluate rigor that are appropriate for different methodologies. In particular, each type of data collection should use rigorous methods that are appropriate for the form of inquiry pursued, to minimize threats to rigor in public health surveillance activities and safeguard the quality of public health surveillance data.

Synthesis of evidence

The use of both qualitative and quantitative methods to address a scientific question requires multiple perspectives: qualitative and quantitative methods often have opposing underlying assumptions that are founded on differing ontological and epistemological positions. For example, works centred on qualitative inquiry may be oriented towards what Lincoln and Guba (1985) call ‘naturalistic inquiry’: a central axiom is that reality is subjective and can only be viewed holistically (restated in (Thorne et al., 2004)). Alternatively, quantitative inquiry may be based on a positivist perspective, grounded in the notion that there is a single truth that can be discovered through objective measurement (Mayan, 2009). The goal of objective measurement, in turn, requires a reductionist approach that breaks down the information sought into discrete quantifiable pieces (Creswell, 2009). The differing worldviews typically employed in qualitative and quantitative inquiry could potentially create barriers to incorporating related evidence obtained using both paradigms.

While to some extent founded on contradictory concepts, scientific inquiry involving both qualitative and quantitative elements permits consideration of the multiple perspectives required for a full understanding of the phenomenon under study. While scientific approaches based on positivism often cast subjective thought outside the realm of science, it is widely acknowledged that intuition and inference are fundamental to forming scientific hypotheses and theories, and to drawing conclusions from data. Thus, a full description of methods for generating rigorous scientific evidence must include best practices for identifying the optimal scientific questions to ask, designing the optimal approaches for collecting the relevant information, and arriving at optimal interpretations of collected data. To this end, qualitative methods can be viewed as enhancing a scientist's intuition and heightening inferential skills pertaining to a given scientific problem, as well as providing contextual details for designing data collection approaches optimized for the setting.

Efforts have been made to identify effective strategies for integrating various forms of evidence to build comprehensive knowledge and inform decision-making (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Jack, 2006; Mays, Pope, & Popay, 2005), however, best approaches to doing so are not always clear, particularly if conclusions are uncertain or evidence is contradictory (Grunwald, 2008; Pluye, Grad, Levine, & Nicolau, 2009; Protheroe, Bower, & Chew-Graham, 2007). Furthermore, while existing literature espouses the benefits of building broad knowledge to capture the depth and complexity of health and disease (Jones et al., 2012; Susser, 2004; Trostle, 2005), there is limited information about the most effective ways to synthesize different forms of evidence so that a comprehensive assessment of public health may be constructed. Finding ways to synthesis information obtained using different methods should not be a barrier to their use; rather, this challenge should be embraced in situations where synthesizing diverse forms of information will bolster public health surveillance resources.

Summary and conclusions

Despite the benefits described here of expanding approaches to public health surveillance activities, the perspectives of the target population are not typically investigated within usual surveillance practice. This is evidenced by the fact that public health surveillance activities do not typically include in-depth exploration of how health and illness are perceived and evaluated, nor do they yield detailed descriptions of the experiences of members of the target population when accessing health services despite regularly reporting on health care utilization patterns across populations. Such elements have been incorporated in specific research projects; however, they are not a typical focus of public health assessments conducted as part of public health surveillance activities. Information regarding public perspectives and quantitative health-related assessments are both essential to policy development so that resulting solutions are appropriate, culturally-sensitive, and cost-effective. We envision a future where qualitative inquiry can be incorporated as a usual practice in public health surveillance.

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5.3 Reflections and summary

While typical epidemiologic inquiry using quantitative approaches contributes to public health action, there are also limitations that inhibit its ability to fully describe disease burden and to effectively inform initiatives aimed at improving health. In the previous sub-chapters, my co-authors and I outlined some of these limitations and provided examples of some proposed solutions. We described how the perspectives of the target population are valuable when attempting to describe disease burden. We also provided suggestions about how these perspectives might be effectively identified: incorporating the views of the target population might be best achieved through qualitative inquiry where an in-depth characterization of these perspectives may be obtained. This additional information is valuable in how it can contribute to the meaningful description of disease burden and inform effective public health action. In particular, an expansion of typical epidemiologic methods to include approaches that use target population perspectives to enrich the design and interpretation of public health surveillance or research might contribute to a more comprehensive description of disease burden.

These subchapters provided an overview of some existing challenges in traditional epidemiologic approaches and suggested solutions to mitigating these barriers. In subsequent chapters, I lay out an applied example that puts these concepts into practice: I provide examples of the kinds of information that might be useful to inform epidemiologic inquiry in community-university partnerships aimed at improving health. I begin with a characterization of the impact of *H pylori* infection among northern Canadian populations and then provide a description of disease burden using more traditional epidemiologic approaches. Finally, I synthesize this information to provide a comprehensive description of disease burden among those impacted.

Chapter 6: Applied example: community perspectives on the *Helicobacter pylori* bacterium and associated diseases

6.0 Introduction

In previous chapters, I outlined some of the challenges and solutions to working in university-community partnerships that aim to improve the health of a population. I provided examples of applied solutions where reciprocal learning environments fostered equitable spaces and where solutions to health problems could be pursued together. I also outlined why information from multiple perspectives enhances the value of epidemiologic descriptions of the health of a population, particularly in situations where there is community concern about a specific health problem.

Here, I explore an applied example of the kinds of information that might be useful for epidemiologic inquiry in community-university partnerships aimed at improving health. To begin, I describe two works that aimed to characterize the perspectives of community members about *H. pylori* and associated diseases. In Chapter 6.1, my co-authors and I conducted a media analysis that explored mass media portrayals of the *H. pylori* bacterium in northern Canadian populations. We examined whether the media described topics related to the bacterium, and how related issues were presented. In Chapter 6.2, my co-authors and I garnered further insights into community perspectives through structured questionnaires and semi-structured interviews. Academic researchers interviewed participants using structured questionnaires in NT and YT communities participating in the CAN*Help* Working Group research program. These questionnaires ascertained respondents' views on *H. pylori*. In three participating communities (Fort McPherson, NT; and Teslin and Ross River, YT), scientists also conducted semi-structured interviews to foster in-depth discussions about the bacterium and related risks.

Together, these works illustrate how community members in northern Canada view *H. pylori* and associated diseases. In doing so, these works reveal community perspectives that contribute to a more complete characterization of how members of communities impacted by *H. pylori* experience this impact. In the following sub-chapters I, along with my co-authors, describe these two research projects in detail. We outline the methods used to develop and implement each initiative and provide in-depth reflections on the key results and lessons learned from each endeavour.

6.1 Media portrayals of *Helicobacter pylori* and related community-driven research in northern Canada

Abstract

Northern Indigenous communities and their healthcare providers have expressed concerns about the impacts of *Helicobacter pylori*, a bacterium known to cause peptic ulcers and stomach cancer. In response to these concerns, a community-driven collaborative initiative emerged that links local community members, health care providers, and territorial health officials with academic researchers. The overall aims of this initiative are to describe the burden of disease and risk factors associated with *H. pylori* infection, and to identify effective public health strategies for infection control. A vital component of this work is the development of knowledge exchange strategies that pursue community goals and promote effective and meaningful communication of research findings.

Individuals understand new information in a manner that depends on their existing conceptualizations and views. As a result, research partners must ascertain existing community perspectives on *H. pylori* and associated diseases to effectively develop knowledge exchange and risk communication strategies. It has been suggested that the examination of mass media messaging and framing may be used to assess public perceptions and behaviours. In this study, frame and content analysis is used to assess media portrayals of *H. pylori* and related community-driven research in northern Canada. We examine how frequently online newspapers, magazines, radio broadcasts, and video describe topics related to *H. pylori* and how these media portray issues inherent in these topics. We describe media portrayals of *H. pylori* and discuss how these results may reflect or contribute to community perspectives.

Background

H. pylori *in northern Canada*

Helicobacter pylori is a bacterium that has been identified as a major cause of chronic gastritis, peptic ulcer disease, and stomach cancer. The transmission pathways of *H. pylori* are not known with certainty; the bacterium is thought to pass from person to person through contact with infectious fecal matter or vomitus (Goodman, Jacobson, &

van Zanten, 2008; Parsonnet, Shmuely, & Haggerty, 1999). Studies suggest that *H. pylori* infection is usually acquired in childhood and often persists long-term; household crowding and exposure to *H. pylori*-infected family members is associated with an increased prevalence of the infection (Mendall et al., 1992; Webb et al., 1994). In 2000, an estimated 70% of residents of lower resourced countries were infected with *H. pylori* (Brown, 2000). Although the prevalence of the bacterium is lower in more resourced countries (40% in 2000), research suggests that northern Indigenous populations have a disproportionately high frequency of *H. pylori* infection and associated diseases, and lower success of treatment aimed at eliminating the bacterium (Goodman et al., 2008; Young, Kelly, Friborg, Soininen, & Wong, 2016).

Residents of the northern community of Aklavik, Northwest Territories (NT), expressed concerns in the years preceding 2006 about an apparent elevation in the number of stomach cancer cases diagnosed in the community. Many residents were aware that higher rates of stomach cancer were linked to a high frequency of *H. pylori* infection. Since then, other communities in the NT and Yukon (YT) have voiced concerns and pursued research on these health issues. In response, a community-driven research program involving several Indigenous communities within northern Canada emerged during 2006-2008. This research program, the Canadian North *Helicobacter pylori* (CAN*Help*) Working Group, is a collaborative initiative that links academic researchers from various disciplines with NT and YT communities as well as health care practitioners and health officials. The overall aims of the program are to describe the burden of disease and risk factors associated with *H. pylori* infection, to identify effective public health strategies for infection control, and to identify effective knowledge translation tools to support the practical application of research lessons.

Theoretical Background

According to a mental models approach described by Morgan et al. (1992), individuals learn new information within the context of their existing knowledge and beliefs (Morgan, Fischhoff, Bostrom, Lave, & Atman, 1992). To develop effective knowledge translation and risk communication strategies, it is therefore necessary to fully ascertain existing internal representations of the intended beneficiaries of specific strategies. Although just one of many factors that contribute to the formation of these perceptions, the media can influence the ways in which an audience interprets and understands an issue (Gamson & Modigliani, 1989; Wahlberg & Sjoberg, 2000). As Gamson and Modigliani (1989) stated, "…media discourse is part of the process by which individuals construct meaning, and public opinion is part of the process by which journalists and other cultural entrepreneurs develop and crystallize meaning in public discourse" (p. 2). As a result, analysis of media discourse can be a useful tool to assess public perception.

There are a variety of ways that media can impact an audience. Research has suggested that media tend not to influence individual level judgments of risk; rather, media tend to generate societal level judgments (Morton & Duck, 2000). Other work has found, however, that when there is a lot of media coverage of a specific issue, the media may influence the public at a personal level (Verbeke, Viaene, & Guiot, 1999). It is during periods when there is large media attention about an issue that media coverage has been proposed to be a contributing factor to the social amplification of risk (McInerney, Bird, & Nucci, 2003), a process by which an individual's risk perceptions are modified based on an interaction between risk events and psychological, social, and cultural perspectives (Kasperson & Kasperson, 2005). The media contribute to these interactions by characterizing the content and portrayal of issues in a way that may influence audience perceptions.

How issues are presented within the media has a strong impact on public attention to health news; this strong impact may be achieved through the framing of narratives (Scheufele, 1999). As Entman (1993) described, "[t]o frame is to select some aspects of a perceived reality and make them more salient in a communicating text, in such a way as to promote a particular problem, definition, causal interpretation, moral evaluation, and/or treatment recommendation" (p. 52). Frames are basic ways of viewing the world that guide people's perception and representation of reality. Frames are impacted by new information as well as how journalists present this information; characterizations of an issue may influence how it is viewed by an audience (Scheufele & Tewksbury, 2007). The framing of messages by the media both reflects and contributes to the creation of public opinion. Assessing how the media portray an issue, therefore, can help us ascertain the ways in which an audience understands a topic or issue.

Aims of the Study

The development of effective knowledge translation and risk communication tools are vital components of the CAN*Help* Working Group. Indeed, these tools are exceptionally important in community-driven research involving Indigenous populations (Estey, Kmetic, & Reading, 2008; Jardine & Furgal, 2010; Smylie et al., 2004). Developing such tools and ultimately addressing community concerns requires ascertaining community perspectives about *H. pylori* and *H. pylori*-associated diseases. Analyzing media messages and how they are framed may reveal how audiences in northern communities perceive and conceptualize *H. pylori*. In this study, we conducted a media analysis to address the following questions:

1) How is *H. pylori* infection and *H. pylori*-associated diseases in the NT and YT portrayed by the media?
2) How is research related to *H. pylori* in the NT and YT portrayed by the media?
3) How is information such as community concerns related to the *H. pylori* bacterium in the NT and YT portrayed?

To address these research questions, we assessed the framing and content of media messages related to *H. pylori* in northern communities.

Methods

We examined media available online: newspaper articles, magazines, radio broadcasts, and videos. First, we collected media from the online data sources Canadian Newsstand, and Canadian Business and Current Affairs; however, media published by northern news sources such as *The Yellowknifer* were not available through these online databases. We expanded the media search, therefore, to include direct searches of northern news websites such as: *CBC News, Yukon News, Northern Journal* (*Slave River Journal*), and *Northern News Services*. *Northern News Services* captures local newspapers across the NT such as *The Yellowknifer*, and *Inuvik Drum*. We compared the media reports collected from online searches to those housed within a database managed by the CAN*Help* Working Group. This database contains listings of known media reports related to *H. pylori* in northern Canada. We added media reports to this study if they were found within this database but not through the online search. To permit an assessment of how the media portrayed *H. pylori* over time, we included all media up until September 2017, regardless of the date of release.

The bacterium is named alternately as *Helicobacter pylori*, *H. pylori*, and Hp. While Hp is occasionally used, it is rarely used in the absence of one of the former two terms. Therefore, 'pylori' was selected as the primary search term. We searched indexes using key words that identify northern regions: "arctic", "north" or "territor" as derivatives, "Yukon", "NWT", "NT", or "YT". We searched online news sites using the search term 'pylori' only. We included media items in the study if they described *H. pylori* in the NT or YT and if they addressed one of the following questions:

1) Does the item describe health risks or health problems related to *H. pylori*?
2) Does the item refer to potential sources or transmission pathways of *H. pylori*?
3) Does the item discuss health research related to *H. pylori*?

To capture all media portrayals of *H. pylori* in NT and YT, we selected media items if they matched the criteria outlined above, even if *H. pylori* was not the main focus of the item.

We performed a quantitative assessment by categorizing media items into frames. We developed categories *a priori* in research team discussions about the team's observations of community perspectives on *H. pylori;* categories were modified as needed in preliminary analysis. We categorized media items as centred on one of the following frames: 1) research on *H. pylori* (i.e. media reports that describe research that was or is currently being conducted in northern communities related to *H. pylori*), 2) community concerns related to *H. pylori* (i.e. media reports that describe concerns about *H. pylori* or *H. pylori*-associated diseases in northern communities) 3) diseases related to *H. pylori* (i.e. media reports that describe diseases such as peptic ulcers or stomach cancer), 4) *H. pylori* risk factors, sources, or transmission pathways (i.e. media reports that describe the frequency of or risk factors for *H. pylori* infection), and 5) other (i.e. media reports that matched the inclusion criteria but did not fit into one of the preceding categories). Following identification of the central frame of each item, we further assessed the media to determine whether they mentioned any of the listed frames as part of the item content. We also assessed differences across media type: content analyses were conducted separately for newspapers, magazines, radio broadcasts, and videos.

If a media item described *H. pylori* research, we performed a content analysis to identify the main focus of the research being described. We also assessed which participating northern community was being discussed, as well as the apparent main goals of the research. Media items that mentioned community concerns were evaluated to identify the focus of concern. For these media items, we further assessed whether the concern was described as originating from community members, researchers, or health professionals. In media items that mentioned or discussed the *H. pylori* bacterium or associated diseases, we noted which risk factors for acquiring the *H. pylori* bacterium or outcomes of infection were described. Lastly, we noted whether a media item mentioned sources or transmission of *H. pylori* and, if so, which sources or transmission pathways were conveyed. Each item was coded by two researchers.

Results

We collected 635 media items from library databases or online news sources (Table 1). Review of the CAN*Help* Working Group media database revealed 29 additional items that met the inclusion criteria but were not captured by online searches (664 in total). Of these, 63 media items met inclusion criteria. Three newspaper articles were printed in more than one newspaper; we included only one copy of each article. We excluded two CBC radio broadcasts for which the audio files or transcripts were no longer available. The resulting study sample was 58 items that described *H. pylori* in the NT or YT and commented on health issues, sources or transmission, or research related to the bacterium.

Table 1: Number of media items reporting on *H. pylori* in the Northwest Territories or Yukon captured in each database or online news site, no date restrictions

	Total items captured	Items fitting inclusion criteria	Items in study Sample*
Canadian Newsstand/Canadian Business and Current Affairs	545	6	6
Northern News Services	18	16	15
Canadian Broadcasting Service	71	11	9
Slave Lake Journal	0	0	0
Yukon News	1	1	1
CAN*Help* Working Group media database	29	29	27
Total	664	63	**58**

*The study sample excluded two radio broadcasts without audio files or transcripts and three duplicate articles that were identified through online searches and met inclusion criteria. Searches of online news sites were conducted April 15, 2017. The CAN*Help* Working Group database contained articles captured through other approaches.

Very few of the selected items were published before 2008 (3/58). The majority (30/58) were published in 2008, which matched the year when researchers and physicians travelled to Aklavik, NT, to offer the first community-wide endoscopy clinic, a procedure that permits the visual inspection of the stomach through images taken via a scope inserted down the throat. There was an annual average of three items published per year thereafter (between 2009 and 2017). There were no apparent differences across media types throughout content analyses; as a result, we pooled these types for reporting results (see Appendix II for tables that include content analyses broken down by media type). Inter-rater agreement for each analytical category was considered acceptable between 76% and 88%, with an average of 82% (Stemler, 2004).

Categorization of media items found that 72% (42/58) were framed around research being conducted on *H. pylori* in northern Canada (Figure 6). Few media items were framed around diseases associated with *H. pylori* (9%; 5/58), related community concerns (3%; 2/58), or *H. pylori* occurrence, risk factors, sources, transmission pathways (3%; 2/58). Seven media items that did not fit into the previous categories fell into the 'other' category (19%). Upon further assessing media items to identify subject content, a given media item might have mentioned the subject of each frame and therefore one media item could contribute to each category. Large proportions of media items mentioned research on *H. pylori* (97%; 56/58), community concerns related to *H. pylori* (84%; 49/58), or *H. pylori*-related diseases such as peptic ulcers or stomach cancer (91%; 53/58). Fewer media items provided detailed descriptions of the occurrence, risk factors, sources, or transmission pathways of the bacterium or discussed sources or transmission (less than 37% (21/58) each).

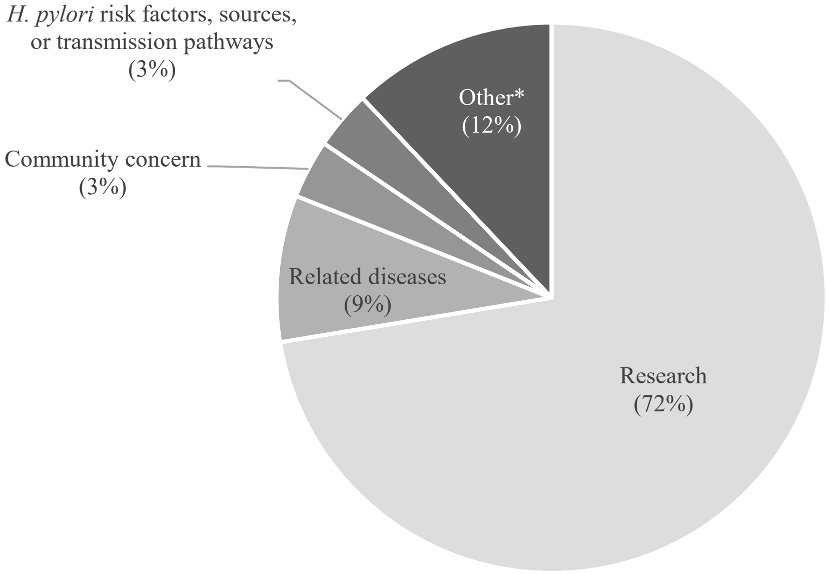


Figure 6: Proportion of 58 media items reporting on *H. pylori* in the Northwest Territories or Yukon in each mutually exclusive media framing category, 2000-2017

* ‘Other’ includes cancers linked to infectious disease agents, clean water, research conducted in the North, community topics, and research participants.

Research

Of the 56 media items that mentioned *H. pylori* research, 80% (45/56) described *H. pylori* as the main focus of the research (Figure 7). Media reports stated, for example, that the research aimed “to better understand the bacterium” (Hopper, 2008). The remaining media reports described stomach cancer (16%; 9/56) or water quality (4%; 2/56) as the research focus. These foci were apparent when media used language that referred to an investigation or study. For example, in the case of stomach cancer, a newspaper article stated, “When doctors investigating stomach cancer in the community…” (Unknown, 2012) and another identified water as the main focus of the research: “Dr. John Morse a doctor of internal medicine at Stanton Hospital in Yellowknife, hopes to undertake a study of water in the North” (Halifax, 2000).

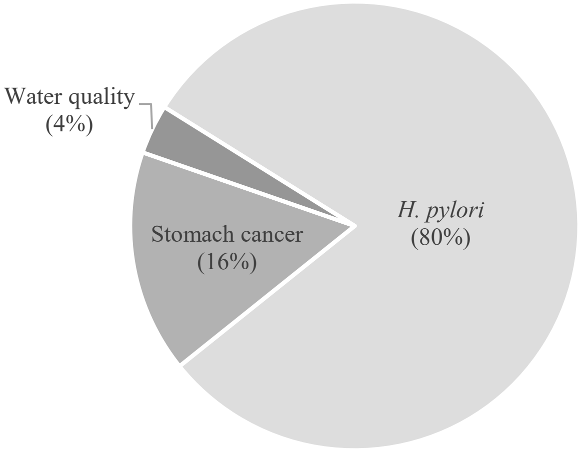


Figure 7: Proportion of 56 items referring to research relating to *H. pylori* in the Northwest Territories or Yukon in each mutually exclusive category of research focus, 2000-2017

The location of the research being conducted was also relatively consistent. Most media reports (79%; 44/56) described research being conducted in Aklavik, NT; the remaining media discussed *H. pylori* research being considered or conducted in Old Crow, Fort McPherson, or other communities or regions within the North. This was consistent with the timing of the publication of the majority of media items in 2008, the year that researchers and health professionals conducted the first endoscopy clinic in Aklavik.

We also assessed whether the media items specified apparent research goals: 52 media items used language that identified at least one specific research goal (Figure 8). These included treating *H. pylori* infection and evaluating the effectiveness of antibiotics aimed at eliminating the infection (both 15%; 8/52). Over two fifths (42%; 22/52), however, reported that testing for *H. pylori* was a main goal; almost a quarter (23%;

12/52) described decreasing negative health outcomes such as *H. pylori* infection and gastric cancer as a main goal of the research being conducted. In most cases, these specific goals were not explicit. For example, a newspaper article described the research activities as "large scale screening for *H. pylori* bacteria" (Thomas, 2008); another headline read, "MLA urges constituents to get tested for bacteria" (Unrau, 2010). While neither example explicitly states that testing for *H. pylori* was the goal of the research, in isolation they imply that this testing activity was a purpose for this work.

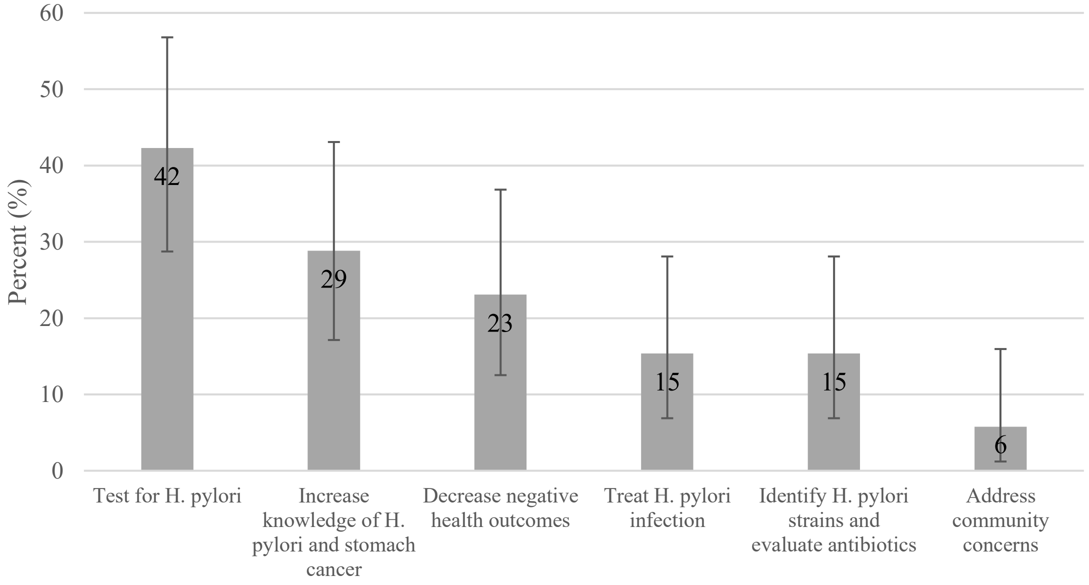


Figure 8: Proportion of 52 media items reporting research goals related to *H. pylori* in the Northwest Territories or Yukon that mention specified research goals, 2000-2017

Percent (%) refers to the proportion of media items reporting a specified research goal among those with apparent mention of research goals. Error bars are binomial exact 95% confidence intervals. Media items may have mentioned more than one goal and, as a result, may be included in multiple categories. 'Negative health outcomes' include *H. pylori* infection, gastric cancer, cancer, and health risks (general)

Community concern

While the main research focus was most often described as *H. pylori*, media that reported community concerns related to *H. pylori* in the NT and YT were most likely to describe cancer as the focus of concern: over half (61%; 30/49) of media that mentioned concerns identified stomach cancer as the cause for concern (Figure 9). An illustration of this and the impact of stomach cancer on community was a quote from a former mayor of Aklavik: "Everybody knows that stomach cancer is a real problem here – it hits the young, the elders, whole families" (Picard, 2008). Other concerns mentioned included the *H. pylori* bacterium itself (22%; 11/49), and unknown origin or source of *H. pylori* (8%; 4/49). The majority of concerns reported, regardless of the main focus of concern, appeared to portray concerns held by community members (90% of total concerns reported; 44/49). In some cases, however, the concerns attributed to community members were made by academic researchers or health professionals such as physicians. For example, when describing the goal of the research program, an academic researcher stated that it was "to address the community's concerns about *H. pylori* infection" (Huntington, 2010).

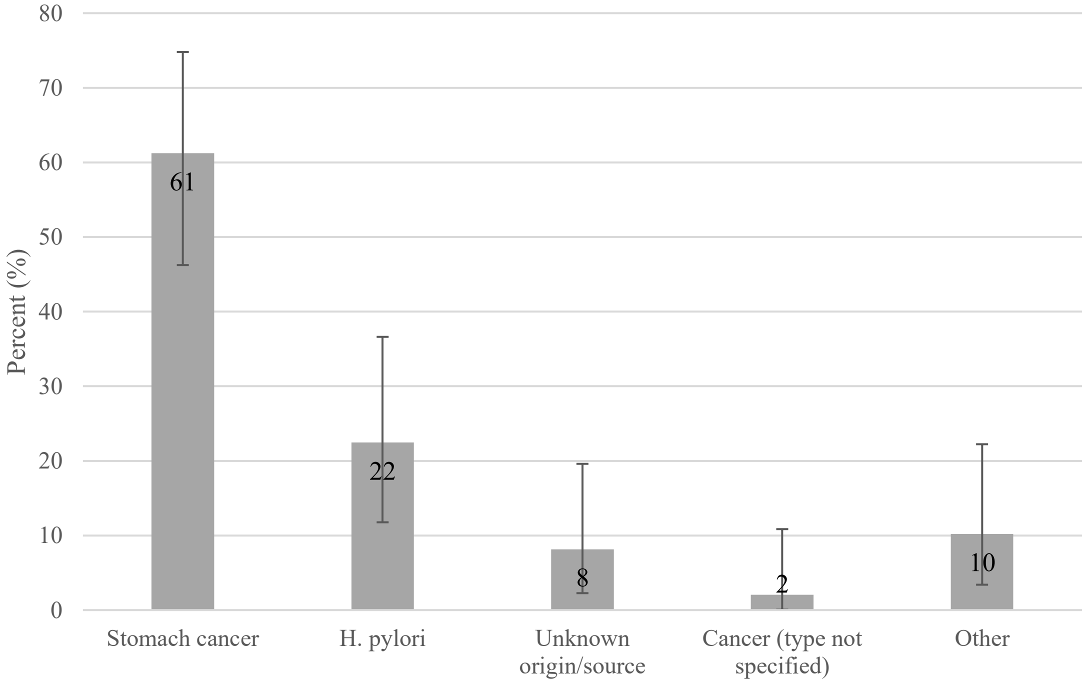


Figure 9: Proportion of 49 media items reporting concerns related to *H. pylori* in the Northwest Territories and Yukon that mention specified concerns, 2000-2017

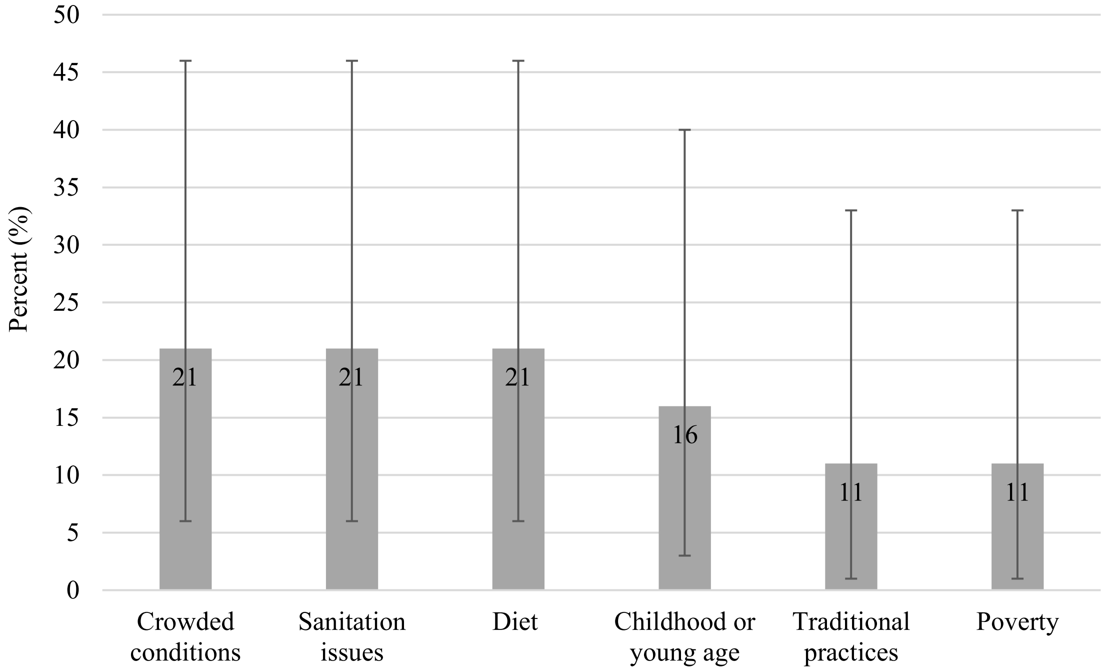
Percent (%) refers to the proportion of media items reporting a particular concern related to *H. pylori* among items that mention concerns. Error bars are binomial exact 95% confidence intervals. Media items may have mentioned more than one concern and, as a result, may be included in multiple categories. 'Other' includes transmission, water, and *H. pylori* diseases (general).

Risk Factors, Diseases, Sources and Transmission Pathways

A third of media reported risk factors for *H. pylori* infection (33%; 19/58) (Figure 10a). Of those, almost two fifths (19%; 4/19) mentioned diet, sanitation issues, or crowded conditions as factors associated with the occurrence of *H. pylori* infection: for example, a newspaper reported that “H. pylori [sic] infection is particularly high in developing countries burdened by crowded living conditions, poor sanitation and lack of clean water” (Unrau, 2010). Similarly, it was reported by an academic researcher in a radio interview that, “we find it more commonly in crowded types of settings” (Ostrem, 2008).

While only a third of media described risk factors for infection, almost all media mentioned potential outcomes of *H. pylori* infection (91%; 53/58) (Figure 10b). In each case, cancer was identified as a potential outcome: 8% (4/53) mentioned cancer without noting a type and 92% (49/53) specified stomach cancer. Over two thirds (68%; 36/53) also identified ulcers as an outcome of infection. Fewer media described stomach issues in general or reported that infection with the bacterium was associated with no symptoms (both 19%; 10/53). When stomach cancer was discussed in detail (47/58 media items), all reported *H. pylori* infection as a cause of the illness; several also described other contributing causes such as smoked or salted meat, diet and exercise, or tobacco consumption (8/47).

a. Proportion of 19 media items reporting risk factors for *H. pylori* infection in the Northwest Territories and Yukon that mention specified risk factor categories, 2000-2017



b. Proportion of 53 media items reporting outcomes of *H. pylori* infection in the Northwest Territories and Yukon that mention specified outcome categories, 2000-2017

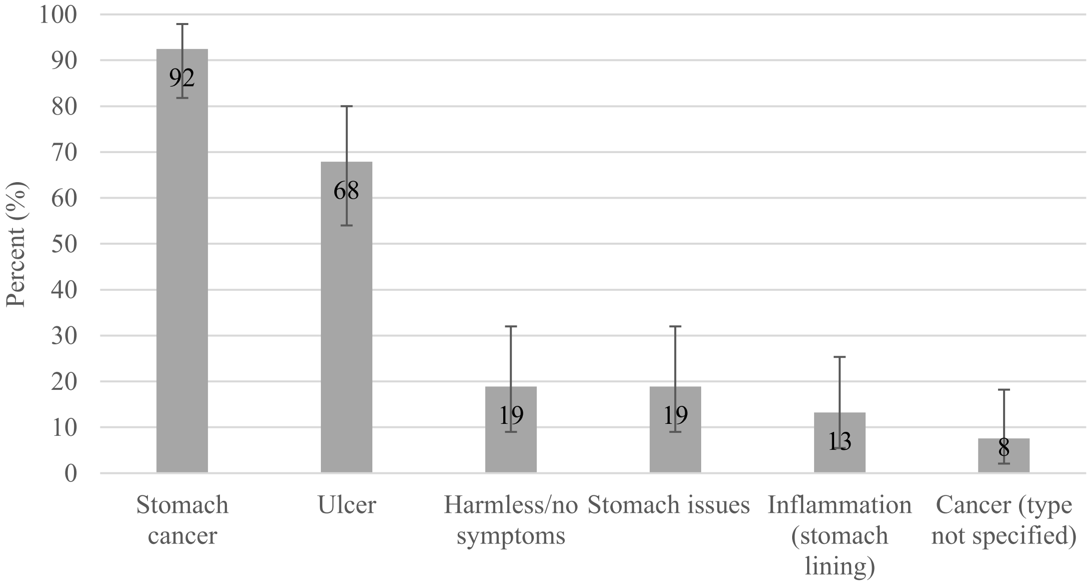


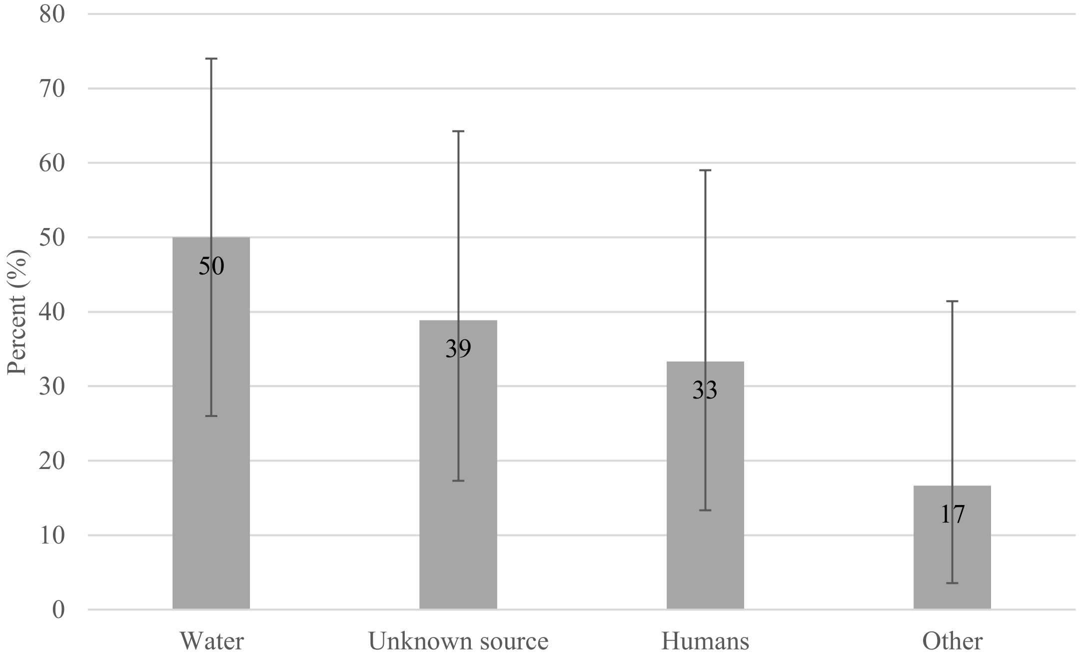
Figure 10: Proportion of media items that mention *H. pylori* infection risk factors (a) or outcomes (b) in the Northwest Territories and Yukon, 2000-2017

Percent (%) refers to the proportion of media items reporting a particular risk factor for *H. pylori* infection among items that mention risk factors (a) or a particular outcome of *H. pylori* infection among items that mention outcomes (b). Error bars are binomial exact 95% confidence intervals. Media items may have mentioned more than one risk factor or outcome and, as a result, may be included in multiple categories. Figure 10a: 'Traditional practices' includes less modernization and chewing food for infants. Figure 10b: 'Stomach issues' includes loss of appetite, general stomach upset, and indigestion.

Few media discussed potential sources of *H. pylori* (18/58) or transmission pathways of the bacterium (21/58). Of those that mentioned sources of the bacterium, the majority either questioned whether *H. pylori* was located in water (50%; 9/18) or described the source as unknown (39%; 7/18) (Figure 11a). For example, a newspaper article referring to Dr. John Morse, a physician involved with the research program reported that "Morse suspected the bacteria comes from domestic water sources…" (Halifax, 2000). Another reported, "…in Aklavik, where a large portion of the population is infected with the H. Pylori [sic] stomach bacterium, many residents continue to boil their water just in case" (May, 2010).

When the source of *H. pylori* was described as unknown, and this description appeared to originate from a community member, the unknown nature of this information was described as a concern or problem that needed to be addressed. For example, a former mayor of Aklavik described research related to *H. pylori*: "We're not pinpointing the source. If it's the water, people are going to get re-infected. So let's pinpoint the source" (May, 2010). Of the media that mentioned how *H. pylori* infection is transmitted, around half (48%; 10/21) mentioned bodily fluids such as feces or saliva as the route of transmission (Figure 11b). Almost a third (29%; 6/21) described the route of transmission as unknown; an additional 29% (6/21) described *H. pylori* as transmitted from person-to-person.

a. Proportion of 18 media items reporting a source (or reservoir) of *H. pylori* bacteria in the Northwest Territories and Yukon that mention specified sources, 2000-2017



b. Proportion of 21 media items reporting a mode of *H. pylori* transmission in the Northwest Territories and Yukon that mention specified transmission pathways or vehicles, 2000-2017

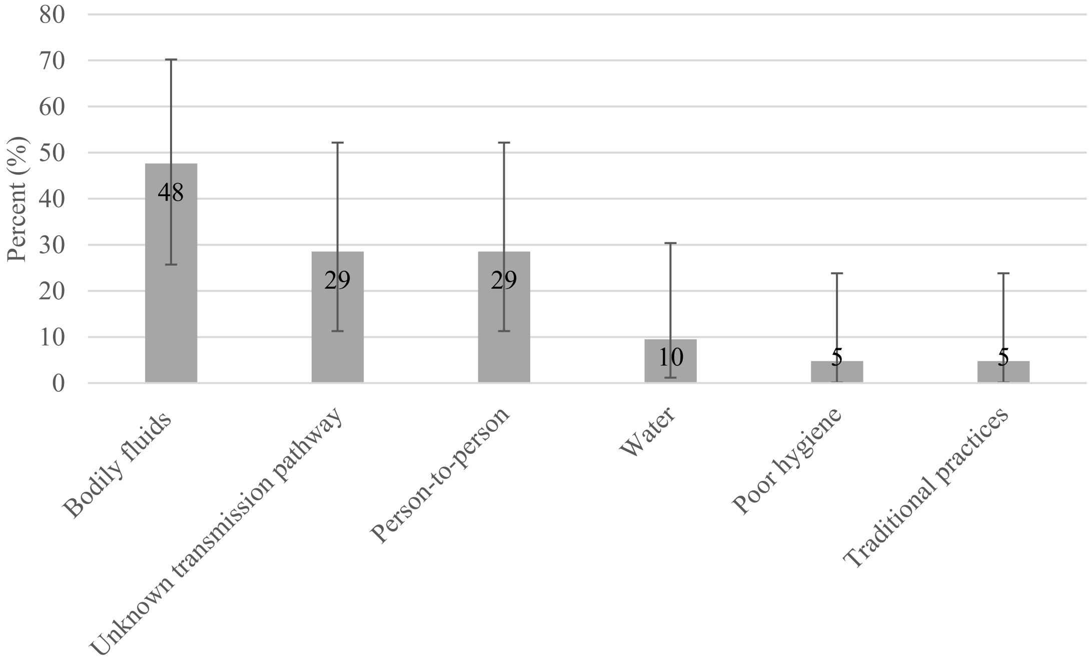


Figure 11: Proportion of media items that mention a source (a) or mode of *H. pylori* transmission (b) in the Northwest Territories and Yukon, 2000-2017

Percent (%) refers to the proportion of media items reporting a specified source of *H. pylori* among items that mention sources (a) or a mode of *H. pylori* transmission among items that mention transmission (b). Error bars are binomial exact 95% confidence intervals. Media items may have mentioned more than one source or pathway and, as a result, may be included in multiple categories. Figure 11a: 'Other' includes food and residential school. Figure 11b: 'Bodily fluids' includes feces, saliva, vomit, and diarrhea; 'Traditional practices' was the term used to describe a possible way that *H. pylori* is spread.

Reflections and discussion

Through a frame and content analysis, we assessed media portrayals of *H. pylori* and *H. pylori*-related research in the NT and YT. The majority of media reports included in analyses were framed around research topics; of those that mentioned research, *H. pylori* was described as the main focus of the work. This differed, however, from the media that mentioned community concerns related to the bacterium: those media focused on stomach cancer as the main issue of concern. This suggests a potential discrepancy between the research being conducted on *H. pylori* in northern Canada and what community members view as their major health concern.

In considering explanations for this discrepancy, it is useful to note that many of the media reports referring to stomach cancer identified *H. pylori* as a cause of the disease. This may reflect an awareness of northern community members of the links between *H. pylori* and stomach cancer and that research focused on *H. pylori* may ultimately contribute to solutions that address their underlying concerns. The rarity of developing stomach cancer among those infected with *H. pylori*, however, and lack of discussion around other causes of stomach cancer in media reports, still signals a potential inconsistency. The questions being asked by community members may differ from the questions and research pursuits of those involved with the CAN*Help* Working Group research program: there may be discordance between expected research outcomes held by academic researchers and those held by community members.

Similarly, most media reports of research that specified apparent goals noted that these included testing for *H. pylori* infection. Others described treating the infection as a specific goal. These narratives may have resulted from a description of research activities without contextualization within a broader research context. From an academic researcher's perspective, this is problematic in how it has the potential to conflate health care and research activities: in the CAN*Help* Working Group research program, testing is a means to determine the prevalence of *H. pylori* in the population and to provide information for further analyses; it is not in itself the goal of the research. Likewise, treatment is offered to research participants who are found to be infected with the bacterium for the purpose of identifying factors associated with treatment failure; from an academic research perspective, treatment it is not an inherent research goal.

Other points to consider include questions around the source or transmission pathways of the bacterium. Although few media mentioned the source or transmission of *H. pylori*, those that did tended to describe the source as unknown or questioned whether *H. pylori* came from contaminated water. This is consistent with work reported previously by the CAN*Help* Working Group that found water as a source of concern among research participants when discussing *H. pylori* infection (Wynne et al., 2013; Carraher, 2013; Highet et al., 2016). Although questions remain about whether there are environmental sources and about the precise transmission pathways, abundant research evidence suggests consistently that *H. pylori* is found primarily within human stomachs and is most likely to pass from person to person when expelled from the stomach rapidly through diarrhea or vomiting in a setting where traces of the infectious secretions come into contact with a new host (Azevedo, Huntington, & Goodman, 2009). If community members are focused on finding the source of the bacterium in an environmental reservoir, there may be restrictions in researchers' abilities to address these specific questions due to scientific limitations: while *H. pylori* organisms have been detected in water, technical constraints limit evidence of bacterial viability in water, thus limiting conclusions about the effectiveness of environmental water sources as reservoirs of *H. pylori* (Azevedo et al., 2009). These issues also highlight challenges in communication with respect to expectations of research outcomes: community members may hope that research will pinpoint an environmental source of *H. pylori* so it can be eliminated, while researchers aim to develop effective public health strategies for infection control, even if no environmental source can be pinpointed.

One of the strengths of this work is the inclusion of multiple forms of media to assess media portrayals of *H. pylori* and associated diseases. It is important to note, however, that media representations are just one of many factors that work together to form an individual's perspectives on a given topic (Wahlberg & Sjoberg, 2000). This study is further limited by what was available online and does not necessarily reflect uptake by community members. Measuring attention to news is thought to be a better measure of the impact of media on public perceptions than presence in media alone (Wahlberg & Sjoberg, 2000); therefore, the results presented here may not fully reflect public discourse about the subject.

Moreover, it is also useful to note that there may be unique considerations that make media analyses an ineffective means of assessing risk perceptions in northern Indigenous communities. The cultural differences that exist between these communities and others in North America and elsewhere may not allow the direct application of frameworks used in this work. For example, the presence of print or online materials may not reflect common ways of communicating news or other information in these communities; northern audiences may rely more heavily on mediums not captured here such as local radio or word of mouth. It is also unclear how other socio-cultural differences such as ways of knowing, reading literacy, or language, play a role in the impact of media in these communities.

Together, the findings of this study contribute insights into how community members in northern Canada may view *H. pylori* and *H. pylori*-associated diseases. This work will support the on-going research on *H. pylori* being conducted in the NT and YT by contributing to the development of effective knowledge translation and risk communication tools that bolster meaningful public health strategies for infection control. To continue building an awareness of community perspectives, future work will include explorations of public perspectives of *H. pylori* and stomach cancer within northern communities through ethnographic approaches that explore these concepts in further depth.

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6.2 Community-driven research on *Helicobacter pylori*: northern Canadian communities' perspectives on a stomach bacterium

Abstract

Northern Indigenous populations in Canada have a disproportionately high frequency of *Helicobacter pylori* infection and associated diseases. To address concerns, a multidisciplinary community-driven research program aims to describe disease burden associated with *H. pylori* infection, and to identify effective public health and knowledge translation strategies to reduce associated health risks. To ensure that solutions developed through research are relevant to those impacted, researchers must consider how affected community members perceive related risks. Here, we aim to characterize community members' views about *H. pylori* and *H. pylori*-associated diseases.

In each of five participating communities, research participants completed interviewer-led structured questionnaires in which they provided information about their views on *H. pylori*: using these data, we performed a descriptive content analysis of the frequency distribution of main response categories. In addition to these structured interviews, in three participating communities (Fort McPherson, Northwest Territories; and Teslin and Ross River, Yukon), semi-structured interviews were also conducted to foster in-depth discussions about the bacterium and related risks. We employed a thematic analysis, using an inductive and iterative approach, to identify prominent themes.

Taken together, it was evident that *H. pylori* is often either unknown or viewed in connection with stomach problems or stomach cancer. These health outcomes were most likely to be reported as a concern by research participants, who also highlighted the potential transmission of *H. pylori* through contaminated water and food sources as a cause of concern. This work revealed community perspectives about the *H. pylori* bacterium and associated diseases and will be useful for informing public health strategies aimed at implementing effective interventions to reduce health risks and to alleviate concerns.

Introduction

Helicobacter pylori is a bacterium known to persist long term in the stomach, where it is accompanied by chronic gastritis and is a risk factor for peptic ulcers and stomach cancer (Goodman & Correa, 1995). In 2000, an estimated 70% of residents of lower resourced countries were infected with the bacterium (Brown, 2000). Although there is a lower prevalence of *H. pylori* in more resourced countries (estimated at 40% in 2000), research shows that northern Indigenous populations have a disproportionately high frequency of *H. pylori* infection and associated diseases (Goodman, Jacobson, & van Zanten, 2008; Young, Kelly, Friborg, Soininen, & Wong, 2016), and relatively low success of treatment aimed at eliminating the infection (Goodman et al., 2008). To address concerns voiced by affected communities and their healthcare providers, a community-driven program has been established involving several communities in northern Canada. This research program, the Canadian North *Helicobacter pylori* (CAN*Help*) Working Group, is a collaborative initiative that links community representatives, faculty from various disciplines at the University of Alberta, as well as Northwest Territories (NT) and Yukon (YT) health care practitioners and health officials.

As of September 2017, seven communities were a part of this research program: Aklavik, Tuktoyaktuk, Fort McPherson, and Inuvik, NT; and Old Crow, Teslin, and Ross River, YT. Each of these communities is located in a remote northern area: five are located north of the Arctic Circle and the remaining two (Teslin and Ross River) are situated in YT close to the British Columbian border. With the exception of Inuvik which has a population around 3,500, the populations of participating communities range from approximately 140 to 900. These communities are comprised of primarily First Nations and Inuvialuit peoples; in the 2011 National Household Survey, over 82% of the residents of each community but Inuvik self-identified as Aboriginal (Inuvik: 68%) (Statistics Canada, 2013). While research implementation occurs through community-specific collaborations, the overarching research program aims to address issues faced across the territories. These overall aims are to describe the burden of disease associated with *H. pylori* infection, to identify effective public health strategies for infection control, and to develop knowledge translation strategies that help community members and health professionals implement solutions that arise from the research.

To ensure that research focused on a given health problem adequately addresses community concerns and that solutions developed through research are relevant to those impacted, researchers must consider how affected community members perceive related risks (Jardine, 2008; Morgan, Fischhoff, Bostrom, Lave, & Atman, 1992). Learning how disease is characterized by those impacted can contribute to a rich description of a given health problem and illuminate more clearly how the disease is experienced (Jones & Williams, 2004; Sofaer, 1999; Trostle, 2005). This kind of information can help inform quantitative research questions by identifying additional avenues for investigation that may further impact public health and well-being (Barbour, 1999; Johnson & Onwuegbuzie, 2004; Trostle, 2005). It can also provide contextual information that helps to explain results of structured quantitative inquiry (Barbour, 1999; Johnson & Onwuegbuzie, 2004). In addition to these benefits, information on public perspectives can support effective communication about a health problem (Jardine, 2008; Morgan et al., 1992): because individuals learn new information within the context of their existing knowledge and beliefs (Morgan et al., 1992), the development of effective knowledge translation and risk communication strategies requires information about how target audiences speak and think about the health problem. Likewise, ascertaining the perspectives of those impacted will be useful for informing public health strategies aimed at implementing meaningful and effective interventions to reduce health risks and alleviate public concern (Brownson, Chriqui, & Stamatakis, 2009; Jones & Williams, 2004; Jones, Podolsky, & Greene, 2012).

The current study characterizes participating community members' views about *H. pylori* and *H. pylori*-associated diseases, thereby contributing to the larger CAN*Help* Working Group research program's efforts to describe the disease burden from this infection and develop effective knowledge translation activities. Here, we aim to address the following questions: 1) How do research participants describe *H. pylori*, and what do they know and think about it? 2) To what extent are research participants concerned about *H. pylori* or believe it is a problem in their community? and 3) How, in their view, do *H. pylori* infection and *H. pylori*-associated diseases impact research participants, and their families, friends, and community?

Methods

To achieve research program goals, community planning committees comprising various local representatives, healthcare providers, and academic researchers were established in each participating community. These planning committees guided local research activities to achieve community-specific goals and to uphold the integrity of the research. Key research components were pursued by all participating communities, with implementation details adapted by each community project planning committee. The research components that contribute to the current study are described in more detail below. In particular, to ascertain participants' perspectives, we interviewed them using two types of questionnaires: structured and semi-structured.

Interviewer-administered structured questionnaires

The CAN*Help* Working Group research program maintains a series of structured questionnaire templates designed to support overarching research program goals ("CAN*Help* Working Group - Our Research Methods," n.d.); these templates are adapted with input from local planning committees to meet the unique needs of each community. Given the sensitive nature of some questions, participants had the option of being interviewed by academic research staff or community residents hired as research assistants based on advice from community project planning committees who correctly anticipated that most participants would be more comfortable responding if questions were asked by an outsider. Our 'Health Questionnaire' includes questions pertaining to participants' knowledge, attitudes, or questions about *H. pylori* (questions 2-3 in Aklavik, 2-5a in all other communities). We excluded participants who did not answer questions on their own, which occurred in most cases if participants were too young to respond for themselves, to ensure that perceptions being captured were those of respondents. Flow charts identifying the number of participants that responded to each question are available in Appendix III, Supplement 1. Using data obtained from participants who articulated explanatory responses to open questions, we performed a descriptive content analysis (Julien, 2008) of the frequency distribution of main response categories and 95% confidence intervals (CI).

Interviewer-administered semi-structured interviews

In three participating communities (Fort McPherson, NT; and Teslin and Ross River, YT), academic researchers conducted semi-structured interviews to foster in-depth discussions about the bacterium and related risks. As with other aspects of the research program, the timing and methods of implementation were guided by project planning committees in each community. For more information on methodological choices, see Appendix III, Supplement 2.

Recruitment

In June 2012, several academic researchers visited Fort McPherson, NT, to facilitate the collection of data to support various CAN*Help* Working Group research activities when the project launched in that community. To minimize research burden, academic researchers invited participants engaging in other aspects of the research program such as *H. pylori* urea breath testing to be interviewed about their perspectives on the bacterium and related topics. During the summer of 2017 in Teslin and Ross River, YT, academic researchers implemented purposeful and snowball sampling to identify potential semi-structured interview participants. Further recruitment included word-of-mouth and the placement of posters around each community. To entice participation, the names of all participants were entered into a draw to win a modest prize.

Data collection

In Fort McPherson, an academic researcher (AC) conducted interviews: one interview was conducted with two participants at the same time by their request; the remaining were one-on-one. All but one interview took place in the Fort McPherson Health Centre; the remaining interview occurred in the participant's home. Each interview was conducted after written consent to participate in the CAN*Help* Working Group research program and before completion of another research activity. The semi-structured interviews followed an interview guide developed in advance through consultations between academic researchers and the community planning committee (see Appendix III, Supplement 2). Interviews conducted in Teslin and Ross River followed the same interview guide revised to incorporate potential improvements based on responses obtained in Fort McPherson (see Appendix III, Supplement 2). An academic researcher (SW) conducted one-on-one interviews in the local Health Centre; each interview was arranged at a time that was convenient for both the researcher and participant. For all interviews, the researchers obtained verbal permission from participants to be audio recorded; researchers also took notes to bolster any information captured through the recordings, to support future reflections, and to maintain an audit trail. Audio recordings were transcribed by a separate research staff member and verified by interviewers through a comparison of the recordings with the transcription documents.

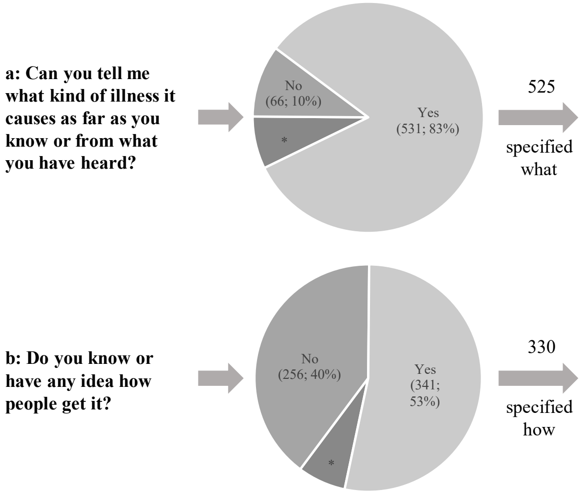
Analysis

To describe perspectives of *H. pylori* and related diseases held by research participants, we employed a thematic analysis (Ayres, 2008; Braun & Clarke, 2006), utilizing an inductive and iterative approach. To begin, an academic researcher (AC) listened to audio recordings, re-read transcripts, and reviewed field notes. She then reviewed the data until initial topics for systematic coding were apparent; further assessment of these codes helped her identify emergent themes or categories where common elements of the codes could be grouped into broader concepts or prominent themes. She documented changes to codes, conceptual re-alignments, and analytic decisions as part of the study audit trail (see Appendix III, Supplement 2). Guided by the principles of interpretive description (Thorne, Kirkham, & MacDonald-Emes, 1997), this work emphasized an application-oriented framework that aimed to describe community perspectives about *H. pylori* and associated diseases in a manner that would be useful for informing actions aimed at mitigating health risks and effectively communicating research results.

Results

Structured questionnaires

As of September 2017, 1,073 research participants across the NT and YT had completed structured questionnaires. We excluded 94 from the present analyses because they did not respond on their own (979 participants included). Participants were further excluded if they indicated they had not, or were unsure, if they had heard of *H. pylori*, or if their response was missing from our data. For example, of the 979 participants who were asked whether they had heard of *H. pylori* infection, we excluded 2 who were unsure or had missing information and 336 who replied “No”: we asked the remaining 641, those who replied “Yes”, additional questions about their knowledge or beliefs (Figure 12). Also, because participants from Aklavik were asked several questions differently than all other communities, in addition to the 94 who did not respond for themselves, we excluded a further 294 Aklavik participants from several questions resulting in the inclusion of 685 total respondents (Figures 13 and 14). Flow charts identifying the number of participants within each response category are available in Appendix III, Supplement 1.



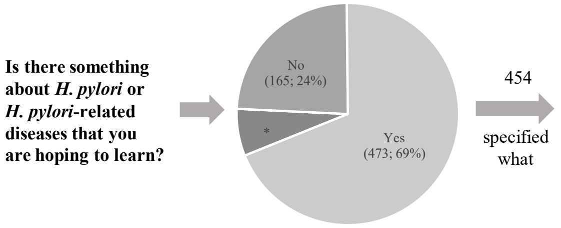
Main response categories	n	%	95% CI
Cancer	235	45	(41, 49)
Ulcers	159	30	(26, 34)
Stomach problems (general)	142	27	(23, 31)
Specified discomfort: cramping, bloating, burping	134	26	(22, 29)
Stomach upset: vomit, diarrhea	79	15	(12, 18)
Impact to stomach lining	43	8	(6, 11)

Main response categories	n	%	95% CI
Water	173	52	(47, 58)
Person-to-Person	65	20	(16, 24)
Food/Diet	62	19	(15, 23)
Body Fluids	34	10	(7, 14)
Germs	32	10	(7, 13)
Behaviour-related	24	7	(5, 11)

Figure 12: Distribution (number and proportion) of responses to *H. pylori* knowledge-related questions among those who had heard of *H. pylori* infection, western Canadian Arctic communities, 2007-2017 (n=641)

Percent (%) in tables refers to the proportion who gave that response among those who indicated that they knew what kind of illness *H. pylori* causes (a) or had an idea about how people get *H. pylori* (b). Note that these are the most frequent response categories (responses mentioned by <5% of respondents are not presented). Individuals may have mentioned more than one response and, as a result, may be included in multiple categories. * = unsure/missing; 7% of respondents

When asked what they know or believe about *H. pylori*, 531 of 641 respondents (83%) reported that they knew what kinds of illness *H. pylori* causes (Figure 12a): 45% (235/525) reported that cancer is one kind of illness caused by the infection; around a third (31%; 159/525) indicated that *H. pylori* causes ulcers. Of those who specified cancer, 38% (90/235) identified stomach cancer specifically; of all 525 who said they knew which illnesses *H. pylori* causes, 17% (90/525) specified stomach cancer. Among the 341 respondents who indicated knowing or having an idea of how people get *H. pylori* (Figure 12b), over half (52%; 173/330) reported that it is transmitted through the water; one fifth (20%; 65/330) stated that individuals get infected through person-to-person contact and almost another fifth (19%; 62/330) stated that people get *H. pylori* through food or diet. While some respondents reported knowing how people get *H. pylori*, others were interested in learning more: of 473 respondents who expressed interest in learning something about *H. pylori*-related topics (Figure 13), a quarter (28%; 126/454) stated that they would like to learn where it comes from; almost a fifth (19%; 87/454) were interested in learning about how the bacterium spreads.

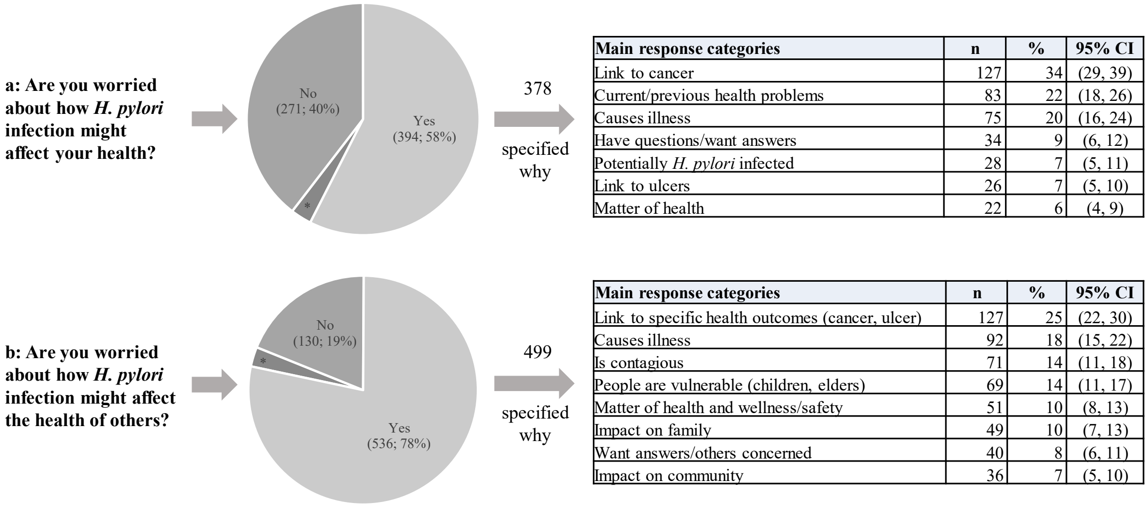


Main response category	n	%	95% CI
Origin/source of *H. pylori*	126	28	(24, 32)
General information/research results	94	21	(17, 25)
Spread/transmission of *H. pylori*	87	19	(16, 23)
Impact/outcome following infection	63	14	(11, 17)
Prevention of infection/disease	56	12	(9, 16)
How to treat/cure infection or diseases	48	11	(8, 14)
Whether they/others infected	40	9	(6, 12)
Why their community has high risk/prevalence	38	8	(6, 11)

Figure 13: Distribution (number and proportion) of responses to questions about what respondents would like to learn about *H. pylori*-related topics, western Canadian Arctic communities excluding Aklavik, 2010-2017 (n=685)

Percent (%) in the table refers to the proportion who gave that response among those who indicated that there was something about *H. pylori* or *H. pylori*-related diseases that they were hoping to learn. Note that these are the most frequent response categories (responses mentioned by <5% of respondents are not presented). Individuals may have mentioned more than one response and, as a result, may be included in multiple categories.
* = unsure/missing; 7% of respondents

When asked about concerns related to *H. pylori*, over a half of respondents (58%; 394/685) indicated that they were worried about how *H. pylori* infection might affect their health (Figure 14a); over three quarters (78%; 536/685) expressed concern about how the infection might affect the health of others (Figure 14b). Of 378 who specified why they were worried about their own health and 499 who specified why they were worried about the health of others, the most common reason reported was its link to specific health outcomes such as cancer and ulcers: 34% (127/378) of those worried about their own health specified cancer as the cause of concern; a quarter (25%; 127/499) of those worried about the health of others reported concerns about a series of health outcomes such as cancer, ulcers, and death. Respondents also voiced concerns about the impacts of *H. pylori* infection on those who they perceive to be at risk: around a fifth (22%; 83/378) of respondents reported being worried about how *H. pylori* infection might affect them because they or their loved ones have had or were currently experiencing health problems. Similarly, respondents voiced concerns about how *H. pylori* might affect the health of others because of the potential for contagion (14%; 71/499) and because people such as children and the elderly may be vulnerable (14%; 69/499).



Main response categories	n	%	95% CI
Link to cancer	127	34	(29, 39)
Current/previous health problems	83	22	(18, 26)
Causes illness	75	20	(16, 24)
Have questions/want answers	34	9	(6, 12)
Potentially *H. pylori* infected	28	7	(5, 11)
Link to ulcers	26	7	(5, 10)
Matter of health	22	6	(4, 9)

Main response categories	n	%	95% CI
Link to specific health outcomes (cancer, ulcer)	127	25	(22, 30)
Causes illness	92	18	(15, 22)
Is contagious	71	14	(11, 18)
People are vulnerable (children, elders)	69	14	(11, 17)
Matter of health and wellness/safety	51	10	(8, 13)
Impact on family	49	10	(7, 13)
Want answers/others concerned	40	8	(6, 11)
Impact on community	36	7	(5, 10)

Figure 14: Distribution (number and proportion) of responses to questions about worries related to *H. pylori* infection regardless of whether respondents had heard of *H. pylori* infection, western Canadian Arctic communities excluding Aklavik, 2010-2017 (n=685)

Percent (%) in tables refers to the proportion who gave that response among those who indicated that they are worried about how *H. pylori* infection might affect their health (a) or affect the health of others (b). Note that these are the most frequent response categories (responses mentioned by <5% of respondents are not presented). Individuals may have mentioned more than one response and, as a result, may be included in multiple categories. * = unsure/missing/refused; 3% of respondents

Semi-structured interviews

Researchers conducted semi-structured interviews with 54 participants (21 men, 33 women; 48% between 50 and 69 years of age) in Fort McPherson and 14 participants from the other two communities (6 from Teslin, 8 from Ross River; 4 men, 10 women; 57% between 30 and 49 years of age). Following initial coding for emergent themes, an iterative review led to a framework for systematic coding and identification of prominent themes (Table 2). We identified four prominent themes for further exploration: 1) *H. pylori* and related experiences, 2) How *H. pylori* spreads and causes disease, 3) Foundational explanations, and 4) Uncertain knowledge base. Below, we describe these prominent themes in detail and outline how they, and their underlying codes and emergent themes, are interconnected (Figure 15). These prominent themes help contextualize how CAN*Help* Working Group research participants view and are impacted by the *H. pylori* bacterium and associated diseases.

Table 2: Codes, emergent themes, and prominent themes captured in responses of community *H. pylori* project participants; Fort McPherson, Northwest Territories and Teslin and Ross River, Yukon; 2012-2017

Code	**Emergent themes (categories)**	**Prominent themes**
Bug Germ Parasite Insect Amoeba Stomach problems Cancer Bloating Heartburn Death Sickness Pills Water Food Industry Contaminants Residential School Smoking/Alcohol Questioning origin/source Questioning what it is Questioning treatment	*H. pylori* defined Personal impacts Community impacts Ingestion/put in body Relates to stomach Relates to cancer Personal choices/behaviours Change/transformation Unknown	*H. pylori* and related experiences How *H. pylori* spreads and causes disease Foundational explanations Uncertain knowledge base

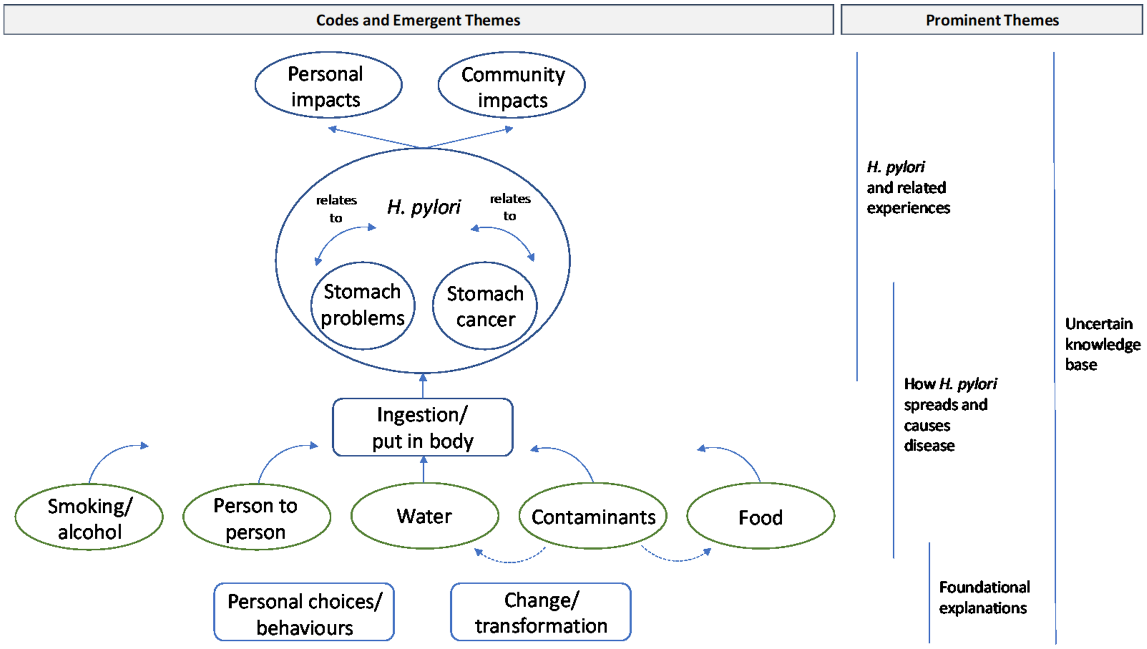


Figure 15: Concept map outlining relationships and connections between codes and emergent themes, and prominent themes captured in responses of community *H. pylori* project participants; Fort McPherson, Northwest Territories and Teslin and Ross River, Yukon; 2012

1. *H. pylori* and related experiences

This research aims to understand community perspectives related to *H. pylori*; as a result, semi-structured interviews included questions that elicited descriptions of *H. pylori* in participants' own terms. Some participants used common language to describe *H. pylori*. For example, the bacterium was occasionally described as a bug, insect, amoeba, or germ that lives in the stomach: "I just know it's a parasite that's in your stomach, that's all, that causes all the damage" (P1). Details about how *H. pylori* acts were included in some of these descriptions: "Um, to tell you the truth, really, I don't even know what it's about. Like, I heard it's…goes in your stomach and eats your, causes, you know, chews up your stomach inside and it just swells up and it, um, germs just start spreading all over" (P41). Other participants used the term 'bacterium' to describe *H. pylori*, though it was unclear whether there is a shared understanding of this term between academic researchers and community participants.

It was also apparent through these descriptions that *H. pylori* may be unknown or understood primarily in connection with the stomach or with cancer. For example, when asked to describe *H. pylori* in their own words, one participant stated, “Um…a stomach problem? I guess that’s the only way I could see it. Is having a stomach problem without knowing what cause it” (P18). Similarly, another described *H. pylori* as, “…some sort of a thing in your stomach that will come out when it wants to, it’s like a cancer cells. Cancer cells is in your body, it’ll come out when it’s gotta come out” (P25). Connections to stomach problems or to stomach cancer were also apparent when participants discussed the impacts of the bacterium. For example, when describing why they believed *H. pylori* was a problem in their community, a participant replied, “Well I just see a lot of people that’s got heartburn all the time” (P1). Another, when describing how people in the community think about *H. pylori* stated, “They never heard about this before. I mean, like, they probably heard it in another way, like, cancer. That’s what they could understand. But they never heard this right here before” (P3).

Many also spoke about the physiological impacts of infection with the bacterium. These personal-level impacts included previous or on-going issues related to heartburn, bloating, and pain. Broader affects were also described, such as the impact of the bacterium on family, friends or the community, though the extent of this impact varied. Some commented on how they did not think it was an issue, having never heard of *H. pylori* before: “…it’s just been brought to everyone’s attention now so I don’t think it’s a problem” (P28). For others, *H. pylori* invoked fearful descriptions of sickness and death: “*H. pylori* could be dangerous because I know of a family friend that passed on from *H. pylori*” (P36). Similarly, when asked how the community would be different without *H. pylori*, one participant responded, “I think we’d have more elders that were still alive” (P56). These disparate descriptions of the bacterium and its impact highlight the notion that there does not appear to be a shared idea of what *H. pylori* is or how it affects communities. Commonalities were evident, however, in the ways in which participants considered *H. pylori* risk factors and plausible transmission pathways.

2. How *H. pylori* spreads and causes disease

As noted previously, *H. pylori* may be defined by its relationship to stomach problems or cancer; it is similarly apparent that these connections may also drive or inform considerations about the ways in which *H. pylori* is transmitted and has an impact. Because the stomach is impacted by the things we ingest, the ingestion or placement of *H. pylori* into one's body could be a potential route of exposure. For example, when asked how the participant thought someone might get infected with *H. pylori*, they responded, "Through the mouth, I guess. Like ingestion of pretty much anything. It could be from the water or from undercooked meals but anything that's ingested, primarily because I correlate it being residing in the gut, in the tummy, and in the stomach" (P68). Another said, "By swallowing" (P61), when responding to the same question. Concepts related to ingestion were also apparent through other discussions, such as when talking about the research program in general: "I think it's good for anybody to go get tested because you never know what you're putting in your body" (P24).

Similarly, because we regularly consume items such as water and food, these were highlighted as possible routes of *H. pylori* transmission. For instance, contemplating where *H. pylori* might come from, one participant stated, "Yeah, and it's like the concern for our water and things like that. Is it safe to drink, you know, because it's going into our body and babies use it, elders use it, young people use it…it goes into our animals and we eat like, you know, off their land and is that *H. pylori* caused from the water or what, like, you know?" (P2). Furthermore, the connection between *H. pylori* and cancer may also have informed considerations around the possible impact of environmental carcinogens on *H. pylori* infection. The consumption of contaminants or poison through the ingestion of chemicals in treated water, or contaminated water or food from natural sources were cited as possible explanatory factors for infection and disease outcomes. For example, referring to nearby water that used to receive sewage, a participant explained what kinds of illnesses they have been witnessing in the community: "Just stomach cancer, colon cancer…well that *H. pylori*…I think people start getting it years ago because they had that intake lake there and that Sewage Lake there and the highway was right between it. Just out here" (P1).

Likewise, the consumption of items through unhygienic conditions or through the consumption of processed foods was also described as a contributing factor to disease. For example, as an explanation for why some people get sick, one participant stated, “They don’t eat traditional foods anymore…they eat too much store food” (P20). Another referred to store-bought foods when asked where they thought *H. pylori* might come from: “Food that people eat. Subs, foods like that…” (P21). Although not typically spoken about directly in relation to *H. pylori*, participants also noted the impact of smoking and alcohol consumption when considering multiple contributing factors to disease outcomes: “…many of the people that have *H. pylori* are chronic alcoholics and smokers. So, I think on top of *H. pylori*, that we do a lot of damage to our body, and with *H. pylori*, it *may* turn to cancer, so that’s what I worry about” (P56). Similarly, when asked if there was anything about *H. pylori* they wanted to learn, another participant was interested in what other factors, such as alcohol, might increase risk of disease: “What triggers it off? Food, alcohol, drugs, you know, whatever, you know. Anything that’s going to trigger it off to come into your body” (P25).

3. Foundational explanations

Through discussions about *H. pylori* and associated diseases, cross-cutting themes emerged around the drivers or explanations for infection with the bacterium and related disease outcomes. The primary overarching themes included reference to personal choices or behaviours that impacted an individual’s risk. Some of these, such as the consumption of processed foods and other behaviours like smoking and drinking alcohol, were described previously. However, thoughts around other contributing determinants that might have led people to make these choices were also apparent. These included considerations related to varying income levels: “I think cost of living is a big issue…I’ve never seen an adequate diet for somebody on a low-income diet, middle-class diet. And when you’re rich, you can have anything, right?” (P62). Similarly, when asked whether they thought *H. pylori* was a problem in their community, one participant answered, “I don’t know…but I hear a lot of people say, “Bad stomach.” Maybe diet, I don’t know…not eating right kinds. People can’t afford fresh fruit and vegetables…and country food is expensive too—fuel, equipment” (P19).

There were also more direct references to the impacts of imposed changes from the ways in which people used to live. These included, for example, the effects of residential school systems on the stomach health of those who attended: "I never heard so much of cancer and stomach ulcers and stomach – like my brother passing away of stomach cancer. And I always suspected that lots of our children that went to Res schools should have had this problem, because their diet was so different from when they left home. And we moved a lot away from traditional diet, and we eat a lot of processed now" (P62). Similarly, another participant described unsanitary conditions within these schools that might have exposed children to contaminants: "…one of the things I begin to wonder about is that we were going to residential school there and …you know, the way that they disposed of stool and garbage and all that wasn't the best disposal system they had. And, so I begin to wonder about all that" (P26).

In addition to residential school, participants shared other plausible explanations for an increased risk of *H. pylori* infection and why *H. pylori*-associated diseases are being experienced by communities. These include, for example, the environmental impacts of industry or other sources of pollution that may have contributed to a movement away from traditional practices towards unsafe food and water consumption. As one participant noted, "Everyone puts cleaning stuff into their toilet and it's bound to go there [the water]. I don't eat fish from this way. People…offer me some but I don't eat it. Further up there was a site from an oil company…they buried barrels of stuff and now it's seeping into the river" (P24). Conversely, changes brought about by the introduction of treated water were also described as a source of concern. One participant recounted how the addition of treated water in the homes of elders might have contributed to their deaths due to stomach cancer:

> And he said these five elders, they moved there. But where he put up the store and build up a house, it's a high bank. And then some government peoples went there and told him it's a beautiful place you put up. But these elders, it's hard for them to pike water. So, they want to put the running water in their homes. Within three years he said every one of them died with cancer. Stomach cancer. So that's what

> I'm thinking about. These young peoples came to Fort McPherson to learn about this and I really think it's water (P5).

Further, in addition to citing contaminants in treated water sources, participants highlighted how the use of natural resources kept them healthy: "Well, look at all the junk that they put into it. I drink water out in the bush, I don't get sick" (P10). The idea of these transformations – imposed or otherwise – were summarized succinctly by one participant who said:

> I always see that people used to be healthy, long time ago, they used to live like in harmony with land and until alcohol came, came into our community, and the government and everything, everything changed, everything was laws and people started drinking alcohol and that's when things changed I guess because before that, people used to never be sick (P32).

4. Uncertain knowledge base

An overarching element that cut across each prominent theme was the concept of the unknown. This was apparent through comments or questions indicating that participants did not have a comfortable understanding of what the bacterium is or how it impacts the body: "I've never heard of it before, I don't know what it is…" (P31). Further, many questioned the cause or source of the bacterium, how it spreads, or how it may be eliminated. As one participant pondered, "I just want to know what it is. Why is it around? Where did it come from? Why does it make people sick? That's it" (P6). Similarly, after suggesting that they were worried that *H. pylori* might be in the water, a participant stated, "You know how cancer works and what certain triggers cause certain cancer, and with *H. pylori* it still seems like a little bit of a mystery" (P67). The impact of these uncertain knowledge foundations was largely unclear; however, in some cases, concepts of the unknown were linked to feelings of fear: "You know, like, I don't know where it comes from. Like, I don't believe it's in the water, like, but it could be from food we eat. It could be from various things. So, it's kind of scary, not knowing where we get it from" (P64).

Discussion

We used two methodological approaches to garner insights into the perspectives of northern communities participating in research related to *H. pylori* infection. Content analyses of structured questionnaires revealed the proportion of research participants who had specific beliefs around *H. pylori* and *H. pylori*-related topics. Enhancing this were insights from thematic analysis of semi-structured interviews, which provided further context from more in-depth discussions: we were able to gain insights into how the concepts identified through structured questionnaires might be connected. Taken together, it was apparent that *H. pylori* is often either unknown or understood in connection with stomach problems or stomach cancer. These outcomes were similarly those most likely to be reported as a concern by research participants. As a result, there seemed to be a blurring between risk factors for *H. pylori* infection and the factors that may increase risk of stomach problems or cancer.

In particular, the physiological process of ingestion or consumption appeared to play a role in how participants view the factors that lead to illness. For example, the majority of respondents who had an idea of how people get *H. pylori* infection reported that it comes from water. Upon further examination, apparent rationales for this perspective emerged. Because *H. pylori* may be understood in connection with stomach problems or stomach cancer, thoughts around the source of the bacterium or its mode of transmission may be linked to physical contact with the stomach through ingestion, a concept typically associated with water and food. Likewise, cancers, including that of the stomach, may be associated with exposure to carcinogens. While *H. pylori* is classified as a Group 1 carcinogen by the International Agency for Research on Cancer (International Agency for Research on Cancer, 1994), carcinogens may be more typically thought of as chemicals that are present in pollution or non-biological materials. Thus, exposure to something that causes cancer may be understood to occur through the consumption of unsafe drinking water from polluted natural sources or household water treated with chemicals.

The connections between *H. pylori* and stomach cancer might also illuminate why *H. pylori* infection and associated diseases were described within the context of changing environments. It has been noted elsewhere that the attribution of cancer risk to environmental factors is influenced by gender and ethnicity, as well as by sociopolitical considerations such as trust and power (Flynn, Slovic, & Mertz, 1994; Olofsson & Rashid, 2011; Palmer, 2003; Slovic, 1999). This may be particularly relevant for Indigenous communities where the historic and on-going impacts of colonialism, including a forced suppression of culture and modification of environmental contexts, have profound impacts on Indigenous peoples and their health (Browne, Smye, & Varcoe, 2005; Czyzewski, 2011; Richmond, 2007). The impacts of these imposed transformations may be reflected in participants' reference to residential schools as plausible explanations for exposure to the *H. pylori* bacterium. Similarly, the effects of colonialism were also referenced when participants reflected on the current day practice of consuming unnatural or processed food and water, particularly when contrasted with historic practices. The movement away from more traditional ways of living where water and nutrition-rich foods were harvested from undisturbed natural resources may lead to an increased consumption of unhealthy foods that increase risk of various health conditions, including cancer (Bjerregaard, Young, Dewailly, & Ebbesson, 2004; Mead, Gittelsohn, Kratzmann, Roache, & Sharma, 2010).

These kinds of insights can help inform considerations for future communications regarding *H. pylori* and related risks: because individuals learn new information within the context of their existing knowledge and beliefs (Morgan et al., 1992), the development of effective knowledge translation and risk communication strategies requires ascertaining the relevant knowledge and beliefs of target audiences. Likewise, ascertained perspectives of the target population can also inform public health strategies so that meaningful and effective interventions can be implemented (Brownson et al., 2009; Jones & Williams, 2004; Jones et al., 2012). For example, it appears that a general focus of concern amongst community members is their stomach health: research discussions around *H. pylori* that do not acknowledge the potential impact of other factors on stomach health could perpetuate misunderstandings. Furthermore, given that community members tended to have an uncertain knowledge base around the bacterium, public health strategies targeted at *H. pylori* infection alone may not alleviate broader concerns. As a result, it might be necessary to pursue additional strategies to address stomach issues more broadly.

Similarly, the identification of future research priorities may benefit from a deeper understanding of how community members view their risks. Here, research participants expressed concerns about stomach issues and cancer broadly – beyond what may have resulted from *H. pylori* infection. As a result, future conversations between community members and their healthcare providers or prospective academic research partners might focus on stomach issues and cancer more broadly. Likewise, there was discussion of health risks imposed by what community members feel are unsafe water and land resources. To support healthier communities, it might be useful to address these issues directly to foster a sense of well-being among community members. Indeed, if community members do not feel comfortable eating foods harvested from the land or drinking water from the tap, they may engage in behaviours that increase cancer risk such as eating store-bought foods and sugary beverages that are high in calories and low in nutritional content (Kushi et al., 2012).

While there are myriad benefits to this work, there are also limitations. The aim of our work was to characterize the self-described perspectives of CAN*Help* Working Group research participants about *H. pylori* and associated diseases. Because there are many participating communities, this was accomplished by conducting interviews when feasible and identified as suitable by community project planning committees. This pragmatic approach limited the ability to pursue more extensive engagement methods that might have provided further insights, such as prolonged engagement through extended time within each community (Saucier Lundy, 2008). Methods that support more in-depth relationship-building could lead to an even deeper understanding of the phenomenon. Similarly, this work would also have been strengthened by the participation of community members in the analysis of semi-structured interviews. Because we bring our culturally-guided perspectives to the research we conduct (Walter & Andersen, 2013), our work is limited by how our worldviews impact our analyses and interpretations. A community knowledge-holder or perhaps a person with similar cultural perspectives might have identified different themes had they been a part of these analyses.

In summary, this work is valuable in how it contributes insights into the perspectives of community members on *H. pylori* and associated diseases. Although additional insights might be achieved through different approaches that directly incorporate community knowledge holders in analysis and interpretation, we were nevertheless able to describe how some individuals at risk understand and are impacted by the *H. pylori* bacterium and associated diseases. As a result, this work supports the development of effective communication strategies and fosters the exchange of knowledge among research partners. In so doing, this work provides opportunities to strengthen understandings of related health risks and of challenges encountered in research aimed at reducing these risks.

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6.3 Reflections and summary

Through an examination of online newspapers, magazines, radio broadcasts, and videos we assessed media portrayals of *H. pylori* and associated diseases (Chapter 6.1). Of the media that mentioned research, *H. pylori* was described as the main focus of the work. This differed, however, from the media that mentioned community concerns related to the bacterium: those media focused on stomach cancer as the main issue of concern. This suggests a potential discrepancy between the research being conducted on *H. pylori* in northern Canada and what community members view as their major health concern. Although few media mentioned the source or transmission of *H. pylori*, those that did tended to describe the source as unknown or questioned whether *H. pylori* came from contaminated water.

In addition, we were also able to garner further insights into the perspectives of northern communities participating *H. pylori*-related research through content analysis of responses to structured questionnaires and thematic analysis of semi-structured interviews (Chapter 6.2). It was apparent from this work that, among research participants, *H. pylori* is often either unknown or understood through its connections with stomach problems or stomach cancer. Stomach health issues such as cancer were similarly those most likely to be reported as a concern by research participants. Furthermore, the consumption of unnatural or processed foods, as well as the ingestion of contaminated food or water related to changing environmental contexts, appeared to play a key role in how participants understood the factors that lead to illness.

Other CAN*Help* Working Group research program activities have also explored how members of participating communities and other populations in northern Canada view *H. pylori* and associated diseases. These included the creation of visual images, drawn by participating community members, which represent the community-specific research project and the bacterium (Chapter 4.2). Similarly, a photovoice project conducted with youth in Fort McPherson showcased how participants view *H. pylori*-related risks (Highet et al., 2016). Other work has included an ethnographic exploration that provided an in-depth understanding of community perspectives of the bacterium in Aklavik, NT (Carraher, 2013). In each case, unique perspectives were identified; however, they all appeared to share common language about the bacterium and a common perspective that stomach cancer is a major concern with environmental elements such as contaminated water being an integral part of how sources of illness are viewed and how solutions to health challenges might be identified.

By characterizing the perspectives of *H. pylori* infection and associated diseases among northern Canadian populations, these projects contribute to the overarching CAN*Help* Working Group research program goals. Characterizing how those impacted view the bacterium and their health risks contributes to information necessary to identify effective communications strategies and promote the exchange of knowledge among partners. Furthermore, by identifying the concerns and perspectives of those impacted, collaborative approaches may be developed to pursue additional inquiries that further the goals of the research program. These initiatives, therefore, provide opportunities to strengthen understandings of health risks associated with *H. pylori* infection and identify other avenues for further scientific inquiry.

These works are also valuable in how they contribute to descriptions of the health of a population: the characterization of *H. pylori* infection among northern Canadian populations contributes knowledge about the burden of disease that can support community-university partnerships aimed at improving health. To continue with the applied example, I provide a description of *H. pylori* and associated diseases in NT and YT using more conventional epidemiologic approaches (Chapter 7). Finally, I synthesize this information to provide a comprehensive description of disease burden among those impacted (Chapter 8). Together, these works contribute a more complete description of disease burden that ultimately supports the identification and implementation of meaningful public health strategies for infection control.

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Chapter 7: Applied example: epidemiologic characterization of *Helicobacter pylori* infection and associated diseases

7.0 Introduction

In previous chapters, I outlined some of the challenges and solutions to working in community-university partnerships that aim to improve the health of a population. I provided examples of equitable and collaborative approaches to addressing health problems in these partnerships. I also outlined why information from multiple perspectives enhances the value of epidemiologic descriptions of disease burden, particularly in situations where there is community concern about a specific health problem.

To present an applied example that puts these concepts into practice, in Chapters 6 through 8, I provide examples of diverse kinds of information that are useful for epidemiologic inquiry in community-university partnerships aimed at improving health. In Chapter 6, I began with a characterization of the impact of *H. pylori* infection among northern Canadian populations through a media analysis and an exploration of the perspectives of participating community members using data obtained from structured and semi-structured interviews.

Here, I continue with the applied example by compiling information on the burden of *H. pylori* and associated diseases using more conventional epidemiologic approaches. In Chapter 7.1, my co-authors and I use *H. pylori* diagnostic data to describe patterns of *H. pylori* testing occurrence and results across NT populations. In the following two sub-chapters, I focus on one *H. pylori*-associated disease: gastric cancer. In Chapter 7.2, to build context for the experience of northern populations relative to other populations around the world, my co-authors and I describe global patterns of gastric cancer subsites. In Chapter 7.3, I turn once again to northern Canada and describe the incidence of overall gastric cancer and gastric cancer by subsite among NT and YT populations.

7.1 *Helicobacter pylori* diagnostic testing patterns in northern Canadian populations

Abstract

Background: Infection with *Helicobacter pylori*, a bacterium, increases the risk of peptic ulcer disease and stomach cancer. In Canada, Indigenous peoples have been identified as a high-prevalence population. Because little data are available on *H. pylori* infection and related healthcare in this population, we aimed to describe patterns of diagnostic testing and proportion testing positive among demographic groups in Northwest Territories (NT), Canada.

Methods: Using diagnostic laboratory data, we identified NT residents tested at least once in a year for *H. pylori* infection between 2009 and 2016. We used NT population data to identify Indigenous residents. We estimated annual age-adjusted rates of being tested for *H. pylori* infection, as well as the prevalence odds of a positive test result by Indigenous status, sex, and year. To compare frequencies across Indigenous and non-Indigenous groups, we estimated age-standardized diagnostic testing rate ratios (SRR) and prevalence odds ratios (POR) with 95% confidence intervals (CI).

Results: During 2009-2016, the average annual percent positive for *H. pylori* infection was 57% (95% CI 50, 64) among Indigenous people tested and 17% (95% CI 11, 24) among non-Indigenous people tested. Diagnostic testing rates for *H. pylori* infection were slightly higher for Indigenous relative to non-Indigenous residents of NT: in 2016, the SRR was 1.2 (95% CI 0.95, 1.5) for females and 1.2 (95% CI 0.89, 1.6) for males. Odds of a positive test result, however, were substantially higher among Indigenous residents: in 2016, the POR was 5.0 (95% CI 3.0, 8.4) for females and 8.3 (95% CI 4.5, 15.6) for males.

Discussion: The results show strong evidence of a higher burden of *H. pylori* infection, a risk factor for stomach cancer, in Indigenous people compared to non-Indigenous people living in NT, Canada. This work describes inequities in the disease burden from *H. pylori* infection among demographic groups in northern Canada.

Introduction

Helicobacter pylori is a bacterium that inhabits the lining of the human stomach and/or duodenum where it induces gastritis, an inflammation of the stomach lining (Ford & Axon, 2010). Colonization by the bacterium can persist indefinitely: chronic infection increases the risk of various gastrointestinal diseases, including peptic ulcer disease and stomach cancer, making *H. pylori* infection a public health concern (EUROGAST Study Group, 1993; Correa, Ruiz, & Hunter, 1991; Parsonnet, 1993; Rugge et al., 1993). An abundance of evidence suggests that *H. pylori* acquisition occurs through direct person to person contact, though the relative importance of fecal-oral, gastro-oral routes, or oral-oral routes remains unclear (Goodman et al., 1996). While extra-gastric sources of *H. pylori* such as food or water have not been ruled out due to technical challenges, the human stomach is the only known reservoir of the bacterium (Travis et al., 2010). Studies have shown that chronic *H. pylori* infection is typically acquired in childhood (Brown, 2000; Goodman & Correa, 1995; Goodman et al., 1996) and that lower socioeconomic status and related factors, such as crowded living conditions, are associated with increased prevalence (Khalifa, Sharaf, & Aziz, 2010).

Variation in the prevalence of *H. pylori* infection has been observed globally. As noted in a review by Brown et al. (2000), the prevalence of *H. pylori* was estimated before 2000 to be 70% or more among developing countries and 40% or less among developed regions (Brown, 2000). Considerable variation across countries was also noted by Hooi et al. (2017) who estimated that 4.4 billion people worldwide were infected with *H. pylori* in 2015. Although poor representativeness limited data in some groups (Sugano, Hiroi, & Yamaoka, 2018), the authors also reported *H. pylori* prevalence ranging across countries from 19% in Switzerland to almost 90% in Nigeria (Hooi et al., 2017). While *H. pylori* prevalence differs across regions globally, it also varies within regions: in more resourced areas, older age groups have a higher prevalence than younger ones (Watanabe et al., 2015). Similarly, *H. pylori* prevalence differs across ethnic populations within countries. In the United States, for example, the prevalence among Hispanic and non-Hispanic African-American populations is higher than among their non-Hispanic white counterparts (Graham et al., 1991; Malaty, Evans, Evans, & Graham, 1992).

Several studies show that *H. pylori* prevalence differs between Indigenous and non-Indigenous populations within countries. In New Zealand, for example, *H. pylori* infection has been shown to be more prevalent among Maori and Pacific Islanders compared to those with European ancestry (Fraser, Scragg, Metcalf, McCullough, & Yeates, 1996; McDonald, Sarfati, Baker, & Blakely, 2015). Likewise, estimated prevalence is higher among Alaskan Natives in the United States, and Indigenous populations in Western Australia, than among their non-Indigenous counterparts (Parkinson et al., 2000; Windsor et al., 2005). Variation across populations has also been observed in Canada: studies have estimated a relatively low prevalence of *H. pylori* infection in multi-ethnic populations located in southern regions of the country (Jacobson, 2005; Naja, Kreiger, & Sullivan, 2007). One study, for example, estimated prevalence among adults between 30 and 38% (Thomson et al., 2003). For children in these multi-ethnic populations, prevalence is even lower: in one study of children in four major cities, estimated prevalence was 5% (Jacobson, 2005). Other studies involving northern Indigenous populations, however, have estimated higher prevalence of *H. pylori* infection, ranging from 51-95% for all ages combined in a variety of northern areas (McKeown et al., 1999; McMahon et al., 2016; Sethi, Chaudhuri, Kelly, & Hopman, 2013; Sinha, Martin, Sargent, McConnell, & Bernstein, 2002).

In northern Canada, communities and their healthcare providers have expressed concern over elevated prevalence of *H. pylori* infection and high rates of stomach cancer (Cheung et al., 2014). To address concerns, a community-driven research program was established through a collaboration of researchers, healthcare providers, health officials, and members of communities in the Northwest Territories (NT) and Yukon (YT), Canada. This team, the Canadian North *Helicobacter pylori* (CAN*Help*) Working Group (www.canhelpworkinggroup.ca), aims to identify effective public health strategies for infection control (Cheung et al., 2008). Results from this work have revealed a high prevalence of *H. pylori* infection in participating communities (Cheung et al., 2014; Hastings, Yasui, Hanington, Goodman, & CAN*Help* Working Group, 2014). Because the research program aims to inform policy at a regional or territorial level, it must also characterize the burden across the northern populations impacted so that effective policies can be developed. Here, we aim to describe patterns of *H. pylori* infection frequency among residents of the NT by describing the occurrence and results of *H. pylori* testing across NT populations.

Methods

H. pylori testing

In the NT, *H. pylori* diagnostic testing is done using the 13C-urea breath test (UBT), a non-invasive, convenient, and accurate way of assessing *H. pylori* infection status (Gisbert & Pajares, 2004). *H. pylori* diagnostic tests ordered by healthcare staff are sent for analysis to DynaLIFE Medical Labs in Edmonton, Alberta ("DynaLIFE Home," n.d.). DynaLIFE holds records of each individual test occurrence and test result. To support the current work, the Epidemiology and Surveillance Unit (ESU) of the Department of Health and Social Services, Government of the Northwest Territories, applied for access to *H. pylori* diagnostic data available through DynaLIFE; they received data on all tests, including results, occurring from 2009 through 2016 for NT residents. These data include the occurrence and result of a first test for individuals for each year during 2009-2016. Individuals tested more than once or testing positive more than once within a year were counted only once within that year; individuals tested in multiple years were counted once in each year tested.

Study population

The ESU linked the diagnostic data to population data housed by the NT via personal health number. A personal health number is assigned to every individual residing in the NT; given that NT residents have universal access to the territorial health care system, these numbers are often used to identify the territorial population in administrative datasets. For purposes of these analyses, the ESU constructed data tables stratified by calendar year of test and further grouped the data by individual attribute: sex, 5-year age group, and Indigenous status. Indigenous status was based on vital statistics data housed by the NT government and includes individuals who identify as Inuit, First Nations, or Métis; non-Indigenous includes everyone else. In 2016, Indigenous groups comprised approximately 51% of the total NT population (Statistics Canada, 2017).

Statistical analyses

We aimed to describe the distribution of individuals tested for *H. pylori* infection and positive test results during 2009 through 2016 across NT study groups. We estimated the number of people tested for *H. pylori* infection, the number of people with positive test results, and the proportion with positive results among those tested (referred to hereafter as "proportion testing positive") by year, age group, sex, and Indigenous status.

To describe patterns of diagnostic testing for *H. pylori* infection across NT groups, we estimated age-specific rates of diagnostic testing, as well as age-standardized rates (ASRs) and 95% confidence intervals (CIs) by year, sex, and Indigenous status. For age standardization, we used the 2011 Canadian population age distribution ("Age standardization," 2016). We used linear regression to assess differences in ASRs over time. To compare diagnostic testing rates across Indigenous and non-Indigenous groups, we estimated standardized rate ratios (SRRs) and 95% CIs by year and sex.

For analyzing prevalence studies, Pearce (2004) recommends using prevalence odds ratios over prevalence ratios. For consistency, to describe the occurrence of positive test results among individuals tested for *H. pylori* infection, we estimated age-adjusted prevalence odds by year, sex, and Indigenous status. Prevalence odds are the proportion of individuals testing positive divided by the proportion of individuals testing negative. To compare prevalence odds across Indigenous and non-Indigenous groups, we estimated age-adjusted prevalence odds ratios (PORs) and 95% CIs by year and sex. We performed data analyses using SAS 9.4 software.

Results

Number of tests and proportion positive

From 2009 through 2016, NT healthcare providers tested an annual average of 686 individuals for *H. pylori* infection (Table 3; see Appendix IV for average age distribution of those tested by Indigenous status). On average over this time period, the annual proportion positive for *H. pylori* infection among individuals tested was 38% (95% CI 34, 42). When observed across sub-groups, the proportion positive differed by Indigenous status and sex. In the Indigenous group, an annual average of 57% (95% CI 50, 64) of diagnostic tests were positive for *H. pylori* infection; this annual average was

55% (95% CI 48, 61) among women and 61% (95% CI 52, 69) among men. In the non-Indigenous group, however, the annual average proportion positive was substantially lower: 15% (95% CI 11, 21) among women, 19% (95% CI 13, 27) among men, and 17% (95% CI 11, 24) in both sexes combined. Across all groups, there were no apparent differences over time in the proportion of positive test results. Further, the proportion positive across age groups for both Indigenous and non-Indigenous people were higher among those older than 24 years of age compared to younger populations (see Appendix IV).

Table 3: Distribution of individuals tested for *H. pylori* infection, individuals with positive test results, and proportion positive (prevalence) by Indigenous status, sex, and year; Northwest Territories; 2009-2016

		Indigenous					non-Indigenous				
	Year	Number Tested*	Number Positive*	Prevalence per 100	95%CI		Number Tested*	Number Positive*	Prevalence per 100	95%CI	
Females	2009	259	143	55	49	61	183	29	16	11	22
	2010	257	142	55	49	61	198	28	14	10	20
	2011	248	139	56	50	62	165	25	15	10	22
	2012	222	118	53	46	60	226	35	16	11	21
	2013	205	113	55	48	62	187	27	14	10	20
	2014	232	123	53	46	60	170	25	15	10	21
	2015	194	115	59	52	66	196	33	17	12	23
	2016	200	100	50	43	57	189	33	18	12	24
Males	2009	156	103	66	58	73	122	27	22	15	31
	2010	123	73	59	50	68	132	22	17	11	24
	2011	139	84	60	52	69	142	30	21	15	29
	2012	142	80	56	48	65	154	32	21	15	28
	2013	118	75	64	54	72	128	17	13	8	20
	2014	145	81	56	47	64	132	23	17	11	25
	2015	135	78	58	49	66	123	23	19	12	27
	2016	135	89	66	57	74	127	25	20	13	28

* Individuals tested more than once or testing positive more than once within a year were counted only once within that year; individuals tested in multiple years were counted once in each year tested.

Diagnostic testing

Annual age-standardized rates of *H. pylori* diagnostic testing during 2009-2016 differed by sex, year, and Indigenous status (Table 4). In the Indigenous population, annual rates among females ranged from 21 (95% CI 18, 24) per 1,000 to 29 (95% CI 25, 33) per 1,000. Among males, annual rates were somewhat lower, ranging from 15 (95% CI 12, 17) per 1,000 to 20 (95% CI 17, 23) per 1,000. A similar pattern was observed in the non-Indigenous population. Time trends in age-standardized diagnostic testing rates also differed by Indigenous status (Table 5): among Indigenous females, the age-standardized testing rate decreased on average each year during 2009-2016 by 1.3 per 1,000 (95% CI -1.8, -0.92). Although less pronounced, a decrease over time was also observed among Indigenous males (average annual change in ASR: -0.40 per 1,000; 95% CI -0.89, 0.08). Among non-Indigenous people, however, diagnostic testing rates remained fairly stable over time (average annual change in ASR for females: -0.31 per 1,000; 95% CI -0.93, 0.31 and for males: -0.01 per 1,000; 95% CI -0.30, 0.28). Among both Indigenous and non-Indigenous NT populations, age-specific diagnostic testing rates during 2009-2016 were higher among those older than 24 years of age compared to younger age groups (see Appendix IV).

Standardized rate ratios comparing diagnostic testing rates across Indigenous and non-Indigenous groups were similar over time and by sex: there were slightly higher testing rates among Indigenous people compared to their non-Indigenous counterparts (Table 6). For women, SRRs during 2009-2016 ranged from 1.0 (95% CI 0.82, 1.2) to 1.5 (95% CI 1.2, 1.8); for men, SRRs ranged from 1.1 (95% CI 0.85, 1.5) to 1.7 (95% CI 1.3, 2.2).

Table 4: Age-standardized rates (ASR) of *H. pylori* diagnostic testing* by Indigenous status, sex, and year; Northwest Territories; 2009-2016

		Indigenous				non-Indigenous			
	Year	Population	ASR per 1,000	95%CI		Population	ASR per 1,000	95%CI	
Females	2009	10,931	30	26	34	9,980	19	16	22
	2010	11,022	29	25	33	10,007	21	18	24
	2011	11,124	27	24	31	10,040	19	15	22
	2012	11,108	24	21	27	10,143	24	20	27
	2013	11,062	22	19	25	10,325	21	18	25
	2014	11,058	24	21	28	10,413	18	15	21
	2015	11,088	21	18	24	10,622	18	15	21
	2016	10,975	21	18	24	10,851	18	15	21
Males	2009	10,975	20	17	23	11,263	12	10	15
	2010	11,054	15	12	18	11,195	13	10	15
	2011	11,135	17	14	20	11,202	14	11	16
	2012	11,148	18	14	21	11,195	15	12	17
	2013	11,118	15	12	17	11,281	13	10	16
	2014	11,132	16	14	19	11,286	13	10	15
	2015	11,169	15	12	18	11,365	12	10	14
	2016	11,038	15	13	18	11,605	13	10	16

*Individuals tested more than once or testing positive more than once within a year were counted only once within that year; individuals tested in multiple years were counted once in each year tested.

Table 5: Average annual change in age-standardized rates (ASR) of *H. pylori* diagnostic testing* by Indigenous status and sex; Northwest Territories; 2009-2016

	Indigenous			non-Indigenous		
	Average annual change in ASR per 1,000	95% CI		Average annual change in ASR per 1,000	95% CI	
Females	-1.3	-1.8	-0.92	-0.31	-0.93	0.31
Males	-0.40	-0.89	0.08	-0.01	-0.30	0.28

*Individuals tested more than once or testing positive more than once within a year were counted only once within that year; individuals tested in multiple years were counted once in each year tested.

Table 6: Standardized rate ratios that compare rates of *H. pylori* diagnostic testing* in Indigenous men/women to rates in non-Indigenous men/women by sex and year; Northwest Territories; 2009-2016

	Year	Standardized Rate Ratio	95%CI	
Females	2009	1.6	1.3	1.9
	2010	1.4	1.1	1.7
	2011	1.5	1.2	1.8
	2012	1.0	0.82	1.2
	2013	1.1	0.84	1.3
	2014	1.4	1.1	1.7
	2015	1.2	0.95	1.4
	2016	1.2	0.95	1.5
Males	2009	1.7	1.3	2.2
	2010	1.2	0.89	1.6
	2011	1.2	0.94	1.6
	2012	1.2	0.92	1.5
	2013	1.1	0.85	1.5
	2014	1.3	0.98	1.7
	2015	1.3	0.97	1.7
	2016	1.2	0.89	1.6

*Individuals tested more than once or testing positive more than once within a year were counted only once within that year; individuals tested in multiple years were counted once in each year tested.

Prevalence odds

The annual age-adjusted odds of testing positive for *H. pylori* infection among those tested were fairly consistent over time during 2009-2016 for both Indigenous and non-Indigenous NT populations (Table 7; see Appendix IV for average age distribution of NT population by Indigenous status). Age-adjusted prevalence odds were marginally lower for females compared to males in both populations. In the Indigenous population, age-adjusted annual odds of testing positive ranged during 2009-2016 from 0.89 (95% CI 0.65, 1.2) to 1.2 (95% CI 0.90, 1.7) among females and from 0.88 (95% CI 0.85, 2.1) to 1.7 (95% CI 1.1, 2.7) among males. Similarly, for the non-Indigenous population, annual age-adjusted odds of testing positive ranged during 2009-2016 from 0.14 (95% CI 0.09, 0.22) to 0.18 (0.11, 0.27) among females and 0.14 (95% CI 0.07, 0.26) to 0.21 (95% CI 0.12, 0.37) among males.

As noted when examining annual age-adjusted prevalence odds, the odds of testing positive for *H. pylori* infection were substantially higher among NT Indigenous groups compared to their non-Indigenous counterparts throughout 2009-2016. PORs displayed in Table 8 reveal the magnitude of this contrast. Among Indigenous females tested, the odds of testing positive ranged between 5.0 (95% CI 3.4, 8.4) and 8.7 (95% CI 5.1, 15) times the odds of testing positive among non-Indigenous females tested. Similar results were observed among males, with PORs ranging from 5.2 (95% CI 3.0, 9.2) to 11.1 (95% CI 5.7, 23).

Table 7: Age-adjusted prevalence odds of testing positive for *H. pylori* infection among those tested (individuals testing positive divided by individuals testing negative)* by Indigenous status, sex, and year; Northwest Territories; 2009-2016

		Indigenous			non-Indigenous		
	Year	Age-adjusted prevalence odds	95%CI		Age-adjusted prevalence odds	95%CI	
Females	2009	1.1	0.75	1.5	0.15	0.09	0.24
	2010	1.2	0.79	1.8	0.15	0.09	0.25
	2011	1.2	0.90	1.7	0.14	0.09	0.23
	2012	0.92	0.65	1.3	0.14	0.09	0.22
	2013	1.2	0.84	1.7	0.16	0.10	0.25
	2014	1.2	0.78	1.7	0.16	0.10	0.27
	2015	1.1	0.77	1.7	0.15	0.09	0.25
	2016	0.89	0.65	1.2	0.18	0.11	0.27
Males	2009	1.6	1.1	2.5	0.21	0.12	0.37
	2010	1.3	0.85	2.1	0.18	0.10	0.32
	2011	0.88	0.51	1.5	0.14	0.07	0.26
	2012	0.95	0.60	1.5	0.18	0.10	0.31
	2013	1.7	1.1	2.7	0.15	0.08	0.27
	2014	0.86	0.51	1.4	0.13	0.07	0.25
	2015	1.4	0.88	2.1	0.21	0.12	0.37
	2016	1.7	1.1	2.6	0.20	0.12	0.33

*Individuals tested more than once or testing positive more than once within a year were counted only once within that year; individuals tested in multiple years were counted once in each year tested.

Table 8: Age-adjusted prevalence odds ratios that compare the odds of testing positive for *H. pylori* infection in Indigenous men/women to the odds of testing positive for *H. pylori* infection in non-Indigenous men/women*; Northwest Territories; 2009-2016

	Year	Prevalence Odds Ratio	95%CI	
Females	2009	7.0	4.3	12
	2010	7.9	4.8	13
	2011	8.7	5.1	15
	2012	6.7	4.2	11
	2013	7.6	4.5	13
	2014	7.0	4.2	12
	2015	7.5	4.6	13
	2016	5.0	3.0	8.4
Males	2009	7.4	4.2	14
	2010	7.4	4.0	14
	2011	6.3	3.6	11
	2012	5.2	3.0	9.2
	2013	11	5.7	23
	2014	6.3	3.5	12
	2015	6.4	3.5	12
	2016	8.3	4.5	16

*Individuals tested more than once or testing positive more than once within a year were counted only once within that year; individuals tested in multiple years were counted once in each year tested.

Discussion

To characterize the distribution of *H. pylori* infection in northern Canadian populations, we described patterns in the occurrence of *H. pylori* diagnostic testing and, among those who were tested, the proportion positive across NT demographic groups. We observed that over half of Indigenous people tested were positive for *H. pylori* infection. In contrast, less than a fifth of non-Indigenous people tested were positive. Males in both groups had somewhat lower diagnostic testing rates with slightly higher proportions testing positive. Furthermore, while the rates of diagnostic testing for *H. pylori* infection were only slightly higher for Indigenous relative to non-Indigenous NT residents, the odds of testing positive were substantially higher among Indigenous residents. This inequity occurred in both sexes consistently over time during 2009-2016.

While the observation of similar diagnostic *H. pylori* testing rates in Indigenous and non-Indigenous groups may reflect similar occurrence of symptomatic stomach illness in these groups, the substantially higher proportion testing positive among Indigenous northerners suggests that Indigenous NT residents are disproportionately burdened by *H. pylori* infection. This pattern is consistent with previous works that have reported elevations in the prevalence of *H. pylori* infection among Indigenous peoples compared to their non-Indigenous counterparts within the same geographic region (Fraser et al., 1996; McDonald et al., 2015; Parkinson et al., 2000; Windsor et al., 2005). Rates of drug dispensations to treat *H. pylori* infection in Alberta, Canada, have also been estimated to be higher among the First Nations and Inuit people compared to non-First Nations or Inuit people (Colquhoun et al., 2015). Observed inequities by Indigenous status may reflect disparities in factors that impact risk of *H. pylori* transmission (Khalifa et al., 2010; Malaty & Graham, 1994; Mendall et al., 1992) or susceptibility to chronic infections (Brown, 2000).

We also noted different time trends by Indigenous status. Among Indigenous NT residents, rates of *H. pylori* diagnostic testing decreased during 2009-2016. Among non-Indigenous NT residents, however, rates were relatively stable over time. It is possible that the observed time trends reflected an NT-specific intervention: the CAN*Help* Working Group research program received substantial northern news media coverage around the year 2008 (Colquhoun, Jardine, & Goodman, 2012). Heightened awareness may have increased *H. pylori* diagnostic testing in 2008-2009, with subsequent decreases reflecting a return to baseline in later years. However, this does not explain why similar patterns were not observed for diagnostic testing among non-Indigenous NT residents. The decreases we observed in Indigenous NT residents are consistent, however, with reports that describe decreasing prevalence among high-prevalence populations in countries like China (Nagy, Johansson, & Molloy-Bland, 2016) and Japan (Kamada et al., 2015), which have been attributed to increasing urbanization and improvements in hygienic conditions among lower resourced areas.

Diagnostic data, such as those used here, primarily capture symptomatic people who seek health care. Because most people infected with *H. pylori* infection do not experience symptoms (Blaser, 1995), they are unlikely to be tested and would not be captured here. Furthermore, to account for differences in testing across study groups, we present prevalence among those tested rather than among the entire NT population. For these reasons, the results we present are likely underestimates of the true population prevalence of *H. pylori* infection in the NT. Because individuals infected with *H. pylori* may be at higher risk of diseases such as peptic ulcers and stomach cancer, even if asymptomatic (Cheung et al., 2014), assessments of *H. pylori* infection burden based on diagnostic testing through healthcare do not describe the comprehensive burden of *H. pylori* infection. This constraint must be considered to develop effective strategies for reducing risks of *H. pylori*-related health outcomes. Despite this limitation, differences in *H. pylori* diagnostic testing occurrence and proportion positive by sociodemographic factors illustrate the disparate burden of infection across demographic groups within the NT.

This study constitutes the first estimation of *H. pylori* diagnostic testing rates and proportion testing positive among northern Canadian populations. Consistent with the literature on *H. pylori* prevalence among northern and Indigenous populations, we found that NT Indigenous populations were disproportionately impacted by *H. pylori* infection compared to their non-Indigenous counterparts. This report illustrates the burden of symptomatic *H. pylori* infection in northern Canadian populations. As a result, this work supports the on-going community-driven CAN*Help* Working Group research program. It will also inform strategies for the control of *H. pylori* infection so that meaningful and effective interventions aimed at reducing related health risks can be identified and implemented.

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7.2 Global patterns of cardia and non-cardia gastric cancer incidence in 2012

Abstract

Objective: Globally, gastric cancer incidence shows remarkable international variation and demonstrates distinct characteristics by the two major topographical subsites, cardia (CGC) and non-cardia (NCGC). Because global incidence estimates by subsite are lacking, we aimed to describe the worldwide incidence patterns of CGC and NCGC separately.

Design: Using Cancer Incidence in Five Continents Vol. X (CI5X), we ascertained the proportions of CGC and NCGC by country, sex, and age-group (below/above 65 years). These derived proportions were applied to GLOBOCAN data to estimate country-specific age-standardized CGC and NCGC incidence rates (ASR) in 2012. Regional proportions were used to estimate rates for countries not included in CI5X.

Results: According to our estimates, in 2012 there were 260,000 cases of CGC (ASR: 3.3 per 100,000) and 691,000 cases of NCGC (ASR: 8.8) worldwide. The highest regional rates of both gastric cancer subsites were in Eastern/Southeastern Asia (in males, ASRs: 8.7 and 21.7 for CGC and NCGC, respectively). In most countries NCGC occurred more frequently than CGC with an average ratio of 2:1; however, in some populations where NCGC incidence rates were lower than the global average, CGC rates were similar or higher than NCGC rates. Males had higher rates than females for both subsites but particularly for CGC (male-to-female ratio: 3:1).

Conclusion: This study has, for the first time, quantified global incidence patterns of cardia and non-cardia gastric cancer providing new insights into the global burden of these cancers. Country-specific estimates are provided; however, these should be interpreted with caution. This work will support future investigations across populations.

Introduction

Gastric cancer is a major contributor to the global cancer burden. In 2012, there were an estimated 952,000 new cases worldwide, making gastric cancer the fifth most common malignancy after lung, breast, colorectal, and prostate cancer (Ferlay et al., 2013). There is considerable variation in gastric cancer incidence by sex and geography.

On average, gastric cancer incidence rates in males are twice those observed in females. Geographically, almost two thirds of all gastric cancer cases occur in Asia, primarily concentrated in China (43% of total global cases) (Ferlay et al., 2013). While incidence rates remain high in countries within Eastern/Southeastern and Central Asia, Eastern Europe, and parts of Central and Southern America, gastric cancer incidence rates are comparatively low in many developed regions such as North America and Western Europe.

Although often reported as a single entity, gastric cancers can generally be classified into two topographical categories: cardia gastric cancer (CGC) arising in the area of the stomach adjoining the oesophageal-gastric junction, and non-cardia gastric cancer (NCGC) arising from more distal regions of the stomach. While both CGC and NCGC are thought to be influenced by cigarette smoking (Cook et al., 2010; Freedman et al., 2007; Ladeiras-Lopes et al., 2008) and possibly by low intake of fruits and vegetables (Freedman et al., 2008; Larsson, Bergkvist, & Wolk, 2006; Lunet et al., 2007), there are other risk factors that differ between the two subsites. Risk factors for CGC are similar to those for oesophageal adenocarcinoma and include obesity (Hoyo et al., 2012; Yang et al., 2009) and gastroesophageal reflux disease (GERD) (Ye, Chow, Lagergren, Yin, & Nyrén, 2001; Whiteman et al., 2008). Barrett's esophagus, a metaplastic condition that can result from GERD, is also thought to be a risk factor for CGC, though not in all populations (Limburg et al., 2001). NCGC, however, is strongly associated with *Helicobacter pylori* infection (EUROGAST Study Group, 1993; Plummer, Franceschi, Vignat, Forman, & de Martel, 2014). Some evidence suggests that *H. pylori* infection may be inversely associated with both oesophageal adenocarcinoma and CGC (*Helicobacter* and Cancer Collaborative Group, 2001; Kamangar et al., 2006), though studies in some populations have suggested a positive association between the bacterium and CGC (Cho et al., 2010; Limburg et al., 2001; Wang et al., 2014). The influence of socioeconomic status (SES) also differs. While indicators of low SES such as household crowding, low income, low education, and increased number of siblings are positively associated with NCGC, they do not appear to be associated with CGC (Brewster, Fraser, McKinney, & Black, 2000; de Martel, Forman, & Plummer, 2013). Given these differences, there is increasing interest in describing the worldwide burden of CGC and NCGC subsites separately.

CGC and NCGC incidence rates have been reported separately for some countries, with CGC rates typically lower than NCGC rates (Derakhshan et al., 2004; Devesa, Blot, & Fraumeni, 1998; Holster, Aarts, Tjwa, Lemmens, & Kuipers, 2014). However, there are currently no global estimates available by gastric cancer subsite and estimates are lacking for most countries. We aim here to describe the global incidence patterns of gastric cancer for each of the two major topographical subsites. Based on data from Cancer Incidence in Five Continents Volume X (Forman et al., 2013) and GLOBOCAN 2012 (Ferlay et al., 2013), using methods similar to those employed to estimate global oesophageal cancer incidence by histological subsite (Arnold, Söerjomataram, Ferlay, & Forman, 2015), we report age-standardized incidence rate estimates for CGC and NCGC in 2012 by country, region, and human development index (HDI) ("Human Development Index (HDI)," n.d.).

Methods

We used Cancer Incidence in Five Continents Vol. X (CI5X), containing cancer incidence data from 290 cancer registries in 68 countries for the period 2003 to 2007 (Forman et al., 2013). The CI5X results are presented according to the *International Classification of Diseases, 10th Revision* (ICD-10).

We first calculated the proportions of CGC (C16.0) cases and NCGC (C16.1-6) cases out of all gastric cancer cases with known topography (C16.0-6) for each country with data included in CI5X (n=53) and stratified these calculations by sex and age group (<65 and ≥65 years of age). Where data were available from multiple cancer registries within one country, these were aggregated without weighting to obtain national estimates of the subsite proportions. If a dataset for a country contained fewer than two cases of CGC or NCGC within any sex and age group stratification (n=15 countries), a second method was employed (see below).

In the second step we estimated the proportion of CGC and NCGC for countries with insufficient subgroup data (small numbers), or those without CI5X data (n=128 countries in total). For these, regional proportions based on non-weighted, aggregated country-level data were calculated to estimate country-specific subsite proportions. To estimate regional proportions, all CI5X data were included: this included all countries with low number of cases within subgroup stratifications based on sex and age group. Regional subsite proportions were calculated based on UN geographical areas (United Nations Statistics Division, 2013) as was done by Arnold et al. (2015): Sub-Saharan Africa, Northern Africa and Western Asia, Central Asia (including India), Eastern/Southeastern Asia (including China), Central/Southern America and the Caribbean, Northern America, Eastern Europe, Northern and Western Europe, Southern Europe, and Oceania (see Appendix V, Supplement 1 for a listing of countries and corresponding regions).

For the available datasets in the Sub-Saharan Africa region (3 registries: PROMEC in South Africa, Harare in Zimbabwe and Kyadondo County in Uganda), approximately 94% of CI5X gastric cancer cases were classified as 'unspecified' (C16.8-9, herein referred to as not otherwise specified 'NOS') and there were fewer than five cases of CGC or NCGC for any sex and age group stratification. Without stratification, the proportion of CGC and NCGC was approximately 50:50; however, this was based on fewer than 15 cases each. In view of the high burden of cancer attributable to infection in Sub-Saharan Africa (Adebamowo & Akarolo-Anthony, 2009; de Martel et al., 2012; Parkin, 2006), the regional CGC/NCGC proportions for Sub-Saharan Africa were calculated by redistributing all cases classified as NOS to NCGC cases. These regional proportions were then applied to all countries in this region (47 countries).

The sex- and age-specific national or regional gastric cancer subsite proportions estimated using the above methods were then applied to the 2012 gastric cancer incidence estimates for each corresponding country (184 countries) in GLOBOCAN 2012 (Ferlay et al., 2013). Estimated age-standardized rates (ASRs per 100,000 person-years) for CGC and NCGC in both men and women were calculated using the World Standard Population as defined by Segi (1960) (Segi, 1960). In addition to national and global estimates of gastric cancer by subsite, we also estimated subsite-specific rates by world region and by human development index category (low, medium, high, or very high) ("Human Development Index (HDI)," n.d.).

In the CI5X data used in this analysis, the proportion of gastric cancer cases categorized as NOS (C16.8-9) ranged from 28% to 98% across countries. As a result, sensitivity analyses were performed to evaluate a variety of potential methods to identify the country- and sex-specific proportions of CGC and NCGC. For a selection of CI5X countries, the proportions of CGC and NCGC were calculated by redistributing NOS cases under six different scenarios. We also evaluated the influence of these different scenarios on the regional proportions of CGC and NCGC. Our preferred method, applied here, falls in the middle of the sensitivity analysis results (see Appendix V, Supplement 2 for more information about the methods used and results obtained).

Results

In 2012, according to our estimates, there were 952,000 cases of gastric cancer globally. Two thirds of these cases were in men (631,000) and one third in women (320,000), corresponding to global gastric cancer age-standardized incidence rates of 17.4 and 7.5 per 100,000 respectively.

Cardia gastric cancer (CGC)

According to our estimates, there were 260,000 CGC cases in 2012 worldwide, comprising 27% of total gastric cancer cases (192,000 cases, 30% of the global total in males and 69,000 cases, 21% of the global total in females). Geographically, the majority of these cases occurred in Eastern/Southeastern Asia (152,000 cases, 59%), followed by Central Asia (39,000, 15%), and Central/Southern America and the Caribbean (16,000, 6%). More than half of the total cases occurred in China (135,000, 52%) (Figure 16).

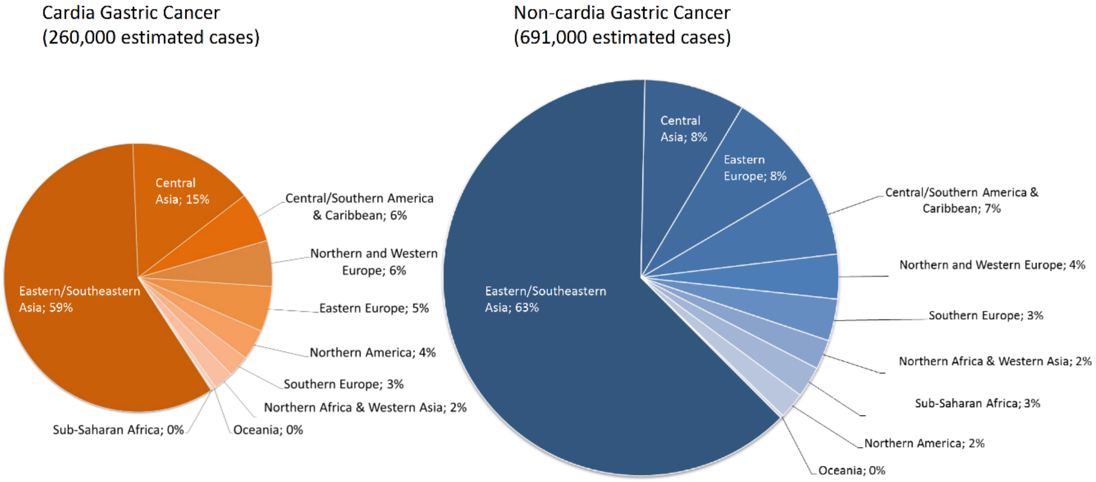


Figure 16: Global incidence estimates of cardia and non-cardia gastric cancer by region, 2012.

In 2012, the estimated global CGC age-standardized incidence rate was 3.3 per 100,000. Rates in men were on average three times the rates in women (ASRs: 5.3 per 100,000 and 1.6 per 100,000, respectively); the male-to-female ratio ranged from 1.5 in Sub-Saharan Africa to 3.9 in Northern America (Figure 17). The highest regional rates of CGC occurred in Eastern/Southeastern Asia and Eastern Europe; the lowest regional rates occurred in Sub-Saharan Africa, followed by Northern Africa and Western Asia, and Northern America for males and females, respectively (Figure 17). A slight gradient across HDI categories was observed when China was excluded for both males and females, with the highest rates found in high HDI countries (ASRs: 4.6 per 100,000 and 1.6 per 100,000, respectively; Figure 18).

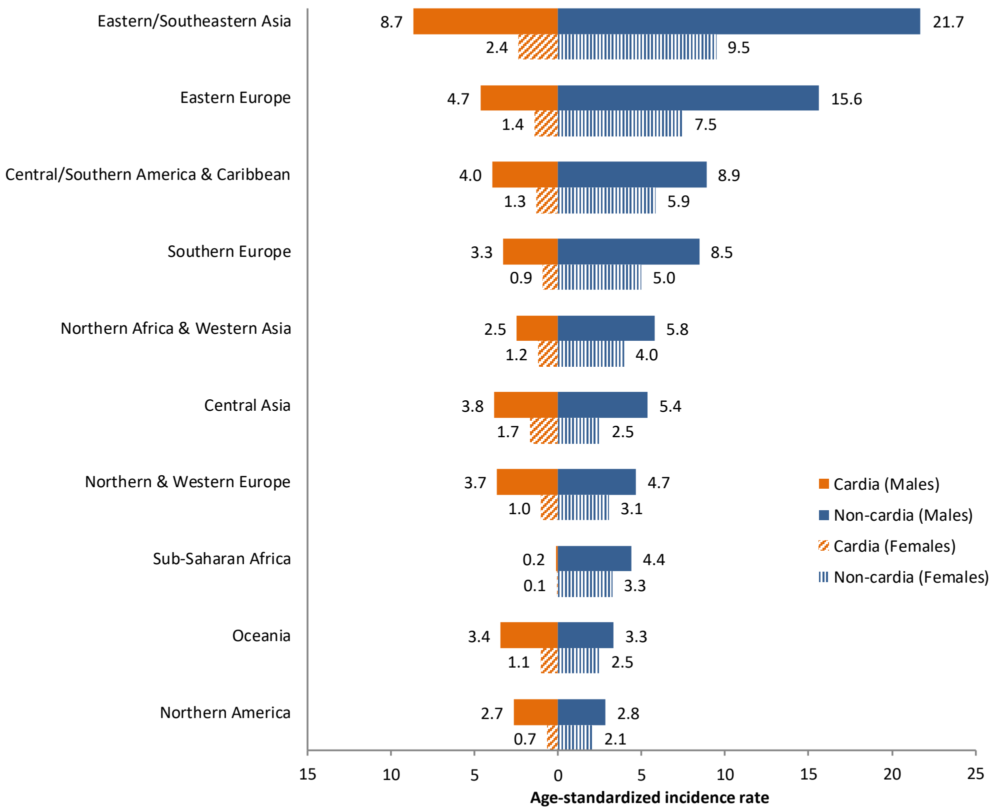


Figure 17: Estimated cardia and non-cardia gastric cancer age-standardized incidence rates (per 100 000) by region and sex, 2012.

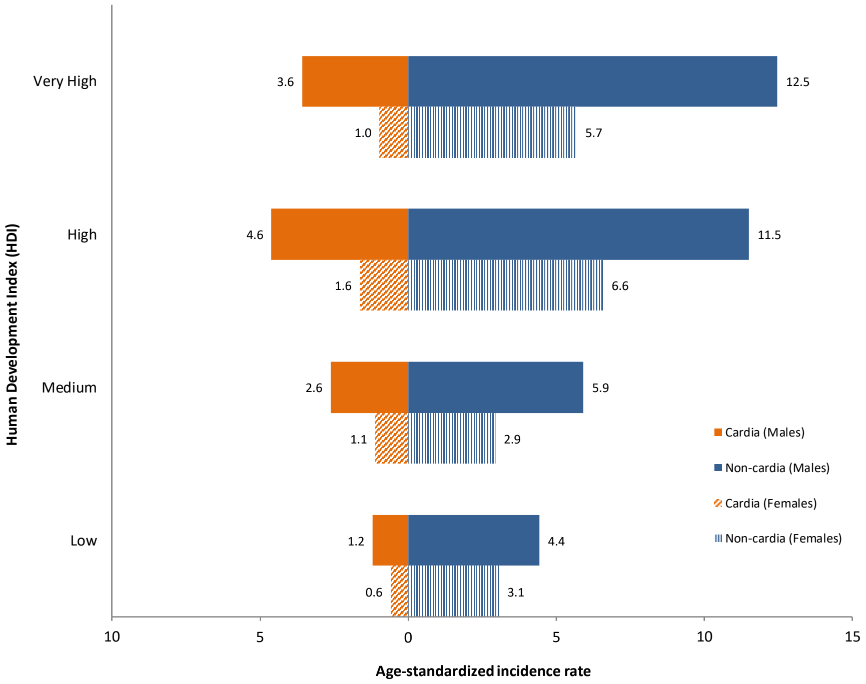


Figure 18: Estimated cardia and non-cardia gastric cancer age-standardized incidence rates (per 100 000) by Human Development Index (HDI) and sex, 2012.

At the country level, the highest estimated rates of CGC occurred in Central Asian countries: in males, age-standardized rates were 14.7 per 100,000 in Kyrgyzstan and 14.6 per 100,000 in Kazakhstan. High rates in males also occurred in Iran and Tajikistan: ASRs of 13.4 and 12.6 per 100,000, respectively. Similarly, in females, countries with the highest rates included Tajikistan (ASR: 6.1 per 100,000), Turkmenistan (ASR: 5.5 per 100,000), Iran (ASR: 5.4 per 100,000), and Kazakhstan (ASR: 5.2 per 100,000). Amongst non-Sub-Saharan African countries with more than 10 cases of CGC in both sexes, the lowest rates were observed in Eastern/Southeastern Asian countries such as Indonesia and Cambodia. (Figures 19a and 19b; see Appendix V, Supplement 1 for a full list of country-specific rates).

Non-cardia gastric cancer (NCGC)

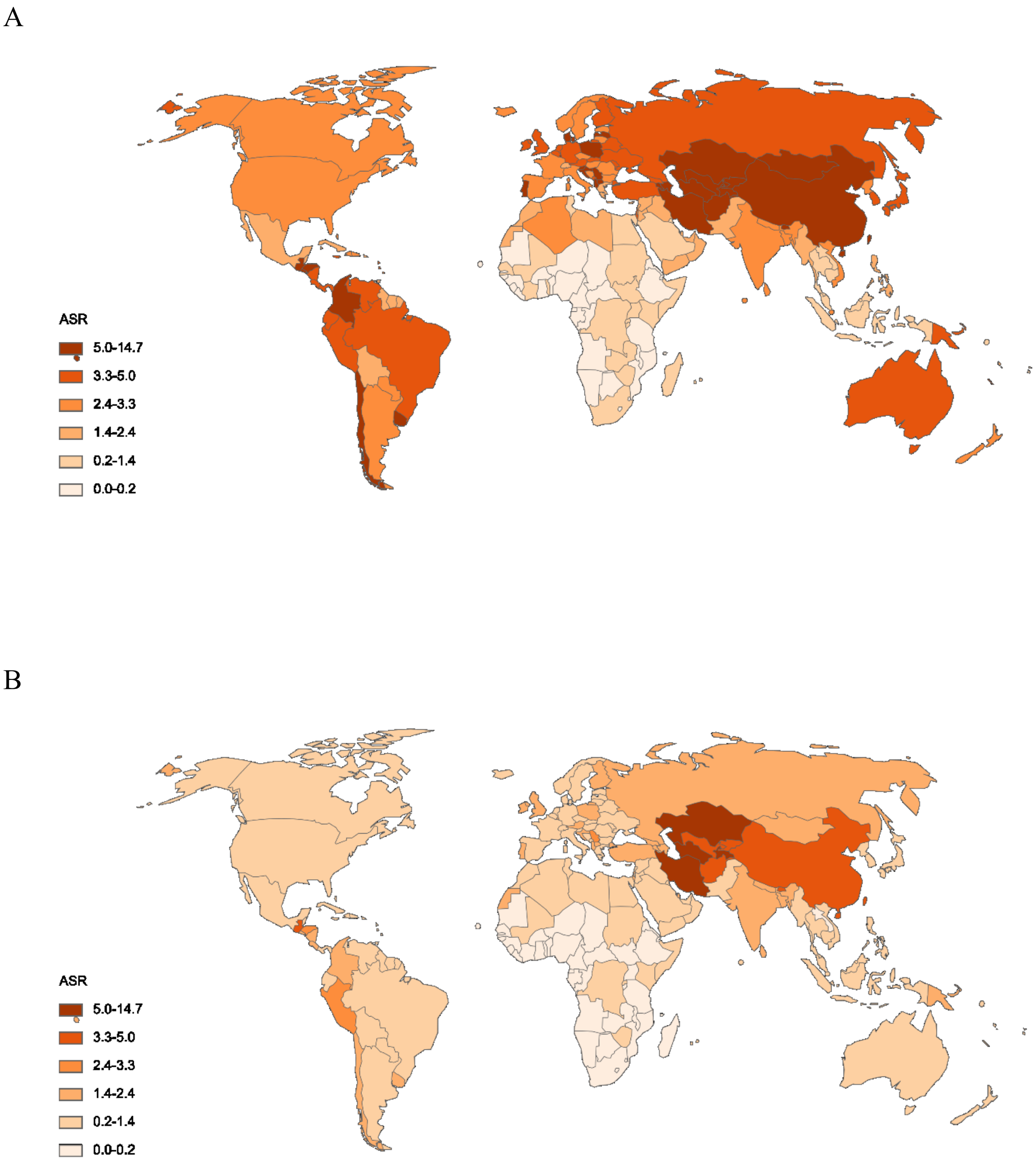
According to our estimates, there were 691,000 NCGC cases in 2012, comprising 73% of total gastric cancer cases worldwide (70% of the global total in males, 440,000 cases; and 79% of the global total in females, 252,000 cases). Almost two thirds of all cases occurred in Eastern/Southeastern Asia (434,000, 63%): more than half of these were in China (270,000, 39% of the global total). Central Asia (57,000 cases) and Eastern Europe (55,000) followed with approximately 8% of global cases each (Figure 19).

Globally, the estimated age-standardized incidence rate of NCGC was 8.8 per 100,000. Rates in men were double those in women (ASRs 12.1 per 100,000 and 5.9 per 100,000, respectively); the male-to-female ratio ranged from 1.3 in Oceania to 2.3 in Eastern/Southeastern Asia (Figure 17). As with CGC, incidence was highest in Eastern/Southeastern Asia with age-standardized rates of 21.7 per 100,000 and 8.7 per 100,000 for men and women, respectively. The lowest regional rates of NCGC occurred in Northern America and Oceania. A gradient across HDI categories was observed when China was excluded, with the highest rates of NCGC in very high HDI countries for males (ASR: 12.5 per 100,000) (Figure 18). Although not as distinct a gradient, countries in higher HDI categories also had higher rates in females.

Differences also existed across countries. The highest NCGC rates in men occurred in countries located within Eastern/Southeastern Asia, including the Republic of Korea (ASR: 58.6 per 100,000), Mongolia (ASR: 42.1 per 100,000), and Japan (ASR: 41.0 per 100,000). Similarly, in women the highest rates occurred in the Republic of Korea (ASR: 23.6 per 100,000) and Mongolia (ASR: 18.5 per 100,000); however, a high rate of NCGC among women also occurred in Guatemala (ASR: 19.5 per 100,000). Amongst countries with more than 10 cases of NCGC in both sexes in 2012, the lowest rates were observed primarily in African countries. (Figures 19c and 19d; see Appendix V, Supplement 1 for a full list of country-specific rates).

Country-specific relative incidence rates of cardia and non-cardia gastric cancer

In most countries, CGC incidence rates were lower than NCGC rates (91% or 167 out of 184 GLOBOCAN countries, Appendix V, Table S7.2.1). There were several countries, however, where CGC rates were similar to or higher than NCGC rates. For males, these included countries located in Oceania (n=6) and countries within the regions of Northern/Western Europe (n=4) such as Denmark and Belgium, and Southern Europe (n=2) such as Malta. This was also true in Poland and Uruguay. Additionally, there were three countries where CGC rates were higher than NCGC rates for both males and females: Iran, Finland, and Serbia.



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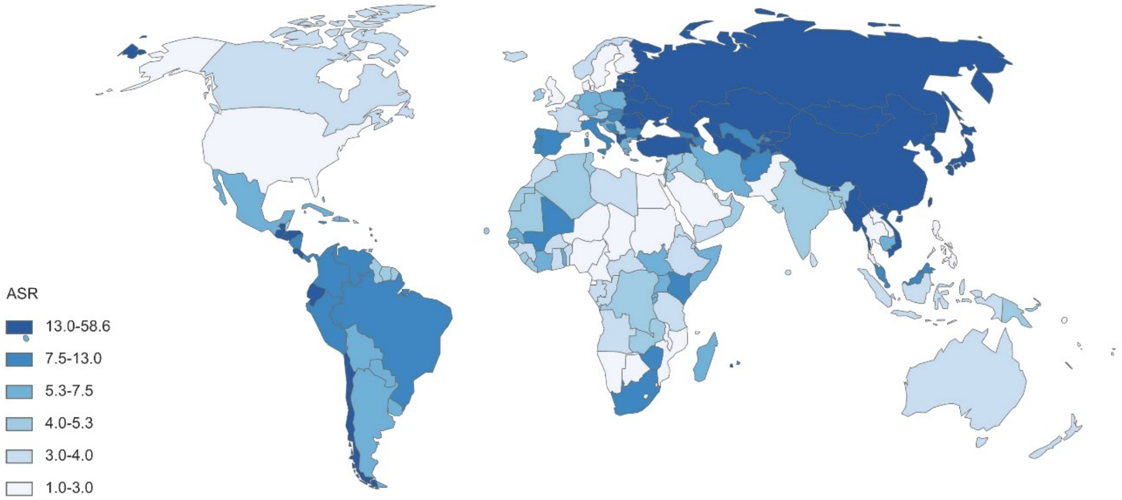

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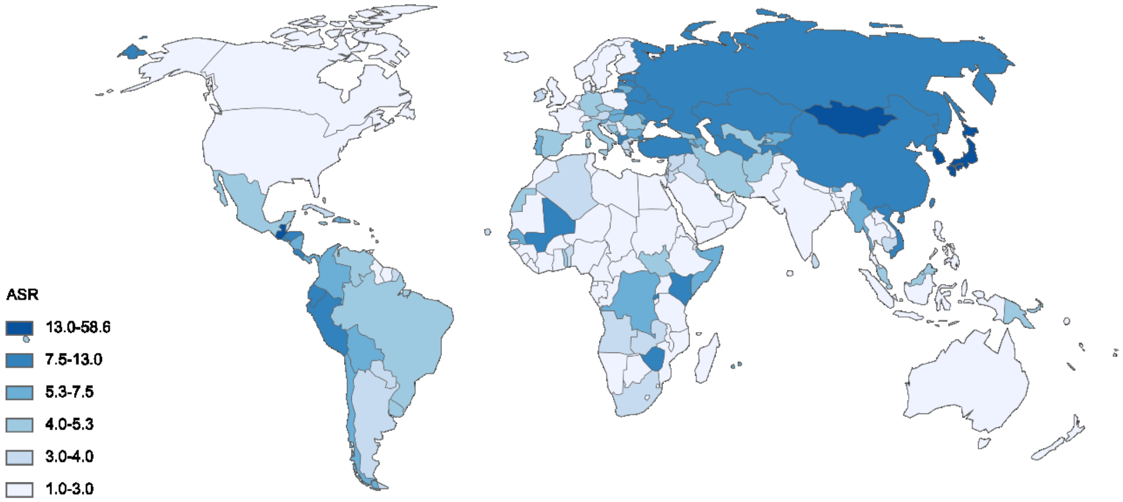

Figure 19: (A) Estimated cardia gastric cancer age-standardized incidence rates (ASRs per 100 000) by country, men, 2012. (B) Estimated cardia gastric cancer ASRs (per 100 000) by country, women, 2012. (C) Estimated non-cardia gastric cancer ASRs (per 100 000) by country, men, 2012. (D) Estimated non-cardia gastric cancer ASRs (per 100 000) by country, women, 2012.

Discussion

In this study, we estimated global, regional- and country-specific incidence rates of gastric cancer by subsite for the first time. Estimated rates varied across regions and countries. The highest estimated regional rates of both CGC and NCGC occurred in Eastern/Southeastern Asia: in both males and females, incidence rates were 47-79% higher than the global average. For country-specific estimates, the highest estimated rates of CGC occurred in countries within Central Asia, such as Iran; estimated NCGC rates were highest in countries within Eastern/Southeastern Asia, such as the Republic of Korea. Although CGC rates were typically lower than NCGC rates, for several populations, CGC rates were similar to or higher than NCGC rates: for example, for males in Australia, the United States, and the United Kingdom, CGC rates were comparable to NCGC rates. Incidence rates also varied by sex; in particular, for CGC, rates in males were three times the rates in females.

Geographic patterns of CGC reported here confirm previous descriptions of elevated rates in some populations. At the country level, the highest CGC rates occurred in countries within Central Asia. In areas within Iran, CGC has been reported to comprise between 40 and 50% of gastric cancer cases (Babaei et al., 2010; Derakhshan et al., 2004; Islami et al., 2004), with incidence rates approximately five times our estimate of the global average (Derakhshan et al., 2004). Similarly, for males and females in Iran, our estimates of CGC incidence rates were 2.5 times and 3.4 times the global average, respectively. High incidence rates also occurred in other countries within this area. For males, CGC rates were highest in Kyrgyzstan and Kazakhstan, both with rates approximately 2.8 times the global average; in females, the highest rates were in Tajikistan (3.8 times the global average). The reason for a higher incidence of CGCs in countries within this geographic area in Central Asia is unknown; however, it has been noted that high risk populations may have a high prevalence of certain risk factors for CGC such as obesity and GERD (Babaei et al., 2010; Malekzadeh, Derakhshan, & Malekzadeh, 2009). Further, given a high prevalence of *H. pylori* infection in countries within Central Asia (Benberin et al., 2013; Malekzadeh et al., 2004), and the disparate influence of risk factors for CGC across some populations (Cho et al., 2010; Limburg et al., 2001; Wang et al., 2014), it is also possible that *H. pylori* infection may contribute to an increased risk of CGC in these populations.

In the case of NCGC estimates, the highest rates occurred in the Republic of Korea, Mongolia, and Japan. Given that approximately 90% of gastric cancer cases in these populations are NCGC, these results confirm high rates of overall gastric cancer previously reported (de Martel et al., 2013; Sandagdorj et al., 2010). In these countries, for men, estimated NCGC rates ranged from 3.4-4.8 times the global average; in women, this range was 2.6-4.0. Environmental factors may play a role: elevated incidence rates may result from a high prevalence of *H. pylori* infection and, in particular, the presence of highly virulent strains of the bacterium in Eastern/Southeastern Asian populations (Yamaoka, Kato, & Asaka, 2008). A high prevalence of risk factors such as the consumption of foods high in salt may also contribute to increased risk of NCGC in Asian populations such as Japan (Joossens et al., 1996; Machida-Montani et al., 2004; Shikata et al., 2006). Furthermore, a high incidence of NCGC in countries like the Republic of Korea and Japan may be partly due to diagnostic practices that detect small lesions not typically identified as cancerous elsewhere (Schlemper et al., 1997).

Differences in the relative frequency of CGC and NCGC have also been observed across populations: a recent report noted that CGC is more common in countries with lower overall gastric cancer incidence (Ferro et al., 2014). Here, in some geographic areas where NCGC incidence rates were lower than the global average (for males, on average four times lower), we found a greater proportion of CGC cases relative to NCGC cases. This was particularly true for males in Iran where the CGC rate was double the NCGC rate, unlike what is observed at a global level, where CGC rates were two times lower than NCGC rates. Similar or higher rates of CGC relative to NCGC in some countries may reflect a decreased prevalence of risk factors for NCGC such as *H. pylori* infection and smoking, and increased prevalence of risk factors that contribute to the development of CGC such as obesity (Brown & Devesa, 2002; Yeh et al., 2013). This may also indicate improvements in gastric cancer subsite recording in some populations: in the United States, for example, the topographical classification of gastric cancer cases to an unspecified location decreased between 1974 and 1998 while those categorized as cardia increased (Corley & Kubo, 2004). Similarly, these results may reflect an overestimation of reported CGC cases as some of these cases may be misclassified adenocarcinomas of the oesophagus (Lindblad, Ye, Lindgren, & Lagergren, 2006; McColl & Going, 2010).

Differential trends in the incidence of NCGC and CGC have also been reported. In the United States and some European countries such as the Netherlands, NCGC incidence rates have decreased annually since the mid-1970s while CGC rates have remained stable or increased (Devesa et al., 1998; Holster et al., 2014; Steevens, Botterweck, Dirx, van den Brandt, & Schouten, 2010). Although the estimation of temporal trends was beyond the scope of the current work, future studies that estimate time trends in global incidence rates by gastric cancer subsite would be greatly beneficial.

Differences in the incidence rates of gastric cancer subsites by sex were also observed: CGC in males was approximately three times the rate in females whereas for NCGC, rates in males were twice as high (Forman & Burley, 2006). The reasons for higher rates of the two subsites of gastric cancer in males are poorly understood. Variations by sex may reflect disparate acquisition of risk factors such as *H. pylori* infection and Barrett's oesophagus (Cook, Wild, & Forman, 2005; Martel & Parsonnet, 2006). Higher rates in men may also result from differences in cigarette smoking behaviour, though work by Freedman et al. (2010) suggests that smoking might not be an explanatory factor. Furthermore, variations by sex may also reflect the protective effect of estrogen in women (Camargo et al., 2012) or a lag in age of intestinal gastric cancer onset in women compared to men (Derakhshan et al., 2009). The potential contribution of these factors, however, to an increased risk in men and to the differential rates by subsite is unclear.

Along with variations by geography and sex, CGC and NCGC incidence rates varied by human development index. Although 58% of all gastric cancer cases occurred in countries with a low or medium HDI, countries with some of the highest rates such as the Republic of Korea and Japan are within the very high HDI category. This in turn elevates rates in this HDI group for both CGC and NCGC. The resulting apparent association between higher HDI and NCGC is likely to reflect an ecological bias: previous studies have indicated an association between low SES and NCGC at the individual level (*Helicobacter* and Cancer Collaborative Group, 2001; Kamangar et al., 2006). Similarly, high-risk groups within low-risk countries may not be represented and the region- and country-level estimates may mask this within-country variation. Risk factors for NCGC such as low SES and *H. pylori* infection status may vary across populations within countries (Dore et al., 2002; Cheung et al., 2014). Likewise, there are variations in both CGC and NCGC rates across ethnic groups: ethnic minorities such as Black or Asian Americans have higher rates of NCGC and lower rates of CGC compared to US Whites (Wu, Rusiecki, Zhu, Potter, & Devesa, 2009; X. Wu et al., 2006), a pattern also observed in Indigenous populations worldwide compared to non-Indigenous counterparts (Arnold et al., 2014).

The estimation of CGC and NCGC incidence was limited by the extent to which topographical information identifying the exact anatomical location of gastric cancer cases was reported by each registry. In the CI5X data used in the current analysis, an average of 41% of gastric cancer cases were categorized as NOS (C16.8-9); however, this ranged from 28% to 98% across countries. Difficulties distinguishing between CGC and NCGC may result from the necessity to rely on surgical judgement for these classifications and, in some cases, it is difficult to determine whether a tumour originated in the stomach or the oesophagus (Lindblad et al., 2006; McColl & Going, 2010). Although some of these challenges are likely to persist, it would be valuable to further understand the barriers and potential solutions to identifying or reporting the topography of gastric cancer cases in order to reduce underreporting and misclassification by gastric subsite.

There were additional data limitations that should be considered as sources of uncertainty regarding the accuracy of country-specific estimates. Firstly, GLOBOCAN numbers of incident gastric cancer cases used to calculate rates are based on estimates (Ferlay et al., 2013). Furthermore, population-based cancer registry data were utilised within the analysis. Although of high quality, data aggregated from multiple cancer registries within one country as a proxy of national data may inadequately represent country-level rates. The use of these data also limited the number of countries that could be included directly in the derivation of proportions. Wherever country-specific proportion estimations were not possible, the information used to calculate country rates was based on regional information; as such, heterogeneity across those countries may not be represented. In particular, proportions for countries in Sub-Saharan Africa were calculated based on regional information only. Moreover, given the generally low burden of gastric cancer reported from registries in this region, all NOS cases were reclassified as NCGC which may overestimate the NCGC rates in Sub-Saharan Africa.

While we believe the estimates presented in this paper are sufficiently reliable to provide an indication of the burden of gastric cancer subsites at the global and regional level, because of the data deficiencies, limitations and assumptions made for individual countries, we think it is prudent to regard the country-level CGC and NCGC incidence rate estimates presented in Annex I as rough approximations, especially for those countries for which the proportion of cardia/non-cardia cancer was based on regional estimates.

Conclusion

This is the first comprehensive attempt to estimate global incidence patterns of gastric cancer subsites. While the highest estimated regional rates for both subsites occurred in Eastern/Southeastern Asia, country-specific estimates identified high rates of CGC in countries such as Iran located within Central Asia, and high rates of NCGC in countries within Eastern/Southeastern Asia such as the Republic of Korea. Further, while CGC rates were typically lower than NCGC, for several countries such as Australia, the United States, and the United Kingdom rates of CGC were comparable or higher. The CGC and NCGC incidence estimates reported here provide new insights into the global burden of gastric cancer and support future ecological investigations across populations. This work will also aid planning and decision-making related to gastric cancer control strategies.

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7.3 Gastric cancer in northern Canadian populations: a focus on cardia and non-cardia subsites

Abstract

Background: Gastric cancer is a key contributor to the global burden of disease. It may be grouped into two major topographical subsites that have distinct characteristics: cardia (CGC) and non-cardia (NCGC). In northern Canada where there is an increased risk of *Helicobacter pylori* infection and associated diseases, there is a paucity of information on gastric cancer by subsite. Here we aim to describe the incidence of CGC and NCGC, separately, among northern Canadian populations.

Methods: We used data from Cancer Incidence in Five Continents Volumes X (CI5X) and XI (CI5XI) to obtain CGC and NCGC incidence for Canada and for Yukon (YT), a northern Canadian territory. Using these data, along with those provided by the Government of the Northwest Territories (NT), we estimated standardized incidence ratios comparing rates among northern populations to rates in Canada. We also estimated age-standardized incidence rates to permit comparisons across populations globally.

Results: NT and YT populations were disproportionately impacted by gastric cancer, particularly cancers of the non-cardia gastric region. This was especially true for Indigenous populations in the NT where 16% of cases, compared to 2% in Canada, were observed in those under the age of 40. Further, NCGC incidence rates among NT Indigenous men were 2.7 times higher than rates among all men in Canada (3.1 times higher among Indigenous women). Similarly, age-standardized rates of NCGC among Indigenous NT residents were comparable to global regions where there is a high burden of NCGC.

Discussion: This study has, for the first time, quantified the incidence of CGC and NCGC for the NT and YT, providing new insights into the burden of these cancers among northern Canadian populations.

Introduction

Gastric cancer is a major contributor to the global burden of cancer: in 2012, there were an estimated 952,000 new cases and 725,000 deaths due to gastric cancer, making it the 5th most commonly diagnosed and 3rd most fatal cancer worldwide (Ferlay et al., 2013). Gastric cancer incidence varies by sex, with rates among men on average twice those observed among women. Variation also exists across geographic regions: gastric cancer incidence rates are high in countries within Asia, Eastern Europe, and parts of Central and South America, while rates are comparatively low in many higher-resourced regions such as North America and Western Europe (Ferlay et al., 2013).

Although often reported as a single entity, gastric cancers can be subdivided into two topographical categories: cardia gastric cancer (CGC) arising in the proximal area of the stomach, and non-cardia gastric cancers (NCGC) arising in more distal regions. As with all gastric cancers combined, there is considerable geographic variation in incidence across these subsites (Colquhoun et al., 2015). This may result, in part, from differences in risk factors by subsite that vary by geography. NCGC risk is increased by *Helicobacter pylori* infection (EUROGAST Study Group, 1993; Crew & Neugut, 2006; Plummer, Franceschi, Vignat, Forman, & de Martel, 2015) and this subsite is more common in less-resourced countries (de Martel et al., 2012; Parkin, 2004); in contrast, CGC is positively associated with obesity and gastroesophageal reflux but not with *H. pylori* infection, evidence that suggests a distinct etiology from *H. pylori*-associated NCGC. Due at least in part to its association with *H. pylori* infection, NCGC is also associated with indicators of low socioeconomic status such as household crowding, low income, low education levels and increased number of siblings (Barker, Coggon, Osmond, & Wickham, 1990).

Lower and steadily declining incidence of NCGC among higher-resourced countries may be attributable to improved sanitation and other factors that reduced the prevalence of *H. pylori* infection, as well as other technological advances of the early 20th century that reduced the occurrence of diseases of the pre-modern era (Howson, Hiyama, & Wynder, 1986; Paik, Saborio, Oropeza, & Freeman, 2001; Ushijima & Sasako, 2004); however, some populations within more developed areas are still at high risk. Studies have documented, for example, a higher burden of gastric cancer in Indigenous populations worldwide compared to their non-Indigenous counterparts (Arnold et al., 2014; Moore et al., 2015). Similarly, others have shown elevated incidence rates across the circumpolar region, particularly among Indigenous populations (Government of the Northwest Territories, 2003; Young, Kelly, Friborg, Soininen, & Wong, 2016). Given the disproportionate impact of *H. pylori* on NCGC incidence relative to CGC incidence, the distribution of gastric cancer by subsite varies by *H. pylori* prevalence within higher-resourced countries. Ethnic minorities in the US, such as African-Americans or Asian-Americans, have higher rates of NCGC and lower rates of CGC compared to non-Hispanic white Americans (Wu, Rusiecki, Zhu, Potter, & Devesa, 2009; Wu et al., 2006). This differing pattern in NCGC and CGC incidence rates has also been observed among Indigenous populations compared to their country-specific non-Indigenous counterparts (Arnold et al., 2014). There remains a paucity of information, however, on differences in gastric cancer subsite incidence among high-risk populations.

In northern Canada, where Indigenous groups comprise a high proportion of the population, communities have expressed concern over their perceived high frequency of stomach cancer (Cheung et al., 2014). To address these concerns, a community-driven research program brings together academic researchers, healthcare providers, health officials, and members of communities in the Northwest Territories (NT) and Yukon (YT), Canada to conduct community *H. pylori* projects. These projects have estimated a high prevalence of *H. pylori* infection in participating communities (Cheung et al., 2014; Hastings, Yasui, Hanington, Goodman, & CAN*Help* Working Group, 2014). Furthermore, participants assessed pathologically through biopsies of the stomach lining had a high prevalence of precancerous lesions of the stomach (Cheung et al., 2014). To characterize the burden of stomach cancer in the northern regions where these communities reside, we aimed to describe the incidence of gastric cancer overall by subsite and compare these estimates to those observed elsewhere.

Methods

Comparison populations

The northern populations available for comparison in this analysis are the NT population dichotomized as Indigenous or non-Indigenous, and the YT population without classification by Indigenous status. As a reference population, we use the total population of Canada, including the NT and YT populations, without classification by Indigenous status. In 2016, Indigenous groups comprised approximately 51% of the NT population of 41,135, 23% of the YT population of 35,110, and 4.9% of the total Canadian population of 34,460,065 (Statistics Canada, 2017). Sex-specific frequencies were available for all comparison populations. Classification by Indigenous status was available for the NT population, but not for the YT or total Canadian populations. NT residents were dichotomized as Indigenous, including individuals who identify as Inuit, First Nations, or Métis, or non-Indigenous, including everyone else.

Data sources

We used data from the Cancer Incidence in Five Continents (CI5), volumes X (CI5X) and XI (CI5XI) published online by the International Agency for Research on Cancer (Forman et al., 2013; Bray et al., 2017). These volumes are the most recent CI5 publications: they report data from select registries around the world for 2003-2007 and 2008-2012, respectively. We used CI5 data on numbers of cases and person-years from the YT and nationwide Canadian registries, available by cancer site, sex, and 5-year age group. CI5X includes disaggregated data by gastric cancer subsite; however, at the time of analysis, CI5XI did not include stratification within subsite groupings, precluding the identification of subsite-specific cases by age group and sex (see Appendix VI). For NT-specific analyses, we used data provided directly by the NT government. These data included gastric cancer cases by subsite, sex, 5-year age group, Indigenous status, and year of diagnosis between 1997 and 2015. The NT dataset included dichotomized Indigenous status linked from vital statistics data housed by the NT government and mid-year populations for estimating person-years.

Statistical analyses

We aimed to describe the incidence of gastric cancer overall and by subsite across study groups in the NT and YT and to compare these estimates to those observed in other populations. To permit comparisons across groups with varying population age distributions, we estimated a weighted average of age-specific incidence rates using weights from a standard population, a process known as standardization. Here, we used two methods to accomplish this: standardized incidence ratios (SIRs) and age-standardized cancer incidence rates (ASRs).

SIRs are the functional equivalent of age- and sex-standardized incidence rate ratios using the study population distribution as the standard. We estimated SIRs and

95% confidence intervals (CIs) by sex for all gastric cancer combined, CGC, and NCGC in YT (2003-2012) and NT Indigenous and non-Indigenous populations (1997-2015). As the referent, which is the denominator, we used incidence rates in Canada; these were restricted to the years 2003-2007 due to the limited availability of data by gastric cancer subsite, age group, and sex. For SIRs, the numerator of the ratio is the total number of cases in the study group, which does not require stratification of cases by age group; thus, for SIRs we were able to include cases from a longer time period for YT despite the shorter time period for which the required data were available for Canada.

For global comparisons, we estimated age-standardized cancer incidence rates (ASRs) and 95% CIs by gastric cancer subsite, geography, and sex. Due to limitations in the years of data available by subsite that were also disaggregated by age group and sex, ASRs by gastric cancer subsite for Canada and YT were limited to 2003-2007; ASRs for NT included data from 1997-2015. ASRs were age-standardized using the World Standard Population as defined by Segi (Segi, 1960); we used world and regional CGC and NCGC ASR estimates reported by Colquhoun et al. (2014). All data analyses, including SIR and ASR estimates and their CIs, were performed using SAS 9.4 software as outlined in the SAS/STAT® 14.3 User's Guide (SAS Institute Inc., 2017).

Case definitions and sensitivity analysis

In the CI5 and NT datasets, gastric cancer cases were classified according to the *International Classification of Diseases, 10th Revision* (ICD-10): gastric cancer (C16), CGC (C16.0), and NCGC (C16.1-9) (see Appendix VI, Supplement 1). NCGC typically includes the following anatomical regions of the stomach: fundus, body, antrum, pylorus, lesser curvature, and greater curvature (C16.1-6) (Anderson et al., 2018; Mahadevan, 2014; Wu et al., 2009). However, the CI5X datasets group cancers of the greater and lesser curvature (C16.5 and C16.6) with cancers classified as overlapping and not-otherwise specified (C16.8 and C16.9). Knowing that a portion of this group includes NCGC cases (C16.5-6), and that other works have allocated some or all C16.8-9 sites to NCGC when data were limited (Abnet et al., 2009; Colquhoun et al., 2015; Freedman et al., 2007; Keszei, Schouten, Goldbohm, & van den Brandt, 2012), here we chose to classify C16.5-9 as NCGC (see Appendix VI, Supplement 2 for more on choice of cases definitions). Because some of these cases might have been misclassified CGC cases, we also estimated SIRs and ASRs for NCGC defined as C16.1-4. Furthermore, in addition to age-standardization using the world population, we also repeated analyses using the Canadian 2011 standard population to permit comparisons across populations within Canada (see Appendix VI, Supplement 3).

Results

Gastric cancer overall

During 2003 and 2012, there was an annual average of 2,638 cases of gastric cancer in Canada: in each of the two northern territories included here, YT during 2003-2012 and NT during 1997-2015, there was an annual average of 3 cases in total (Table 9). In all populations defined by geography or Indigenous status, there were proportionally more cases of gastric cancer observed among men than women. Disparities in the distribution of age at diagnosis were apparent by geography and Indigenous status. In Canada, less than 25% of gastric cancer cases were diagnosed among individuals under the age of 60 (Figure 20). Among northern populations, however, over 40% of cases were observed among those younger than 60 years of age: 42% of total cases in YT and the non-Indigenous NT population, and 48% in the Indigenous NT population. The disproportionate impact on younger populations was particularly pronounced among Indigenous people in the NT: 16% of cases were observed in 0-39-year-olds (7/44) compared to 2% in Canada (646/26,382).

Table 9: Number of gastric cancer cases and person-years by gastric cancer subsite, population and sex; northern territories, Canada; various years

Population	Gastric Cancer Type*	Calendar Years	Men		Women	
			Number of cases	Person-years	Number of cases	Person-years
Canada	All	2003-2012	16,872	144,495,378	9,510	147,171,135
	CGC	2003-2007	3,151	79,864,738	857	81,320,815
	NCGC	2003-2007	6,489	79,864,738	4,544	81,320,815
Yukon	All	2003-2012	21	169,680	12	162,500
	CGC	2003-2012	7	169,680	3	162,500
	NCGC	2003-2012	14	169,680	9	162,500
NT - non-Indigenous	All	1997-2015	16	225,396	3	199,893
	CGC	1997-2015	7	225,396	0	199,893
	NCGC	1997-2015	9	225,396	3	199,893
NT – Indigenous	All	1997-2015	26	215,886	18	214,022
	CGC	1997-2015	1	215,886	0	214,022
	NCGC	1997-2015	25	215,886	18	214,022

CGC, cardia gastric cancer; NCGC, non-cardia gastric cancer
*CGC defined as C16.0; non-cardia gastric NCGC defined as C16.1-9.

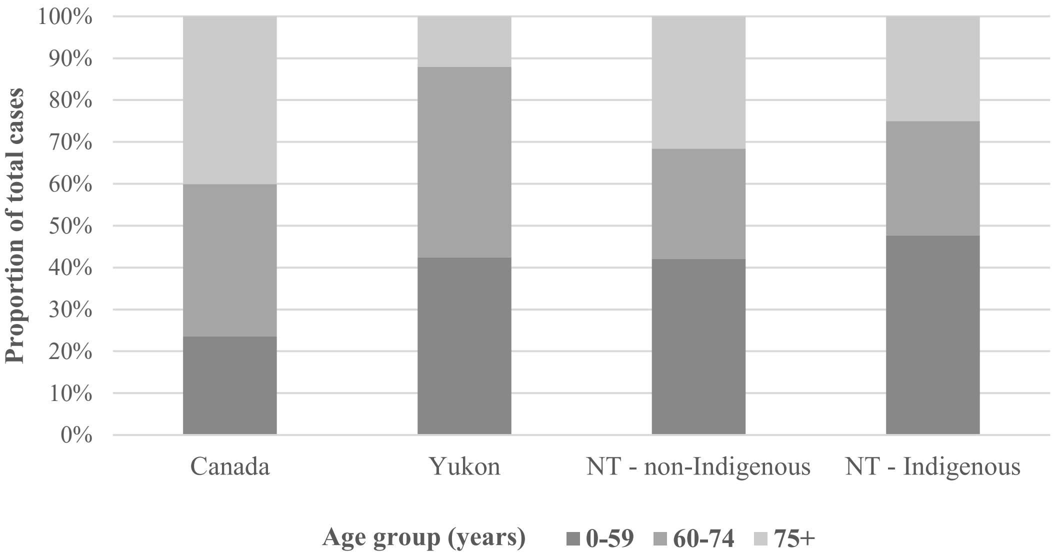


Figure 20: Age distribution of total gastric cancer cases by population; northern territories, Canada; various years*

*Canada and Yukon include cases diagnosed 2003-2012; Northwest Territories (NT) includes cases diagnosed 1997-2015.

Cardia and non-cardia subsites

The proportion of total gastric cancer cases classified as cardia varied by geography and Indigenous status (Figure 21). In Canada, YT, and the non-Indigenous NT population, the proportional CGC incidence ranged from 29-37% of total gastric cancer cases observed. In contrast, only 2% of gastric cancer cases in the Indigenous NT population were classified as CGC (1/44). This population also had the lowest proportion of cases classified as 'other and not otherwise specified' (23%; see Appendix VI, Supplement 2). The distribution of gastric cancer by subsite also varied by sex. Among men, CGC cancers comprised an average of 25% (range 4%-44%) of total gastric cancer cases; among women, this proportion was 9% (range 0%-25%) on average.

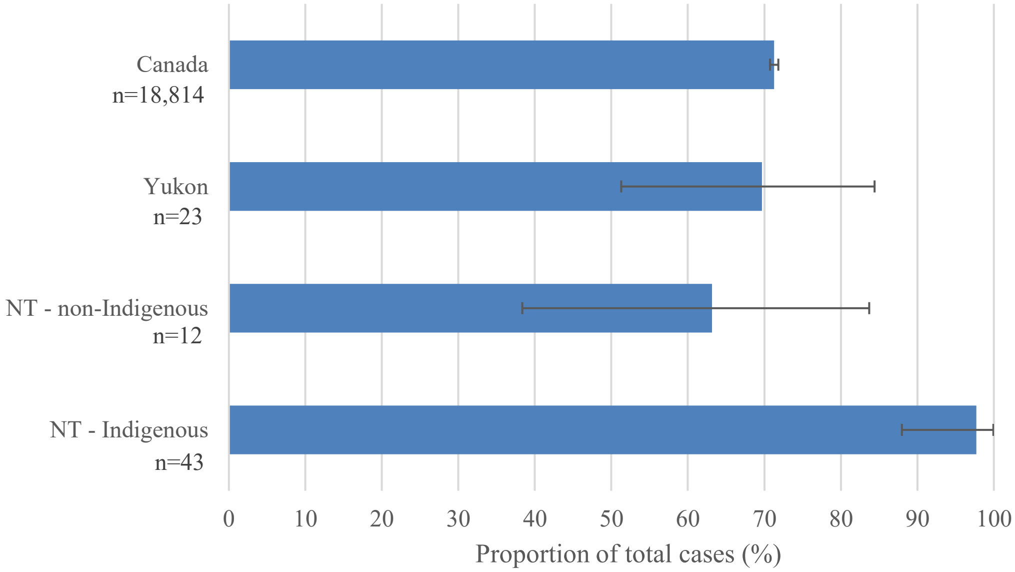


Figure 21: Proportional NCGC incidence by population; northern territories, Canada; various years*

*Canada and Yukon include cases diagnosed 2003-2012; Northwest Territories (NT) includes cases diagnosed 1997-2015. Non-cardia gastric (NCGC) defined as C16.1-9.

Comparisons across populations

NCGC incidence rates were higher among Indigenous NT men compared to all Canadian men (SIR 2.7, 95% CI 1.6-3.7) (Table 10). Similarly, Indigenous NT women had a higher incidence of NCGC compared to all women in Canada (SIR 3.1, 95% CI 1.7-4.5). For non-Indigenous NT men and women, incidence rates were similar to Canada. However, in YT, NCGC rates among both men and women were elevated compared to Canada (30% and 60% higher, respectively). For CGC, with the exception of YT men and women and non-Indigenous NT men in whom there was an apparent elevation, rates were lower compared to Canadian rates. It should be noted, however, that for some groups there were either no cases of CGC or a relatively small number of cases, resulting in imprecise estimates vulnerable to fluctuation with a difference in one case of CGC.

Table 10: Number of cases and estimated standardized incidence ratios (SIR) comparing northern populations to Canada as a whole on gastric cancer incidence rates by gastric cancer subsite, population, and sex; various years*

	Gastric Cancer	Men				Women			
		Cases	SIR*	95% CI		Cases	SIR*	95% CI	
Yukon	All	21	1.3	0.77	1.9	12	1.8	0.76	2.8
	CGC	7	1.2	0.31	2.09	3	2.6	0.00	5.5
	NCGC	14	1.3	0.62	2.0	9	1.6	0.54	2.6
NT - non-Indigenous	All	16	1.1	0.57	1.7	3	0.52	0.00	1.1
	CGC	7	1.3	0.33	2.2	0	0.00	0.00	0.00
	NCGC	9	0.94	0.33	1.6	3	0.62	0.00	1.3
NT – Indigenous	All	26	1.9	1.2	2.7	18	2.6	1.4	3.9
	CGC	1	0.21	0.00	0.62	0	0.00	0.00	0.00
	NCGC	25	2.7	1.6	3.7	18	3.1	1.7	4.5

*Standardized Incidence Ratios (SIR) compare study population to Canada 2003-2007. Yukon includes cases diagnosed 2003-2012; Northwest Territories (NT) includes cases diagnosed 1997-2015. Cardia gastric cancer (CGC) defined as C16.0; non-cardia gastric (NCGC) defined as C16.1-9.

Comparisons with other regions across the globe revealed similar patterns of variation in the distribution of gastric cancer subsites by geography and Indigenous status. For CGC among men, ASRs for Canada, YT, and the non-Indigenous NT population (Table 11) were comparable to regions such as Oceania, Southern Europe, Northern Africa & Western Asia (ASRs ranging from 2.5 to 3.3 per 100,000). These estimates were low relative to high-incidence regions such as Eastern/Southeastern Asia and Eastern Europe. Among Indigenous and non-Indigenous NT women, there were no cases of CGC. For Indigenous NT men, CGC incidence rates were based on a very small number of cases and, as a result, were very low. Conversely, NCGC incidence rates were markedly high in the Indigenous NT population (ASRs 13.3 and 7.7 per 100,000 among men and women, respectively), similar to high-incidence regions like Eastern Europe. For all of Canada, and in YT men and women and non-Indigenous NT men, NCGC rates were comparable to regions such as Northern and Western Europe (ASRs in Canada, YT and non-Indigenous NT groups ranged from 5.0 to 6.1 per 100,000 men and 2.8 to 4.5 per

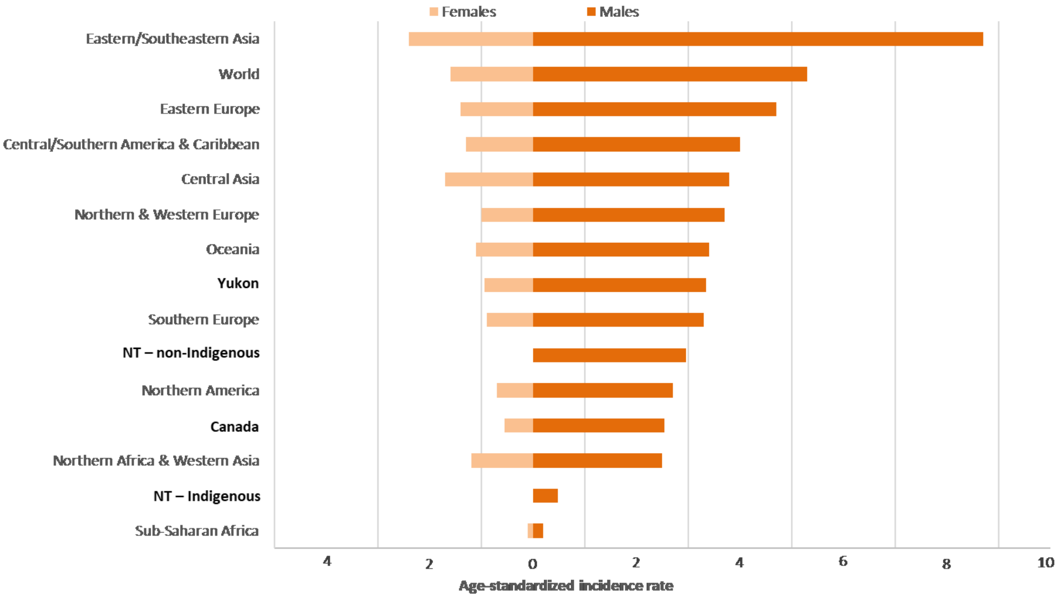
100,000 women). The NCGC incidence rate among non-Indigenous NT women was even lower (ASR 2.0 per 100,000) (Figures 22a and 22b; see Appendix VI, Supplement 3 for a full list of ASRs standardized to the World Population and to the Canadian 2011 Population).

Table 11: Estimated gastric cancer age-standardized incidence rates (ASRs per 100,000) by subsite, population, and sex; northern territories and Canada; various years*

	Gastric Cancer	Men				Women			
		Cases	ASR*	95% CI		Cases	ASR*	95% CI	
Canada	All	16,872	7.0	6.9	7.1	9,510	3.2	3.2	3.3
	CGC	3,151	2.5	2.5	2.6	857	0.6	0.5	0.6
	NCGC	6,489	5.0	4.8	5.1	4,544	2.8	2.7	2.8
Yukon	All	9	9.2	5.2	13.2	5	5.8	2.4	9.2
	CGC	3	3.3	0.0	7.3	1	0.9	0.0	2.8
	NCGC	6	6.1	1.1	11.1	4	4.5	0.0	9.1
NT - non-Indigenous	All	16	8.8	3.9	13.7	3	2.0	0.0	4.3
	CGC	7	3.0	0.6	5.3	0	0.0	0.0	0.1
	NCGC	9	5.8	1.5	10.1	3	2.0	0.0	4.3
NT - Indigenous	All	26	13.8	8.4	19.2	18	7.7	4.1	11.2
	CGC	1	0.5	0.0	1.4	0	0.0	0.0	0.0
	NCGC	25	13.3	8.0	18.6	18	7.7	4.1	11.2

*Age-standardized incidence rates (ASRs) standardized to the World Population. For Canada, all gastric cancer cases combined include cases diagnosed during 2003-2012; gastric cancer subsites include cases diagnosed 2003-2007. Yukon includes cases diagnosed during 2003-2007. Northwest Territories (NT) includes cases diagnosed during 1997-2015. Cardia gastric cancer (CGC) defined as C16.0; non-cardia gastric (NCGC) defined as C16.1-9.

(a)



(b)

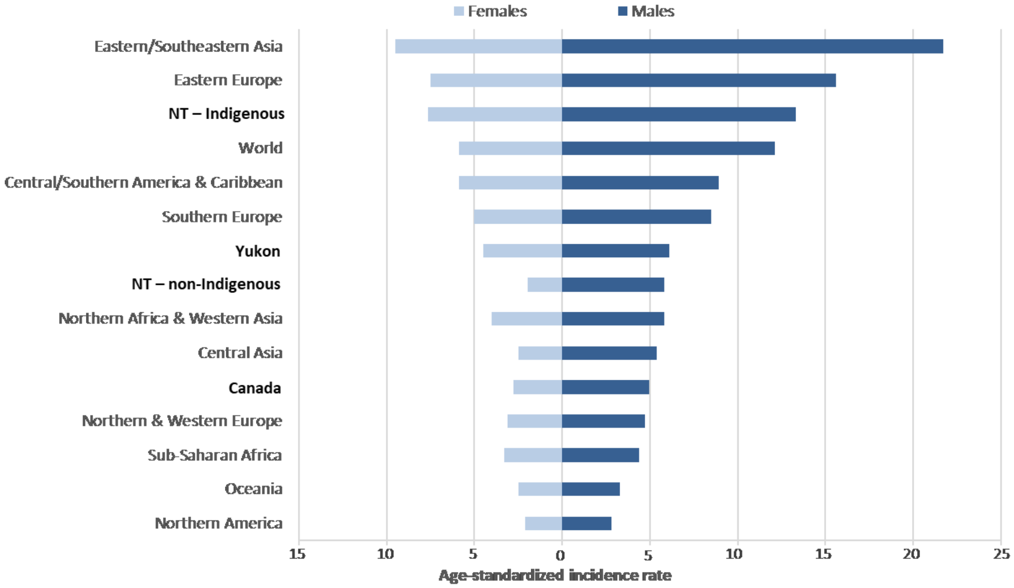


Figure 22: (a) Estimated cardia gastric cancer age-standardized incidence rates (ASRs per 100,000) by population and sex. (b) Estimated non-cardia gastric cancer ASRs (per 100,000) by population and sex; northern territories, Canada, and world regions; various years*

*Age-standardized incidence rates (ASRs) standardized to the World Population. Canada and Yukon include cases diagnosed during 2003-2007; Northwest Territories (NT) includes cases diagnosed during 1997-2015. World and regional cardia and non-cardia gastric cancer ASR estimates from Colquhoun et al. (2014).

Sensitivity Analysis

As part of a sensitivity analysis to assess the impact of the attribution of all C16.8-9 cases to NCGC, we estimated SIRs for NCGC defined as C16.1-4 (see Appendix VI, Supplement 3). SIR estimates based on this revised NCGC case definition were similar to those estimated using the original definition for NCGC (C16.1-9). For Indigenous people in the NT, SIR estimates increased with the more restricted case definition: in men, the SIR for NCGC increased 33.3% to 3.6 (95% CI 1.7-5.5); in women, the SIR increased 58% to 4.9 (95% CI 2.1-7.7).

Compared to ASRs estimated using the broader case definition, ASRs estimated using NCGC defined as C16.1-4 were lower for Canada and for the study populations in the NT and YT. This, in turn, resulted in lower estimates among the study groups and for Canada relative to the global populations that maintained a broader definition of NCGC.

Discussion

To characterize stomach cancer burden in NT and YT, we estimated the incidence of gastric cancer overall and by subsite and compared these estimates to rates estimated for Canada nationwide. We observed that NT and YT populations are disproportionately impacted by gastric cancer compared to Canada, particularly at younger ages when a larger proportion of NT and YT cases are diagnosed. This was especially true for the Indigenous NT population, in whom 16% of cases were observed in those under the age of 40, in contrast to 2% of cases in Canada diagnosed in this age group. Further, NCGC incidence rates were 2.7 times higher among NT Indigenous men and 3.1 times higher among Indigenous women than rates among their counterparts in Canada. To provide a global context for these observations, we also compared the estimated NT and YT rates to those observed elsewhere globally and found that NCGC incidence rates in the Indigenous NT population were similar to regions such as Eastern Europe where there is a high burden of gastric cancer.

Our analysis is consistent with previous work that demonstrated elevations in gastric cancer rates across northern populations. Young et al. (2016), for example, reported that gastric cancer rates among Inuit populations in the circumpolar region of Canada are higher than global rates. Similarly, other work has shown that gastric cancer rates are higher in northern regions compared to rates observed in more southern parts of the same country (Friborg, Koch, Wohlfarht, Storm, & Melbye, 2003; Lanier, Kelly, Maxwell, McEvoy, & Homan, 2006). In addition to geographic variation, our findings are consistent with reports of differences in the stomach cancer burden among Indigenous populations compared to their non-Indigenous counterparts (Arnold et al., 2014). In some regions, gastric cancer rates among Indigenous peoples were over two times the rates of non-Indigenous people living in the same area (Arnold et al., 2014): in Alberta for example, a Canadian province south of NT, gastric cancer rates between 2009 and 2016 among First Nations men and women were 1.5 and 2.3 times higher, respectively, compared to their non-First Nations counterparts (Alberta Health, 2018).

As with all gastric cancers combined, there is also geographic variation across regions for gastric cancer subsites (Colquhoun et al., 2015). Because *H. pylori* is a risk factor for gastric cancer arising in distal portions of the stomach (Plummer et al., 2014), it is unsurprising that regions with higher prevalence of this infection are impacted more greatly by NCGC. Further, elevations in NCGC incidence have been observed to coincide with an increased burden of *H. pylori* infection among Indigenous populations (McDonald, Sarfati, Baker, & Blakely, 2015; McMahon et al., 2016; Windsor et al., 2005). Among American Indians and Alaska Natives combined relative to non-Hispanic whites in the United States, for example, estimated NCGC incidence rates during 1999-2004 were 5.8 and 14.9 times higher among men and women, respectively (Wiggins et al., 2008). Similarly, NCGC incidence rates were reported to be higher among Native Americans compared to other ethnic groups in the United States (Brown & Devesa, 2002; Kubo & Corley, 2004) and also among Maori New Zealanders compared to non-Maori New Zealanders (Armstrong & Borman, 1996). Despite the higher burden of *H. pylori* infection and gastric cancer among Indigenous populations, there is relatively little information on CGC and NCGC in these groups across the globe.

While our analysis of gastric cancer incidence by subsite in northern Canada contributed to reducing this information gap, there were data restrictions that limited this assessment. When disaggregating rates by age category, the CI5X and CI5XI datasets combined gastric cancers of the lesser and greater curvature (C16.5 and C16.6) with those classified as ‘overlapping lesion of stomach’ and ‘stomach, not otherwise specified’

(C16.8 and C16.9). Because C16.5-6 are typically classified as cancers of the non-cardia gastric region (Anderson et al., 2018; Mahadevan, 2014; Wu et al., 2009), and because other analysts have reclassified all or some C16.8-9 cases as NCGC when these classifications are relatively common (Abnet et al., 2009; Colquhoun et al., 2015; Freedman et al., 2007; Keszei et al., 2012), we chose to attribute all cases classified as C16.5-9 to NCGC. It is possible that some of the cases classified as overlapping or unknown topography (C16.8-9) are, in fact, cancers of the cardia and were misclassified here; however, given the low proportion of cases classified as CGC in global populations, the degree of any potential misclassification is likely small.

To assess the extent to which misclassification of cases could have impacted comparisons of NCGC incidence estimates across populations, we also performed a sensitivity analysis where NCGC cases were redefined as C16.1-4: we found that SIR estimates with the more restricted definition were similar to those estimated using the original definition for NCGC (C16.1-9). In contrast, ASRs based on the restricted definition of NCGC (C16.1-4) resulted in lower estimated rates for the study groups and Canada relative to the global populations, which maintained a broader definition of NCGC. Despite this, ASRs of NCGC among Indigenous populations in the NT remained high relative to global estimates.

The relatively small number of gastric cancer cases observed in northern Canadian populations created imprecise incidence rate estimates that are vulnerable to large fluctuations if the numerator is off by as little as one case. To account for this, we used SIRs to compare the observed number of cases in the study populations with the number of cases expected based on Canadian rates. This method of age-adjustment is beneficial when age-specific rates are unstable due to small numbers (Szklo & Nieto, 2014). Unfortunately, because the age distribution of the study population is used as the standard for these methods, age adjustment through the use of SIRs limits comparisons over time or across multiple populations (Julious, Nicholl, & George, 2001). To support comparisons with global rates, we also estimated ASRs, using CIs to acknowledge imprecision in these age-standardized rates due to small numbers of cases.

Furthermore, we used data on gastric cancer in Canada during 2003-2007 as a comparison to rates that included cases diagnosed in more recent years in NT and YT.

Given that gastric cancer rates are decreasing in Canada (Xie, Semenciw, & Mery, 2015), in line with observations that NCGC rates are declining in developed regions of the world (Devesa, Blot, & Fraumeni, 1998; Holster, Aarts, Tjwa, Lemmens, & Kuipers, 2014; Steevens, Botterweck, Dirx, van den Brandt, & Schouten, 2010), our SIRs comparing NT and YT rates to Canadian rates are likely to be underestimated. While gastric cancer rates are decreasing overall in developed regions of the world, Anderson et al. (2018) demonstrated through stratification by age group that NCGC rates may be increasing in younger non-Hispanic white populations in the United States. Although the number of cases in NT and YT populations were too small to examine age-specific incidence rates in detail, increasing incidence in younger age groups over time could explain why the proportion of gastric cancer cases corresponding to younger age groups was larger in NT and YT than in Canada as a whole, given that NT and YT data included cases diagnosed in more recent years.

This study has, for the first time, estimated the incidence of CGC and NCGC among NT and YT populations. Consistent with other work describing gastric cancer among northern and Indigenous populations, we found that NT and YT populations were disproportionately impacted by gastric cancer, particularly of the non-cardia gastric region. These estimates provide new insights into the burden of gastric cancer in northern Canadian populations. As a result, this work supports the on-going community-driven CAN*Help* Working Group research program. In particular, it will be used to inform gastric cancer control strategies aimed at achieving the goal identified by impacted Indigenous Arctic communities of implementing effective interventions to reduce their disproportionate gastric cancer disease burden.

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7.4 Reflections and summary

In this chapter, I compiled information on the burden of *H. pylori* and associated diseases among northern Canadian populations using conventional epidemiologic approaches. I began with a characterization of the impact of *H. pylori* infection among northern Canadian populations: my co-authors and I outlined patterns in the occurrence of *H. pylori* diagnostic testing and, among those who were tested, the proportion positive across NT demographic groups. We observed that over half of Indigenous people tested were positive for *H. pylori* infection. In contrast, less than a fifth of non-Indigenous people tested were positive. Males in both groups had somewhat lower diagnostic testing rates with slightly higher proportions testing positive. Furthermore, while the rates of diagnostic testing for *H. pylori* infection were only slightly higher for Indigenous relative to non-Indigenous NT residents, the odds of testing positive were substantially higher among Indigenous residents. This inequity occurred in both sexes consistently over time during 2009-2016.

To quantify the burden of stomach cancer in the NT and YT, my co-authors and I described the incidence of overall gastric cancer and gastric cancer by subsite and compared these estimates to those observed across other populations. We observed that NT and YT populations are disproportionately impacted by gastric cancers compared to Canada as a whole, particularly at younger ages when a larger proportion are diagnosed. This was especially true for Indigenous populations in the NT where a large proportion of cases were diagnosed among those under 40 years of age and where rates of non-cardia gastric cancer were higher than rates among their counterparts in Canada. To provide context for these observations across the globe, we also compared rates among study populations to those observed elsewhere globally, estimated in Chapter 7.2, and found that rates of non-cardia gastric cancer among Indigenous populations in the NT were similar to regions such as Eastern Europe where there is a high burden of disease.

Taken together, these works add substantially to the small body of prior evidence of the disproportionate burden of *H. pylori* infection and gastric cancer among northern Canadian Indigenous populations. Their findings are consistent with other reports of a high prevalence of *H. pylori* infection among Indigenous populations in circumpolar regions (McMahon et al., 2016). Previous works conducted as part of the CAN*Help* Working Group research program include studies that estimated, across participating communities, a high prevalence of *H. pylori* infection and other characteristics of *H. pylori* infection that increase the risk of adverse health outcomes such as stomach cancer (Goodman, Jacobson, & van Zanten, 2008). Similarly, high incidence rates of gastric cancer have been reported previously for circumpolar populations, particularly for Indigenous populations relative to their non-Indigenous counterparts (Young, Kelly, Friborg, Soininen, & Wong, 2016). While variations exist across populations, the available evidence consistently shows an increased burden of *H. pylori* infection and an elevated risk of associated diseases such as cancer.

The works outlined in this chapter illustrate the magnitude of the burden from *H. pylori* infection and associated diseases for the populations of the NT and YT. As a result, these works inform epidemiologic inquiry aimed at describing the health of northern Canadian populations, thus supporting the overarching CAN*Help* Working Group research program. These works also provide examples of the kinds of information that may be generated using conventional epidemiologic approaches to describe burden of disease. In the next chapter, I synthesize this information with the work presented in Chapter 6 to produce a comprehensive description of disease burden on those impacted. I also reflect on this applied process, identifying key limitations and potential future improvements.

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Chapter 8: Applied example: Synthesis of multiple forms of evidence and reflections

8.0 Introduction

In a previous chapter, I outlined key principles that guide my work in epidemiologic inquiry: pragmatism, collaboration, and justice (Chapter 2). In subsequent chapters, my co-authors and I described some challenges and solutions to working in community-university partnerships that aim to improve community health (Chapter 3). We also provided examples of approaches that create reciprocal learning environments to foster equitable spaces so solutions to health problems can be pursued together (Chapter 4). Driven by my guiding principles of pragmatism, collaboration, and justice, my co-authors and I then explained in detail the value of considering different perspectives when attempting to describe the health of a population (Chapter 5): we outlined why information from multiple perspectives enhances the value of epidemiologic descriptions of disease burden, particularly in situations where there is community concern about a specific disease.

To demonstrate how these concepts can be incorporated into practice, my co-authors and I provided examples of the kinds of information that might be useful for epidemiologic inquiry in community-university partnerships aimed at improving health: in Chapter 6, we characterized how community members in northern Canada view *H. pylori* infection and associated diseases; in Chapter 7, we described the burden from *H. pylori* infection and associated diseases using more conventional epidemiologic approaches. In Chapter 8.1, we integrate the information presented in Chapters 6 and 7 to produce a comprehensive description of disease burden among those impacted. This integration enriches quantitative descriptions of disease burden with qualitative first-hand portrayals of this burden. I then reflect on the applied process described in Chapters 6-8, identifying key limitations and potential future improvements.

8.1 Integrating qualitative and quantitative evidence for a comprehensive description of the disease burden from *Helicobacter pylori* in northern Canada

Abstract

Northern Indigenous populations in Canada have a disproportionately high frequency of *Helicobacter pylori* infection and associated diseases. To address concerns, a multidisciplinary community-driven research program aims to identify effective public health strategies to reduce associated health risks. Here, we aimed to describe comprehensively the disease burden from *H. pylori* and associated diseases in northern Canada by synthesizing evidence obtained through a series of distinct research studies on *H. pylori* infection and associated diseases.

We identified key concepts across studies and described the similarities and differences between them. We then identified concepts that emerged from this integration to achieve a description of the synthesized evidence obtained from diverse research approaches. The studies shared a variety of perspectives; in particular, they commonly reported a disproportionate burden of *H. pylori* and stomach cancer among northern populations compared to other geographically-defined populations. However, there does not appear to be a shared understanding of *H. pylori* and its impacts within communities and across research program collaborators. Further, the burden attributed to *H. pylori* infection as characterized by northern communities may be broader than what is typically described by academic scientists and healthcare providers.

This synthesis offers new insights into the disease burden from *H. pylori* in Arctic Indigenous populations and points to the need for targeted public health action. It also facilitates the identification of knowledge gaps that warrant further research. Beyond this, it provides an example of how descriptions of disease burden can be strengthened through community-university research partnerships that incorporate the voice of those impacted in investigations aimed at reducing the disease burden under study.

Background

Helicobacter pylori is a bacterium that has been identified as a major cause of chronic gastritis, peptic ulcer disease, and stomach cancer. With the human stomach as its niche, evidence suggests that the usual transmission pathways are from person to person through contact with infectious fecal matter or vomitus (Goodman, Jacobson, & van Zanten, 2008; Parsonnet, Shmuely, & Haggerty, 1999). *H. pylori* infection is usually acquired in childhood and often persists long-term; household crowding and exposure to *H. pylori*-infected family members are associated with increased prevalence (Mendall et al., 1992; Webb et al., 1994). Variation in the prevalence of *H. pylori* infection has been observed globally: although there was limited representativeness in some groups, Hooi et al. (2017) reported prevalence across countries ranging from 19% in Switzerland to almost 90% Nigeria. Within-region differences have also been reported: northern Indigenous populations have a disproportionately high frequency of *H. pylori* infection and associated diseases, and lower success of treatment aimed at eliminating the bacterium compared to more southern populations (Goodman et al., 2008; Young, Kelly, Friborg, Soininen, & Wong, 2016).

In northern Canada, where a high proportion of the population is Indigenous, communities and their healthcare providers have expressed concern over elevated frequencies of *H. pylori* infection and stomach cancer (Cheung et al., 2014). To address concerns voiced by affected communities and their healthcare providers, a community-driven program involving several communities in northern Canada emerged during 2006-2008. This research program, the Canadian North *Helicobacter pylori* (CAN*Help*) Working Group, is a collaboration of academic researchers from various disciplines at the University of Alberta with community representatives, health care practitioners and health officials in the Northwest Territories (NT) and Yukon (YT). The overall aims are to describe the burden of disease and risk factors associated with *H. pylori* infection, identify effective public health strategies for infection control, and identify effective knowledge translation tools to support the practical application of research lessons.

To support these goals, we have previously described the disease burden from *H. pylori* and associated diseases in northern Canadian populations using diverse approaches. One of these approaches characterized community members' views of the bacterium and related diseases. We characterized the impact of *H. pylori* infection using a media analysis that examined topics covered in mass media portrayals of the bacterium and how related issues were presented (Colquhoun, Desai, Hik, Jardine, & Goodman, 2018). We also garnered insights into community perspectives through content and thematic analysis of data obtained from structured questionnaires and semi-structured interviews (Colquhoun, Werner, Jardine, Goodman, & CAN*Help* Working Group, 2018). Additionally, we used more conventional epidemiologic methods to describe the occurrence of *H. pylori* infection and associated diseases using quantitative measures applied in descriptive epidemiology. In one quantitative study, we used diagnostic data to describe patterns of *H. pylori* testing and test results across NT demographic groups (Colquhoun, Hannah, Corriveau, Yuan, & Goodman, 2018). In another, we described the incidence of gastric cancer overall and by subsite among NT and YT populations (Colquhoun, Hannah, Corriveau, Hanley, Yuan, & Goodman, 2018). Each of these previous works illustrated the disease burden from *H. pylori* infection and associated diseases in northern Canada from a unique perspective. The current study aims to integrate information obtained through previous works for a comprehensive characterization of the disease burden from *H. pylori* and associated diseases in northern Canada.

Methods

Rationale for combining qualitative and quantitative methods

This analysis integrates qualitative and quantitative data, an approach sometimes called “mixed methods” (Creswell & Plano Clark, 2011), which offers a variety of benefits. As Guetterman et al. (2015) noted, “Mixed methods research increasingly is being used as a methodology in the health sciences to gain a more complete understanding of issues and hear the voices of participants” (p. 554). Synthesizing information obtained from qualitative and quantitative inquiry yields a host of benefits (Bryman, 2006; Creswell, 2015). Among these benefits, according to Bryman (2006), is the “notion that the researcher can bring together a more comprehensive account of the area of enquiry in which he or she is interested if both quantitative and qualitative research are employed” (p. 106). Similarly, Bryman (2006) also notes that the integration of qualitative and quantitative methods may support a diversity of views through the combination of researchers’ and participants’ perspectives.

Qualitative and quantitative evidence can be integrated in a variety of ways (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Mays, Pope, & Popay, 2005) at different stages of the research (Fetters, Curry, & Creswell, 2013). Fetters et al. (2013) described integration at study design: in a convergent research design, for example, qualitative and quantitative data are collected and analysed during concurrent timeframes. In these cases, integration is typically achieved through a merging process where researchers bring two databases together for analysis and comparison. Fetters et al. (2013) also noted that integration may occur at the interpretation and reporting levels of the research, resulting in confirmation, expansion, or contradiction of the data. In these studies, the integration of qualitative and quantitative evidence occurs as the data are compiled and communicated.

Methods have also been developed for integrating information from diverse studies completed previously. Critical Interpretive Synthesis (CIS), for example, is a methodological approach to synthesizing evidence obtained using diverse methods. Originally proposed by Dixon-Woods et al. in 2006, it is founded upon the concepts of meta-ethnography, which synthesizes interpretations and contexts across qualitative studies (Noblit, 2004). CIS, however, permits synthesis beyond evidence restricted to qualitative studies: evidence from a variety of methods is integrated by identifying and transforming diverse kinds of evidence into new forms and then forming a synthesized argument based on identified constructs (Dixon-Woods et al., 2006; Flemming, 2010). In this way, CIS differs from aggregative data summaries (Dixon-Woods et al., 2006). It has been used primarily in health research to conduct systematic reviews including various forms of evidence aimed at informing decision-making (Dixon-Woods et al., 2006; Flemming, 2010). As Dixon-Woods et al. (2006) stated, “using CIS to synthesise a diverse body of evidence enables the generation of theory with strong explanatory power” (“Background,” para. 2).

Implementation

Here, we synthesized evidence obtained through a series of distinct research studies on the burden of disease from *H. pylori* infection and associated diseases conducted to support the CAN*Help* Working Group research program (Table 12). These include four studies conducted separately: two that aimed to characterize community members’ views of the bacterium and related diseases (Colquhoun, Desai, et al., 2018;

Colquhoun, Werner, et al., 2018) and two that aimed to describe *H. pylori* infection and associated diseases in northern Canada using conventional epidemiologic methods (Colquhoun, Hannah, Corriveau, Yuan, & Goodman, 2018; Colquhoun, Hannah, Corriveau, Hanley, et al., 2018). The integration of qualitative and quantitative information obtained through these works was guided, in part, by CIS. In interpretive synthesis, a precise research question is not selected *a priori*; rather, specification of the research question is iterative (Dixon-Woods et al., 2006). In this study, the general research question we used “as a compass rather than an anchor” (Dixon-Woods et al., 2006, "Methods," para. 3) was, “How does *H. pylori* infection impact populations in NT and YT?”

Using data obtained from the studies listed in Table 12 and adopting a critical and reflexive approach whereby analyses are thoughtful and deliberate, we identified key concepts from each research finding and assessed the similarities and differences between them. We then identified common concepts emerging from this integration for a synthesized description of the evidence obtained from all research modules. In the current study we employed joint displays, which are figures or tables where quantitative and qualitative data can be directly compared to guide the thematic narration of research results (Fetters et al., 2013).

Table 12: Title of selected research studies on *H. pylori* infection and associated diseases in northern Canada and a summary of their respective research approaches

Study title	Approach summary
Media portrayals of *H. pylori* and related community-driven research in northern Canada (Colquhoun, Desai, Hik, Jardine, & Goodman, 2018)	To describe how media portrays *H. pylori* infection, associated diseases, and research in NT and YT, researchers conducted a media analysis by assessing framing and content of media messages related to *H. pylori* in northern communities.
Community-driven research on *Helicobacter pylori*: northern Canadian community perspectives on a stomach bacterium (Colquhoun, Werner, Jardine, Goodman, & CAN*Help* Working Group, 2018)	To ascertain community perspectives on *H. pylori* and associated diseases, researchers conducted a content and thematic analysis of data obtained from interviewer-led structured questionnaires and semi-structured interviews.
Helicobacter pylori diagnostic testing patterns in northern Canadian populations (Colquhoun, Hannah, Corriveau, Yuan, & Goodman, 2018)	To describe patterns of *H. pylori* testing occurrence and results across NT populations between 2009 and 2016, researchers analyzed *H. pylori* diagnostic data obtained from the NT government.
Gastric cancer in northern Canadian populations: a focus on cardia and non-cardia subsites (Colquhoun, Hannah, Corriveau, Hanley, Yuan, & Goodman, 2018)	To describe the incidence of gastric cancer overall and by subsite in the NT and YT populations, researchers estimated age-standardized incidence rates by sex and Indigenous status, and standardized incidence ratios for comparing rates in northern populations to rates in Canada.

Notes: NT = Northwest Territories; YT = Yukon Territory

Results and reflections

Each of the studies included here characterized impacts of *H. pylori* infection and associated diseases, contributing information on the burden from this infection and related conditions in northern Canadian populations. Following compilation of key research findings (Table 13), and assessment of similarities and differences, an iterative review led to the identification of prominent themes (Table 14). We identified four common themes for further exploration: 1) Health outcomes related to *H. pylori* infection, 2) Sources or transmission of the *H. pylori* bacterium, 3) Disparities across populations, and 4) Knowledge gaps. Below, we describe these common themes in detail and outline how they are interconnected. We also outline concepts that emerged from this integration, thus contributing to a comprehensive description of the disease burden from *H. pylori* and associated diseases in northern populations.

Table 13: Key findings of selected research studies on *H. pylori* infection and associated diseases in northern Canada

Key findings			
Media portrayals	**Community perspectives on *H. pylori* and associated diseases**	**Patterns in *H. pylori* diagnostic testing and results**	**Gastric cancer incidence**
H. pylori is the main focus of research being conducted in northern communities Stomach cancer is major concern; other potential health outcomes of *H. pylori* infection included peptic ulcers and stomach issues Risk factors for *H. pylori* infection include contaminated water Contributing factors for *H. pylori* infection include crowded conditions and childhood or young age Source of *H. pylori* unknown; transmission pathways are unknown or through bodily fluids The unknown origin or source of *H. pylori* is a concern	*H. pylori* viewed in connection with stomach problems or stomach cancer; these health outcomes most likely to be reported as a concern by participants *H. pylori* transmitted through contaminated water and food; over half of people who said they have an idea of how people get *H. pylori* infection specified that it was through water Personal choices or behaviours increase risk of negative health outcomes; other contributing risk factors include low income, attendance at residential school, and environmental impacts of industry Participants worried about how *H. pylori* might affect their health or the health of others because of existing health issues or other vulnerabilities *H. pylori* and associated diseases not an issue in communities previously; occurrence increasing over time *H. pylori* is unknown; there does not appear to be a shared idea of what *H. pylori* is or how it affects communities	Over half of Indigenous people tested were positive for *H. pylori* infection compared to less than a fifth of non-Indigenous people tested The rates of diagnostic testing for *H. pylori* infection were slightly higher for Indigenous relative to non-Indigenous NT residents The odds of testing positive among those tested were substantially higher among Indigenous compared to non-Indigenous NT residents. This inequity occurred in both sexes consistently over time during 2009-2016 Age-specific diagnostic testing rates and, among those tested, the proportion positive were higher among those older than 24 years of age compared to younger age groups For Indigenous groups in the NT, diagnostic testing rates decreased between 2009 and 2016 Study includes only symptomatic people in the NT who sought care that resulted in a diagnostic test	Rates of non-cardia gastric cancer among NT Indigenous populations higher than their counterparts in Canada Age-standardized rates of non-cardia gastric cancer among Indigenous populations in the NT comparable to global regions with high rates Younger age groups disproportionately impacted by gastric cancer in the NT and YT compared to Canada as a whole Most gastric cancer cases diagnosed in the NT Indigenous population were non-cardia Study based on a relatively small number of cases observed in northern populations

Notes: NT = Northwest Territories; YT = Yukon Territory

Table 14: Common themes and comparisons across selected research studies on *H. pylori* infection and associated diseases in northern Canada: summary of emerging concepts

Common themes	Comparisons across studies
Health outcomes	• Stomach cancer a major concern for northern populations • A small proportion of NT residents are tested for *H. pylori* each year • On average, a relatively small number of cases of stomach cancer are diagnosed in the territories each year • Burden attributed to *H. pylori* infection as characterized by northern communities may be broader than that typically described by academic scientists and healthcare providers
Sources and transmission	• Questions remain about the source and transmission of the bacterium • *H. pylori* thought by some community members to be transmitted through contaminated water or food • Not addressed in conventional epidemiology studies included here but estimates across geographies may be erroneously interpreted as reflecting associations with source
Disparities across populations	• Disparities exist in the rates of stomach cancer and *H. pylori* positive diagnostic test results across populations • Impacts highlighted by community members focused on those most vulnerable within the community; quantitative assessments described disease burden across populations • Community members characterize *H. pylori* infection and impacts as a new phenomenon; limited time trends evidence based on quantitative results
Knowledge gaps	• Questions remain about the source and transmission of the bacterium • Limitations exist across studies that restricted the extent of disease descriptions • There is no shared understanding of *H. pylori* and its impacts

Summary of emerging concepts

Stomach cancer a major concern for northern populations, particularly Indigenous populations

Questions remain about the source and transmission of the bacterium

There does not appear to be a shared understanding of *H. pylori* and its impacts by community members and other research collaborators

Burden of *H. pylori* infection characterized by northern communities is broader than typically described through conventional epidemiologic methods

Health outcomes

Health outcomes related to *H. pylori* infection were characterized in each of the studies included here. In the media portrayals and community member descriptions, several health outcomes were reported as concerns. These concerns focused primarily on the impacts of stomach cancer, but also referenced other diseases such as stomach ulcers and stomach problems in general. Similarly, quantitative descriptions of *H. pylori* diagnostic testing and test result patterns, as well as gastric cancer incidence, illustrated that northern Indigenous populations were disproportionately impacted by these health outcomes. Taken together, these works highlight the impact of *H. pylori* infection and gastric cancer on NT and YT communities and, in particular, Indigenous populations.

Despite these similarities, comparison of the diverse kinds of evidence revealed subtle discrepancies. For example, some community member characterizations of *H. pylori* infection suggested that the bacterium was ubiquitous: it was described as impacting large numbers of people in communities, particularly those exposed to risk factors such as contaminated water sources. However, this does not coincide with care-seeking patterns observed through comparisons of diagnostic testing frequency across NT residents: annually, a relatively small proportion of NT residents were tested for *H. pylori* and, of those tested, the proportion with negative test results indicated that many NT residents seek health care for stomach complaints that are not due to *H. pylori* infection. Likewise, while stomach cancer was reported as a major concern among community members, it was a rare outcome considering the rates of new cases diagnosed each year across the territories.

A further discrepancy was the apparent attribution of various ailments to *H. pylori* infection: when describing the impacts of the bacterium, there seemed to be a blurring by community members between risk factors for *H. pylori* infection and the factors that may increase risk of stomach problems or cancer. Similarly, community member characterizations of *H. pylori* infection appeared to relate to stomach issues and cancer more broadly than what may have resulted from *H. pylori* infection. Conversely, the quantitative works using more conventional epidemiologic approaches focused on research questions that aim to inform public health strategies targeted at *H. pylori* infection specifically. While these works were also limited in how they were unable to isolate health outcomes directly impacted *H. pylori* infection, they did not seek to explore the potential impact of other factors on stomach health more broadly.

Source and transmission of H. pylori

The media analysis and additional works that characterized community perspectives of *H. pylori* and associated diseases highlighted the source and transmission of *H. pylori* as a major concern amongst communities in northern regions. In particular, many community members expressed concerns about the potential transmission of *H. pylori* through contaminated water or food. This seemed to be driven by community members' knowledge of potential health outcomes related to the stomach and the connection between the stomach and the ingestion of food or water. While these concepts were mentioned frequently in discussions related to *H. pylori* and its impacts on community members, conventional epidemiologic descriptions of disease burden did not address possible connections between a source of *H. pylori* and disease outcomes, which would require descriptions beyond occurrence by broad categorizations of person, place, and time.

Given that source and transmission were dominant concerns of community members, it should be acknowledged that quantitative descriptions arising from conventional epidemiologic methods could be interpreted as evidence supporting or disputing a connection between rates of disease and environmental risk factors. For example, with increased rates of stomach cancer in northern populations compared to rates in Canada and other global regions, one might interpret this as strong evidence that exposure to contaminated environmental sources in northern regions drives this disparity. Such interpretations would be misguided within a conventional epidemiologic framework: given that there are a host of possible contributing factors to differences in rates of disease across populations, and that testing patterns may differ for reasons beyond the prevalence of *H. pylori* infection, one can only speculate on what could be driving these disparities without more information. This potential discrepancy in interpretation reflects disparate expectations of epidemiologic research: epidemiologists estimating conventional measures of disease burden typically regard the resulting description as the starting point of a long investigative road before potential public health action can be advised, while those impacted by disease seek rapid identification and elimination of root causes.

Disparities across populations

Each of these research studies described a disproportionate burden from *H. pylori* and associated diseases among northern populations and, in particular, among Indigenous populations compared to their non-Indigenous counterparts. While this theme arose across kinds of evidence, further analysis revealed a discordance between how community members characterize these disparities and how conventional quantitative epidemiologic approaches describe them. Among the epidemiologic studies, *H. pylori* infection and disease frequencies were compared across territorial and other large populations. As a result, estimates reported differences between Indigenous and non-Indigenous populations, or between populations in the territories and Canada as a whole. An elevated burden compared to other populations is consistent with reported impacts characterized by community members; however, descriptions reflecting the perspectives of the target population did not focus on comparisons between their experiences and those of other populations.

Instead, community member characterizations of the impact of *H. pylori* infection focused on within-group differences, highlighting groups within their communities who might be particularly vulnerable to infection or negative health outcomes. Groups identified at potential risk included younger and older populations, people living with comorbidities, and those impacted by trauma or poor economic conditions. Available data for quantitative descriptions of *H. pylori* infection and gastric cancer, however, were limited in detail with respect to within-population differences. There were some descriptions of disease frequencies across age groups in quantitative works: rates of *H. pylori* diagnostic testing and the proportion of positive test results among those tested increased with age; whereas stomach cancer appeared to impact younger populations in the NT and YT disproportionately compared to Canada.

Furthermore, community member characterizations of *H. pylori* often referred to the impacts of the bacterium and associated diseases such as stomach cancer as a relatively new phenomenon, with rates increasing in modern times, reflecting disparities between them and their ancestors. The quantitative epidemiologic methods were limited in the extent to which they could describe temporal trends. Patterns of *H. pylori* test data in the NT suggested that diagnostic testing for *H. pylori* infection has been decreasing over recent years in some groups; however, observed decreases may have resulted from bias inherent in using a population undergoing diagnosis for symptomatic illness rather than prevalence in the population as a whole, and data are lacking in earlier eras. Time trends could not be estimated for gastric cancer rates in northern populations given the small number of cases and lack of historical data.

Knowledge gaps

In analyzing media portrayals and community member characterizations of *H. pylori* and associated diseases, we ascertained that many research participants were not comfortable in their understanding of what the bacterium is or how it impacts the body. The impact of these uncertain knowledge foundations was largely unclear; however, in some cases, concepts of the unknown were linked to feelings of fear. Quantitative descriptions arising from conventional epidemiologic methods were also restricted in the extent to which they could contribute knowledge about the burden of disease. This resulted from a relatively small number of events and lack of historical data that limited the description of diseases within sub-populations and over time. Despite these limitations, it was apparent that the burden characterized by community members was generally concordant with the information on disease burden described by quantitative data related to health outcomes.

Integration summary and emerging concepts

The evidence arising from these diverse studies shared similarities in how the burden of disease was characterized: there is a disproportionate burden of *H. pylori* infection and stomach cancer, particularly among northern Indigenous populations compared to their primarily non-Indigenous counterparts. Through a process of reflection, however, it was also apparent that some discrepancies exist. In particular, while the quantitative description of disease burden arising from conventional epidemiologic methods focused on disparities across large population groups, the impacts highlighted by community members focused on those most vulnerable within their community, such as those living with comorbidities or younger and older populations. Similarly, because there does not appear to be a shared understanding of *H. pylori* or its potential negative health impacts, the burden as characterized by community members appears to be broader than that described by conventional epidemiologic methods. This is evidenced, for example, in how community members appear to focus on goals aimed at pinpointing and eliminating the source of the bacterium while academic scientists use conventional epidemiologic descriptions to support the development of public health strategies for infection control, even if no source can be pinpointed.

Discussion

We integrated information obtained from previous research studies on *H. pylori* and associated diseases. These works included characterizations of media portrayals and community members' views of the bacterium and related diseases. It also included analyses that utilized conventional epidemiologic methods to describe disease burden. Together, the synthesized information provided a comprehensive description of disease burden among those impacted. A variety of common themes emerged across studies, in particular, a disproportionate burden of *H. pylori* infection and stomach cancer among northern populations compared to other regions. However, there does not appear to be a shared understanding of *H. pylori* and its impacts within communities and across research program collaborators. Further, the overall impacts of *H. pylori* infection may be conflated with other factors that impact stomach health. As a result, the burden characterized by northern communities appears to be broader than is typically measured through the quantifiable impacts of *H. pylori* infection and related diseases using conventional epidemiologic methods.

Conventional approaches to assessing disease burden, such as the quantitative description of the distribution of disease incidence in a population, are useful in how they contribute information about the disease burden across demographic groups and over time. Similarly, self-described perspectives of health provide in-depth information on how populations understand their health, and how they are experiencing disease. By incorporating various descriptions of the burden from *H. pylori* infection and associated diseases in northern Canadian populations, this work permitted "a more comprehensive account of the area of enquiry" (Fetters et al., 2013, p. 106). In addition to the insights provided by quantitative analysis of health outcomes related to *H. pylori* infection, we were also able to incorporate contextual information obtained from community members' descriptions of this burden in relation to themselves and their community.

In addition to a fuller description of the burden from *H. pylori* and associated diseases in the target population, these syntheses also yielded further information about community health impacts. For example, comparisons of community characterizations and quantitative descriptions of disease burden revealed that many members of the target population attributed broader stomach health issues to *H. pylori* infection than can be attributed to this infection based on epidemiologic evidence reported in the published literature. This discrepancy suggests that other public health issues need to be addressed. Moreover, while quantitative analyses of *H. pylori* infection and gastric cancer identified a disproportionate burden of disease among Indigenous populations, research characterizing community perspectives provided further insights on vulnerable subgroups such as those dealing with co-morbidities, younger or older age groups, or those with fewer resources. These insights highlight within-group vulnerabilities that should be considered when contemplating how to target public health action. Furthermore, there remains the need to address the community expectation of research with respect to pinpointing and eliminating health threats.

Despite the recognized importance of various sources and types of information when developing public health strategies, it is not always clear how to incorporate different forms of evidence when making decisions (Black, 2001; Brownson, Chriqui, & Stamatakis, 2009; Rycroft-Malone et al., 2004). While there are available examples of efforts to identify effective strategies for integrating various forms of evidence (Grunwald, 2008), best approaches to doing so are not always clear, particularly if conclusions are uncertain or if evidence is contradictory (Grunwald, 2008; Pluye, Grad, Levine, & Nicolau, 2009; Protheroe, Bower, & Chew-Graham, 2007). Furthermore, while existing literature espouses the benefits of building broad knowledge to capture the depth and complexity of health and disease (Jones, Podolsky, & Greene, 2012; Trostle, 2005), there is limited information about the most effective ways to synthesize different forms of evidence so that a comprehensive assessment of disease burden can be constructed. The process used here provides an example of how to synthesize different forms of evidence for a comprehensive description of disease burden.

While there are a host of benefits to the integrative approaches employed here, there are also limitations. One such limitation is the necessary reliance on previous works which may have their own inherent weaknesses. As noted in the reports of studies that contributed to the analyses here, works characterizing community perspectives on *H. pylori* infection and associated diseases were restricted by the lens of academic researchers with different cultural backgrounds and perspectives. Similarly, the research contributing quantitative descriptions of *H. pylori* infection and gastric cancer incidence were limited by issues related to data access and a small number of cases which led to imprecise estimates. Additionally, these quantitative descriptions did not summarize all health outcomes related to *H. pylori* due to data access challenges. Furthermore, the process of integrating works compiled as part of the same overarching research program may have inadvertently constrained the evidence contributing to a comprehensive description: the current analyses might have been strengthened by including research identified through other means such as a systematic review. A gathering of related works more broadly, however, was beyond the scope of the current work.

Summary

In summary, through the integration of information obtained using various methods of inquiry, we compiled a comprehensive description of *H. pylori* and associated diseases in northern Canadian populations. Through this synthesis, we were able to garner new insights into how individuals at risk understand and are impacted by the *H. pylori* bacterium and associated diseases. We were also able to identify knowledge gaps that warrant further research and public health action. As a result, this work supports the development of effective communication strategies and fosters the exchange of knowledge among community and academic research partners. It also provides opportunities to strengthen understandings of related health risks and of challenges encountered in research aimed at reducing these risks.

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8.2 Reflections and summary

To compile a comprehensive description of the burden from *H. pylori* infection and associated diseases in northern populations, my co-authors and I integrated information obtained from various forms of inquiry. The synthesized studies, conducted separately, included characterizations of community members' views of the bacterium and related diseases (Chapter 6) and descriptions of *H. pylori* infection and associated diseases in northern Canada using conventional epidemiologic methods (Chapter 7).

The synthesis of qualitative and quantitative information provided insights arising from a comprehensive description of disease burden among those impacted. A common theme across qualitative and quantitative studies included the disproportionate burden of *H. pylori* infection and stomach cancer among northern populations compared to other regions. However, there did not appear to be a shared understanding of *H. pylori* and its impacts within communities and across research program collaborators. Further, the burden attributed to *H. pylori* infection as characterized by northern communities may be broader than what is typically described by academic scientists and healthcare providers.

Here, I reflect on this applied example of synthesizing qualitative and quantitative studies, along with related elements of my dissertation using key principles as a framework for reflection: pragmatism, collaboration, and justice. I describe strengths and limitations of this work and consider ways in which these approaches may be improved in future endeavours.

Pragmatism

Pragmatic approaches in research permit the flexibility required to work with people of various backgrounds and perspectives. They also help with logistic realities of time constraints, heavy workloads, and limited resources. Being practical is useful because it ensures that knowledge gained through research has beneficial consequences. Throughout this dissertation, I identified the most pragmatic ways to fulfill research goals available. I contemplated this at various stages within each research initiative: in the selection of research methods, in their application, and in the compilation and reporting of research results.

To provide examples with greater potential for practical application, I aimed to conduct each research element in isolation. That is, rather than one element of the research informing the other sequentially, I pursued research based on qualitative inquiry and quantitative inquiry in tandem and integrated results afterwards, an approach sometimes referred to as a convergent mixed methods design (Fetters, Curry, & Creswell, 2013). Alternative approaches to mixed methods research such as exploratory or explanatory approaches (Bryman, 2006; Creswell, 2015) might have provided slightly different information or might have permitted more structured integration. However, my approach focused on research elements that could be valuable independently while permitting flexibility in their integration.

Despite its benefits, the application of research methods using pragmatic approaches limited the extent to which research results incorporated the perspectives of the target population as intended. For example, each aspect of the research was conducted when feasible and identified as suitable by community planning committees. This limited the ability to pursue more extensive or prolonged engagement methods within each community that might have provided further insights (Saucier Lundy, 2008). Methods that incorporated more in-depth relationship-building could have led to an even deeper understanding of the phenomenon. Similarly, this work might have been strengthened by the participation of community members in the analysis of semi-structured interviews. Because we bring our culturally-guided perspectives to the research we conduct (Walter & Andersen, 2013), this work was limited by how our worldviews impacted our analyses and interpretations. A community knowledge-holder or perhaps a person with similar cultural backgrounds and perspectives might have identified different themes had they contributed to interpreting the data.

Collaboration

The overarching CAN*Help* Working Group research program is a large intersectoral team. There are a host of strengths in this kind of approach, many of which I was able to leverage within this dissertation: for example, working collaboratively with community partners ensured that the research was implemented in meaningful ways. These collaborative approaches supported the incorporation of multiple perspectives and expertise, including the perspectives of knowledge beneficiaries, to maximize the benefits. Work with government partners had additional benefits: in particular, access to data, such as cancer registry and administrative data that may otherwise be difficult for academic researchers to access and use for research purposes.

While the CAN*Help* Working Group is bolstered by positive relationships with territorial data custodians, there were substantial delays in accessing data from both NT and YT government partners. There were also challenges in identifying what data were available, the level of aggregation that would permit the pursuit of specific research questions while also protecting the privacy of individuals, and other communication challenges. Given the daily business of our government partners, it is understandable that data supports for the research program may not be a priority for health officials and members of their teams who are dealing with competing public health priorities. These challenges illustrate the necessity of working collaboratively with public health surveillance teams to address research questions and of clearly outlining collaborator expectations at the beginning stages of the research.

Justice

These works supported equitable approaches to addressing epidemiologic research questions. Equity was achieved in a variety of ways. For example, community-university partnerships created reciprocal opportunities for knowledge exchange by collaboratively identifying research questions and planning in partnership to ensure that research was implemented in meaningful ways for each community. Likewise, the co-development and co-implementation of reciprocal learning initiatives facilitated understanding among research partners about one another's perspectives. Rather than relying solely on conventional epidemiologic indicators for disease burden, characterizations of the burden from *H. pylori* infection and associated diseases included descriptions from the target population. This facilitated the incorporation of the voices of target populations when aiming to describe their health.

Some epidemiologists argue that the potential for public health impact and, by extension, the target population's perspectives, are not relevant to epidemiology (Rothman, Adami, & Trichopoulos, 1998). I have heard some academic scientists with backgrounds in epidemiology say, for example, that the views of the target population about a given health issue "are perceptions, not facts." As I described in Chapter 2, I believe that socially responsible science must consider the greater good. For this reason, I view epidemiology as the study of the distribution and determinants of a spectrum of health states for the purpose of identifying effective actions for improving health. In this framework, how members of a target population view a health topic and describe its impact does not dispute facts; rather, it provides context for them. This context is vital to the identification and implementation of effective public health actions aimed at improving community health.

The necessity of incorporating context into descriptions of disease burden is in line with aspects of Indigenous research methods. In particular, Indigenous research methods acknowledge that researchers are participants in the production of knowledge, and that language and narratives are not limited to describing facts but instead play a role in establishing facts (Blackstock, 2009; Kovach, 2010; Wilson, 2001). That is, facts are not objective realities; rather, they emerge and are shaped by our perspectives, the questions we ask, the methods we apply in garnering new knowledge, and the results we communicate. These concepts apply to research methods grounded in both qualitative and quantitative inquiry (Walter & Andersen, 2013).

In my view, the examples included in this dissertation do not go far enough to incorporate perspectives of the target population. A key limiting factor is that I have described perspectives that are not my own through my lens as an academic researcher with a cultural background that differs from the populations I have characterized. To more accurately incorporate the perspectives of those impacted, the voices of those impacted should factor more heavily in the interpretation and reporting of data. Similar shortfalls were highlighted above when considering pragmatic approaches: methods that support more in-depth relationship-building could have led to an even deeper understanding of the phenomenon. Likewise, participation of community members in the identification, application, and analysis of research methods throughout the dissertation would have bolstered efforts aimed at incorporating the perspectives of the target population.

Summary

In this applied example, my co-authors and I characterized the disease burden from *H. pylori* infection as described by northern Canadian populations (Chapter 6). We also described the disease burden from *H. pylori* infection and associated diseases in NT and YT populations using more conventional epidemiologic approaches (Chapter 7). Finally, we integrated this information to provide a comprehensive description of disease burden among those impacted (sub-Chapter 8.1). While there were many strengths of the works included within this dissertation, I have identified improvements that would have supported more pragmatic, collaborative, and equitable approaches. The value of this work arises from its comprehensive description of the disease burden from *H. pylori* infection in northern Canadian populations, as well as the examples it provides of how community-university partnerships can achieve meaningful descriptions of disease burden that go beyond conventional epidemiologic measures to enhance the potential for supporting the identification and implementation of effective public health strategies for disease control.

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Chapter 9: Summary and next steps

Throughout this dissertation, I aimed to incorporate key principles that guide my work in epidemiology: pragmatism, collaboration, and justice. Driven by these principles, I found myself questioning the meaningfulness of typical epidemiologic approaches when describing the burden of disease in a population, particularly when addressing community concerns about a specific health condition. I sought pragmatic solutions to methodological challenges in community-university research endeavours and opportunities to incorporate collaborative approaches so that each aspect of the research pursued could be accomplished through partnership. Through these collaborative pragmatic pursuits, and in particular by incorporating the voices of those impacted in descriptions of their disease burden, I also aimed to bring elements of equity to the process of epidemiologic investigation. The ultimate overarching goal of my dissertation, therefore, was to actively apply these principles to identify gaps in typical methods of descriptive epidemiology and provide working examples of how these methods may be supplemented to better incorporate these principles.

To fulfill this overarching goal, I provided examples of how pragmatic, collaborative, and equitable approaches may be applied in epidemiologic investigations that aim to address community concerns about an identified threat to their health. This included, for example, two collaboratively developed and implemented community-university projects that contributed to knowledge sharing across research partners. In the first, a knowledge exchange initiative brought community youth to the University of Alberta to learn about aspects of the research program conducted at the academic institution. In the second, contests were held across participating communities to identify a visual image, drawn by a community member, which would be used to represent the community-specific research project.

I also applied these principles in an expansion of conventional methods of public health surveillance and descriptive epidemiology to achieve a more comprehensive description of disease burden. To accomplish this, I began by outlining concepts from the literature on the importance of incorporating the perspectives of those impacted into descriptions of disease burden and the value of using multiple forms of inquiry to achieve this. I followed this by providing an applied example of the kinds of information that might be useful in community-university partnerships that use epidemiologic inquiry to describe disease burden as an initial step in collaborative research aimed at improving health. I characterized the disease burden from *Helicobacter pylori* infection qualitatively from the perspective of residents of northern Canadian communities and then described this disease burden using conventional quantitative methods of descriptive epidemiology. Finally, I synthesized this qualitative and quantitative information to provide a comprehensive description of disease burden among those impacted.

My applied examples generated knowledge on how community members characterize the disease burden from *H. pylori* and associated diseases; they also provided quantitative descriptions of the occurrence of *H. pylori*-related disease across populations in which this occurrence had not been described previously. In addition to these contributions, this dissertation informs knowledge translation and risk communication strategies that will ultimately enhance the quality and relevance of my research. This was achieved through multiple collaborative endeavours where I worked with community and university research partners to create opportunities to exchange perspectives on biomedical research, explore research questions of interest, and discuss varying approaches to respectful research implementation. Such endeavours also promote meaningful reciprocal learning spaces that provide opportunities to build bridges between multiple worldviews and bolster more equitable landscapes.

Moreover, this dissertation provides examples for best practices when using epidemiologic approaches to describe the burden of disease, particularly when addressing community concerns about an identified health threat. By integrating the voices of the target population along with evidence from conventional epidemiologic measures, I was able to construct a comprehensive description of disease burden, garner new insights into how individuals at risk understand and are impacted by disease, and identify knowledge gaps that warrant further research. As a result, this dissertation contributes to the discipline of epidemiology by offering a methodologic approach to characterizations of disease burden informed by the perspective of those burdened; this approach can be applied in other university-community research partnerships aiming to address the community's questions about a specific health problem. Thus, by keeping in mind that, "We are not bound to a particular worldview and set of methods that are invariant prerequisites for production of legitimate knowledge" (Wing, 1998, p. 242), this dissertation highlights the value of incorporating various perspectives when using epidemiologic approaches to identify effective – and equitable – public health solutions.

Despite the many benefits of this work, as with any challenging endeavour, there is always room for improvement. For example, to extensively characterize community perspectives, spending more time in communities, building relationships and trust would likely have added value; in particular, additional aspects of community perspectives might have become apparent. Similarly, the direct participation of community members in the analysis and interpretation of data would have offered opportunities to more effectively incorporate perspectives of community members otherwise lost through the lens of an academic researcher. These processes, however, would have required time and resources beyond what was feasible for me. By completing this work within the bounds of my logistic constraints, it supports efforts to find pragmatic solutions that can be implemented feasibly by public health practitioners, such as those who practice public health surveillance. Further limitations constrained my attempts to compile quantitative elements of the applied work: reliance on data that was either not accessible or difficult to obtain limited my ability to more fully describe the disease burden in the target and comparison populations.

Furthermore, while I employed a narrative synthesis to incorporate knowledge obtained in parallel through various forms of inquiry, there are other approaches that might be effective. I look forward to exploring alternative strategies to incorporating the voice of the target population in future research endeavours. These efforts might include the identification, implementation, and formal evaluation of reciprocal learning opportunities in future collaborative university-community research partnerships. Similarly, in partnership with those impacted, I hope to identify and evaluate alternative – and perhaps more effective – research approaches aimed at describing burden of disease that incorporate the target population's descriptions into this characterization. This may include employing different strategies for the integration of diverse forms of evidence, such as pursuing separate research inquiries in sequence so they could inform one another (rather than executing research projects concurrently as done in this dissertation). This could involve comparing conventional epidemiologic measures of disease burden to self-characterizations of disease across different populations in order to evaluate the extent to which they align in various scenarios.

Inspired by work I conducted for my dissertation to highlights the benefits of collaborative approaches in epidemiology, I have been fortunate to have opportunities to apply similar actions in public health surveillance initiatives through the Epidemiology and Surveillance team at Alberta Health (the provincial Ministry of Health). There, I work with Indigenous communities and organizations to identify and solve data challenges, and to compile Indigenous-specific health information through respectful processes. For example, in partnership with the Alberta First Nations Information Governance Centre ("Alberta First Nations Information Governance Centre", n.d.), we aim to build respectful and collaborative ways to compile First Nations-specific health information such as monthly one-page reports based on a topic selected by First Nations communities. We also foster reciprocal learning environments where we can learn about meaningful public health surveillance approaches together; this has included the placement of a First Nations intern with our team at the Ministry. These endeavours are particularly rewarding given the gross and persistent health inequities that exist across populations, such as a growing gap in life expectancy between First Nations and non-First Nations in Alberta (Alberta Health, 2016): working in collaboration with those impacted to identify pragmatic ways to describe health profiles of interest to the target population contributes to efforts aimed at improved and equitable public health.

Through all of these experiences, I have bolstered my desire to question typical epidemiologic approaches. Indeed, my experiences in completing this dissertation have revealed to me more intriguing questions than answers. As a result, I am excited about future opportunities – additional journeys – to work collaboratively with others to identify more effective and equitable solutions for improved public health using tools provided by epidemiology. I imagine this will include the respectful identification of research questions of interest to those impacted, the exploration of various scientific approaches that may be employed to answer these questions, and the compilation and communication of resulting knowledge in ways that support meaningful change. Ultimately, I seek to contribute to a future where we will learn how to incorporate various perspectives throughout epidemiologic research endeavours in meaningful ways for more effective and equitable action. In the words of the late Steve Wing (1998), "Constructing health for all requires constructing an epidemiology for all" (p. 251).

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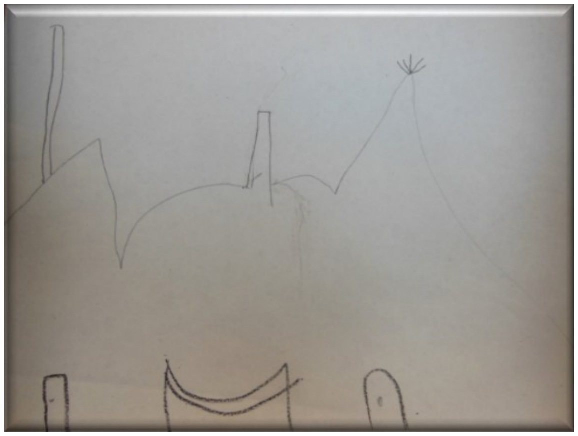
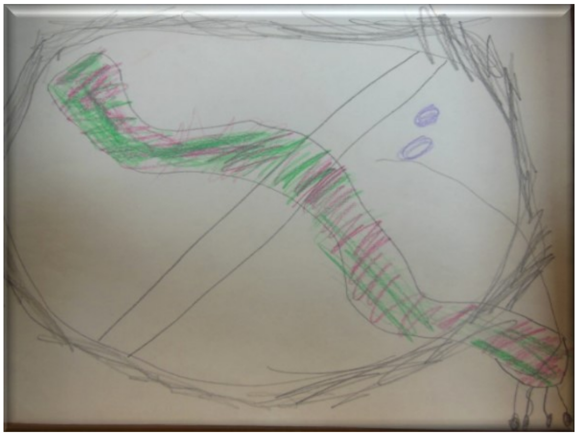
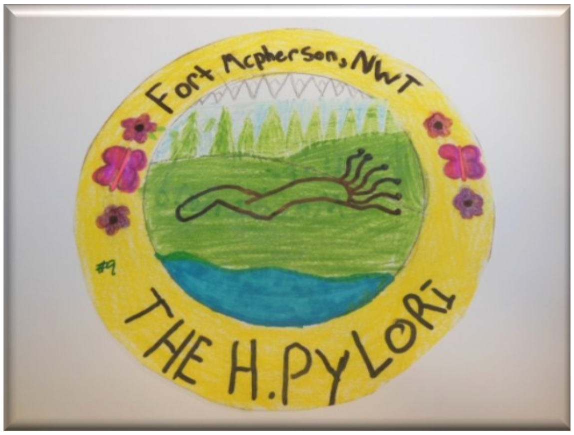
Appendices

Appendix I: Supplemental material for Chapter 4.2

Drawings submitted by Fort McPherson *H. pylori* Project logo contest participants. All drawings were submitted by children (younger than 18 years of age) living in Fort McPherson, Northwest Territories, as part of a logo contest held in the community June, 2012.






Fort Mcpherson, NWT
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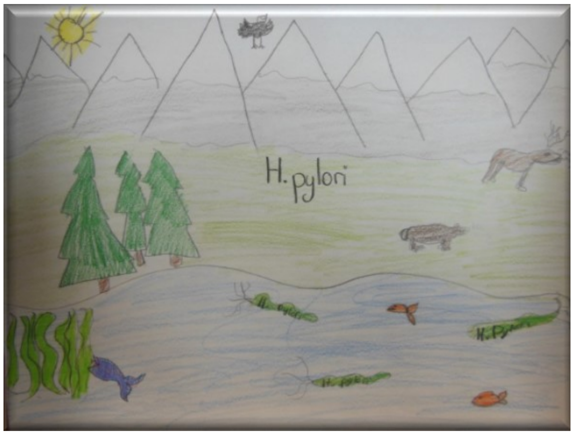
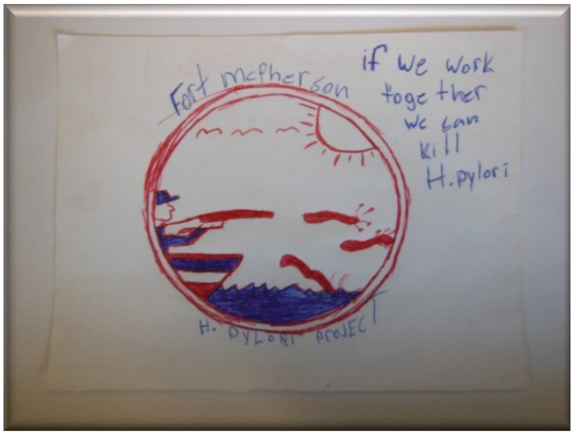


H. pylori
H. pylori
H. Pylori
H. pylori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H. PYLORI PROJECT


FORT McPHERSON
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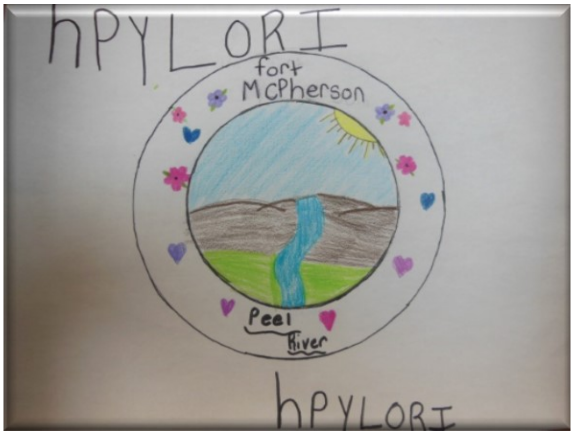
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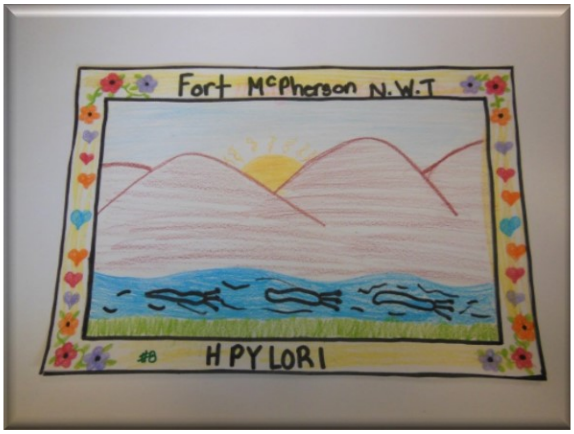
H-Pylori


Fort McPherson N.W.T
#8
HPYLORI


Fort McPherson
#7
HPYLORI


Fort McPherson Northwest Territories
The H. PYLORI PROJECT NWT


Old Crow, Yukon
H. Pylori Project

Appendix II: Supplemental material for Chapter 6.1

Table S6.1.1: Number of media items reporting on *H. pylori* in the Northwest Territories or Yukon included in the study sample by media source and media type, no date restrictions

	Media Type				
	Online Print		Radio/Video		
Media Source	**Newspapers**	**Magazines**	**Radio**	**Video**	**Study Sample**
Canadian Newsstand/ Canadian Business and Current Affairs	4	1	0	1	6
Northern News Services	15	0	0	0	15
Canadian Broadcasting Service	7	0	2	0	9
Slave Lake Journal	0	0	0	0	0
Yukon News	1	0	0	0	1
CAN*Help* Working Group media database	7	1	19	0	27
Total	34	2	21	1	58

Table S6.1.2: Number and percent of 58 media items reporting on *H. pylori* in the Northwest Territories or Yukon by frame of media item and media type, 2000-2017

Main frame of media	Online print	Radio/video	Total	Percent	95% CI
Research	24	18	42	72	(55, 83)
Related diseases	2	3	5	9	(3, 19)
Community concern	2	0	2	3	(0, 12)
H. pylori description	1	1	2	3	(0, 12)
Other*	7	0	7	12	(5, 23)

*'Other' includes cancers linked to infectious disease agents, clean water, research conducted in the North, community topics, and research participants.
95% CI = 95% Confidence Interval

Table S6.1.3: Number and percent of 56 media items reporting on *H. pylori* in the Northwest Territories or Yukon that mention research by main focus of research and media type, 2000-2017

Focus of research	**Online print**	**Radio/video**	**Total**	**Percent**	**95% CI**
H. pylori	27	18	45	80	(68, 90)
Stomach cancer	5	4	9	16	(8, 28)
Water quality	2	0	2	4	(0, 12)

95% CI = 95% Confidence Interval

Table S6.1.4: Number and percent of 52 media items and media types reporting on *H. pylori* in the Northwest Territories or Yukon that report research goals by goal category and media type, 2000-2017

Main goals of research	**Online print**	**Radio/video**	**Total**	**Percent**	**95% CI**
Test for *H. pylori*	15	7	22	42	(29, 57)
Increase knowledge of *H. pylori* and stomach cancer	6	9	15	29	(17, 43)
Decrease negative health outcomes	5	7	12	23	(13, 37)
Treat *H. pylori* infection	5	3	8	15	(7, 28)
Identify *H. pylori* strains and evaluate antibiotics	8	0	8	15	(7, 28)
Address community concerns	1	2	3	6	(1, 16)

Percent (%) refers to the proportion of media items reporting a specified research goal among those that report on research goals. Media items may have mentioned more than one goal and, as a result, may be included in multiple categories.

'Negative health outcomes' include *H. pylori* infection, gastric cancer, cancer, and health risks (general)

95% CI = 95% Confidence Interval

Table S6.1.5: Number and percent of 49 media items reporting on *H. pylori* in the Northwest Territories or Yukon that report concerns related to *H. pylori* by cause of concern and media type, 2000-2017

Focus of concerns	**Online print**	**Radio/video**	**Total**	**Percent**	**95% CI**
Stomach cancer	18	12	30	61	(46, 75)
H. pylori	3	8	11	22	(12, 37)
Unknown origin/source	4	0	4	8	(2, 20)
Cancer (type not specified)	1	0	1	2	(0, 11)
Other	4	1	5	10	(3, 22)

Percent (%) refers to the proportion of media items reporting a specified concern among media items that report concerns. Media items may have mentioned more than one concern and, as a result, may be included in multiple categories.

'Other' includes *H. pylori* transmission, water, and *H. pylori* diseases (general).

95% CI = 95% Confidence Interval

Table S6.1.6: Number and percent of 19 media items reporting on *H. pylori* in the Northwest Territories or Yukon that report risk factors for *H. pylori* infection by risk factor category and media type, 2000-2017

***H. pylori* risk factors**	**Online print**	**Radio/video**	**Total**	**Percent**	**95% CI**
Crowded conditions	1	3	4	21	(6, 46)
Sanitation issues	3	1	4	21	(6, 46)
Diet	4	0	4	21	(6, 46)
Childhood/young age	2	1	3	16	(3, 40)
Traditional practices	1	1	2	11	(1, 33)
Poverty	1	1	2	11	(1, 33)

Percent (%) refers to the proportion of media items reporting a specified risk factor among media that mention risk factors. Media items may have mentioned more than one risk factor and, as a result, may be included in multiple categories.

‘Traditional practices’ includes less modernization and chewing food for infants.

95% CI = 95% Confidence Interval

Table S6.1.7: Number and percent of 53 media items reporting on *H. pylori* in the Northwest Territories or Yukon that report outcomes of *H. pylori* infection by outcome category and media type, 2000-2017

Outcome of *H. pylori* infection	**Online print**	**Radio/video**	**Total**	**Percent**	**95% CI**
Stomach cancer	28	21	49	92	(82, 98)
Ulcer	23	13	36	68	(54, 80)
Stomach issues	8	2	10	19	(9, 32)
Harmless/no symptoms	5	5	10	19	(9, 32)
Inflammation (stomach lining)	5	2	7	13	(6, 25)
Cancer (type not specified)	4	0	4	8	(2, 18)

Percent (%) refers to the proportion of media items reporting a specified outcome among media items that mention outcomes. Media items may have mentioned more than one outcome and, as a result, may be included in multiple categories.

‘Stomach issues’ includes loss of appetite, general stomach upset, and indigestion.

95% CI = 95% Confidence Interval

Table S6.1.8: Number and percent of 18 media items reporting on *H. pylori* in the Northwest Territories or Yukon that report a source of *H. pylori* by source and media type, 2000-2017

Source of *H. pylori*	Online print	Radio/video	Total	Percent	95% CI
Water	8	1	9	50	(26, 74)
Unknown source	5	2	7	39	(17, 64)
Humans	4	2	6	33	(13, 59)
Other	3	0	3	17	(4, 41)

Percent (%) refers to the proportion of media items reporting a specified source among media items that mention sources. Media items may have mentioned more than one source and, as a result, may be included in multiple categories.

'Other' includes food and residential school.

95% CI = 95% Confidence Interval

Table S6.1.9: Number and percent of 21 media items reporting on *H. pylori* in the Northwest Territories or Yukon that report a mode of *H. pylori* transmission by reported pathway and media type, 2000-2017

Transmission pathway	Online print	Radio/video	Total	Percent	95% CI
Bodily fluids	8	2	10	48	(26, 70)
Unknown transmission pathway	2	4	6	29	(11, 52)
Person-to-person	4	2	6	29	(11, 52)
Water	2	0	2	10	(1, 30)
Poor hygiene	0	1	1	5	(0, 24)
Traditional practices	0	1	1	5	(0, 24)

Percent (%) refers to the proportion of media items reporting a specified mode of transmission among media items that mention transmission. Media items may have mentioned more than one transmission pathway and, as a result, may be included in multiple categories.

'Bodily fluids' includes feces, saliva, vomit, and diarrhea. 'Traditional practices' was the term used to describe a possible way that *H. pylori* is spread.

95% CI = 95% Confidence Interval

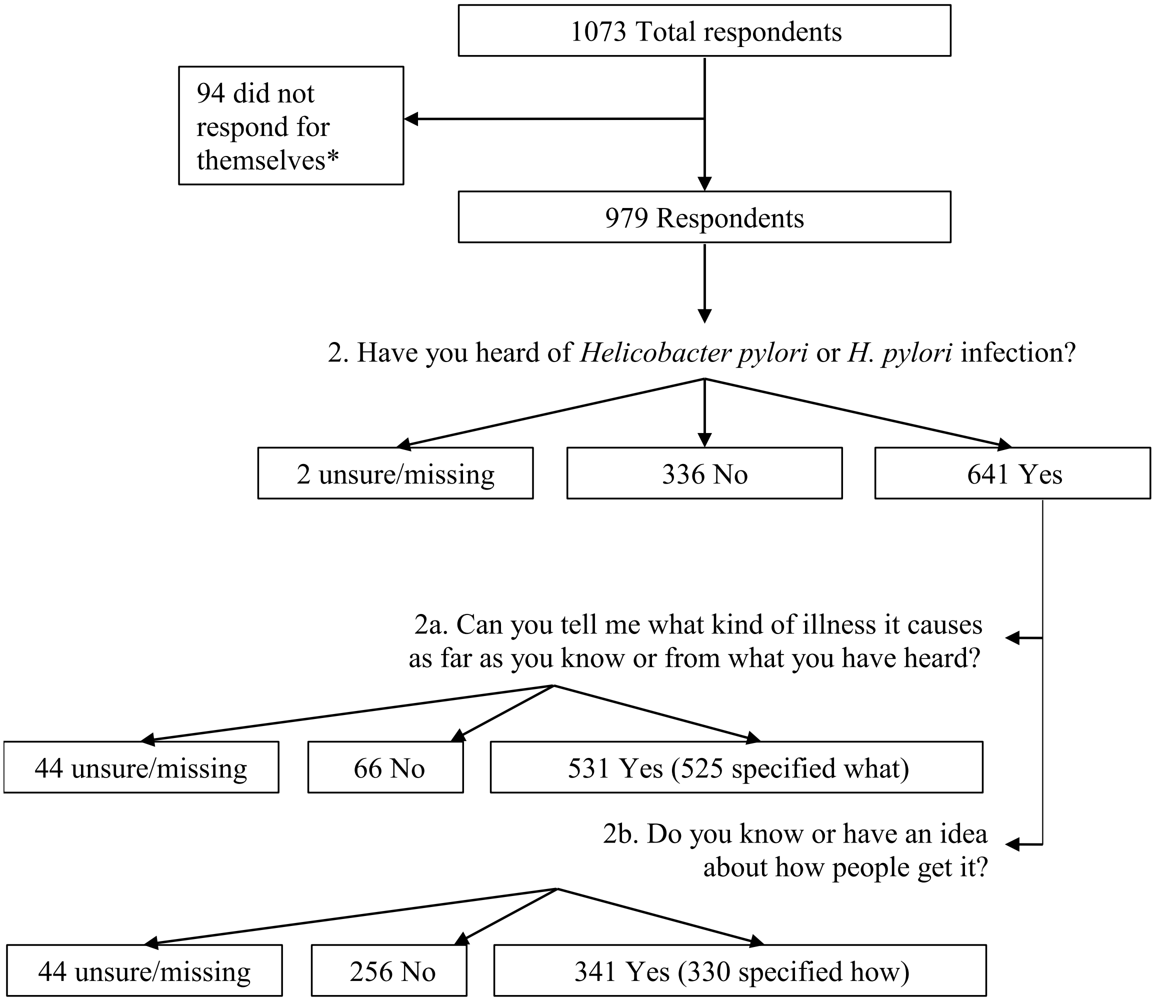
Study Sample Media List

Number	Media Type	Publisher	Date Published	Journalist	Title	Source
1	Newspaper	Northern News Services	2000-04-24	Terry Halifax	Keeping water clean	Northern News Services
2	Newspaper	Northern News Services	2000-09-04	Terry Halifax	In search of cancer clues	Northern News Services
3	Newspaper	Northern News Services	2004-12-13	Dorothy Westerman	How the communities crumble	Northern News Services
4	Newspaper	Northern News Services	2008-02-06	John Curran	Aklavik scoped for stomach cancer	Northern News Services
5	Newspaper	Yellowknifer	2008-02-08	John Curran	Stanton docs assist in Aklavik	CAN*Help* Working Group media database
6	Newspaper	CBC News	2008-02-08	Unknown	Bacteria tests in Arctic hamlet may unlock stomach cancer mystery	Canadian Broadcasting Service
7	Newspaper	Edmonton Journal	2008-02-09	Jodie Sinnema	Call for help	Canadian Newsstand/Canadian Business and Current Affairs
8	Newspaper	The Gazette	2008-02-09	Jodie Sinnema	Hamlet's residents under microscope after Arctic stomach cancer outbreak	Canadian Newsstand/Canadian Business and Current Affairs
9	Newspaper	Globe and Mail	2008-02-11	Andre Picard	Medical team targeting stomach cancer in North	Canadian Newsstand/Canadian Business and Current Affairs
10	Newspaper	SIKU news	2008-02-13	Unknown	Why more stomach cancer in Aklavik, NWT?	CAN*Help* Working Group media database
11	Newspaper	CBC News	2008-02-29	Unknown	High rates of stomach bacteria in Arctic hamlet: study	Canadian Broadcasting Service
12	Newspaper	SIKU news	2008-02-29	Unknown	Many in NWT community at risk	CAN*Help* Working Group media database
13	Newspaper	Northern News Services	2008-03-10	Brodie Thomas	Tests show half of Aklavik has *H. pylori*	Northern News Services
14	Newspaper	Slave River Journal	2008-03-12	Gabriel Zarate	Arctic hamlet discovers cancer cause	CAN*Help* Working Group media database
15	Newspaper	News North NWT	2008-03-24	Brodie Thomas	Bacteria not a big concern	CAN*Help* Working Group media database
16	Newspaper	News North NWT	2008-03-24	Antoine Mountain	Cancer rates in Aklavik?	CAN*Help* Working Group media database
17	Newspaper	CBC News	2008-07-17	Unknown	Researchers offer to bring NWT stomach bacteria study to Yukon	Canadian Broadcasting Service
18	Newspaper	Yukon News	2008-07-21	Tristin Hopper	Researchers may tackle stomach cancer in Old Crow	Yukon News
19	Newspaper	Northern News Services	2008-10-20	Brodie Thomas	Woman warns of stomach bacteria	Northern News Services
20	Newspaper	Northern News Services	2009-05-18	Andrew Livingstone	Stomach virus may be linked to diet	Northern News Services
21	Newspaper	CBC News	2009-05-26	Unknown	Aklavik residents, scientists hopeful antibiotics curb cancer-causing bacteria	Canadian Broadcasting Service
22	Newspaper	SIKU news	2009-05-27	Unknown	Taking aim at cancer	CAN*Help* Working Group media database
23	Newspaper	Northern News Services	2009-12-07	Katie May	Three vie for mayor of Aklavik	Northern News Services
24	Newspaper	Northern News Services	2010-04-03	Katie May	NWT residents question drinking water quality	Northern News Services
25	Newspaper	Northern News Services	2010-11-15	Katie May	Looking for medical answers	Northern News Services
26	Newspaper	CBC News	2010-11-16	Unknown	Stomach bacteria study goes to Yukon	Canadian Broadcasting Service
27	Newspaper	Whitehorse Star	2010-11-18	Jason Unrau	MLA urges constituents to get tested for bacteria	Canadian Newsstand/Canadian Business and Current Affairs
28	Newspaper	Northern News Services	2011-11-17	Samantha Stokell	More Northern researchers needed	Northern News Services
29	Newspaper	CBC News	2012-01-06	Unknown	Researchers re-test Aklavik, N.W.T., residents for *H. Pylori*	Canadian Broadcasting Service
30	Newspaper	Northern News Services	2014-03-03	Chris Puglia	Aklavik man immortalized on U of A art wall	Northern News Services
31	Newspaper	Inuvik Drum	2015-10-22	News Briefs	Group invites residents	Northern News Services
32	Newspaper	Northern News Services	2015-11-02	Sarah Ladik	Stomach bacteria study lands in Inuvik	Northern News Services
33	Newspaper	Northern News Services	2017-02-16	Stewart Burnett	Testing begins for *h. pylori*	Northern News Services
34	Newspaper	CBC News	2017-02-24	Mackenzie Scott	Ongoing stomach infection study reaches Inuvik, NWT	Canadian Broadcasting Service
35	Magazine	Maclean's Magazine	2008-10-09	Kate Lunau	Eradicating a bad bacteria	Canadian Newsstand/Canadian Business and Current Affairs
36	Magazine	Reader's Digest	2010-07-01	Claudia Cornwall	Can you catch cancer?	CAN*Help* Working Group media database
37	Radio	CBC Radio - Northbeat	2008-02-06	Nadira Bagg	Research into link between bacteria and cancer in Aklavik	CAN*Help* Working Group media database
38	Radio	CBC Radio - Special Report	2008-02-06	Randy Henderson	Testing for link between bacteria and stomach cancer in Aklavik	CAN*Help* Working Group media database
39	Radio	CBC Radio	2008-02'	Unknown	Hansen	CAN*Help* Working Group media database
40	Radio	CBC Radio	2008-02'	Austrum	Hansen and Goodman	CAN*Help* Working Group media database
41	Radio	CBC Radio	2008'	Unknown	Morse	CAN*Help* Working Group media database
42	Radio	CBC Radio	2008-07	Unknown	Goodman	CAN*Help* Working Group media database
43	Radio	CBC Radio	2008-07	Linkletter	Kassi, Goodman, Munday	CAN*Help* Working Group media database
44	Radio	CBC Radio	2008'	Unknown	Cheung 1	CAN*Help* Working Group media database
45	Radio	CBC Radio	2008'	Unknown	Cheung 2	CAN*Help* Working Group media database
46	Radio	CBC Radio	2008'	Unknown	Elias	CAN*Help* Working Group media database
47	Radio	CBC Radio	2008'	Harbord	Hansen and Cheung	CAN*Help* Working Group media database
48	Radio	CBC Radio	2008'	Harbord	Morse, Elias	CAN*Help* Working Group media database
49	Radio	CBC Radio	Year unknown-05-26	Unknown	Edwards	CAN*Help* Working Group media database
50	Radio	CBC Radio	Year unknown-05-26	Harbord	Edwards and Huntington	CAN*Help* Working Group media database
51	Radio	CBC Radio	2009-05-26	Unknown	Huntington	CAN*Help* Working Group media database
52	Radio	CBC Radio	2010-05-14	Unknown	Huntington	CAN*Help* Working Group media database
53	Radio	CBC Radio	2010-11-09	Linkletter	Huntington and Butler-Walker	CAN*Help* Working Group media database
54	Radio	CBC Radio	2011-08-17	Sandi Coleman	Researchers test Old Crow residents for stomach bacteria	Canadian Broadcasting Service
55	Radio	CBC Radio	2012-01-06	Joslyn Oosenburg	H. pylori: Round 2 (S. Carraher)	Canadian Broadcasting Service
56	Radio	CBC Radio	2012-06-06	Wanda McLeod	Liz Wright	CAN*Help* Working Group media database
57	Radio	CBC Radio	2012-06-06	Joslyn Oosenburg	A. Colquhoun	CAN*Help* Working Group media database
58	Video	CBC - Decouverte	2010-11-07	Charles Tisseyre	Incidence du cancer - le mystere d'Aklavik	Canadian Newsstand/Canadian Business and Current Affairs

Appendix III: Supplemental material for Chapter 6.2

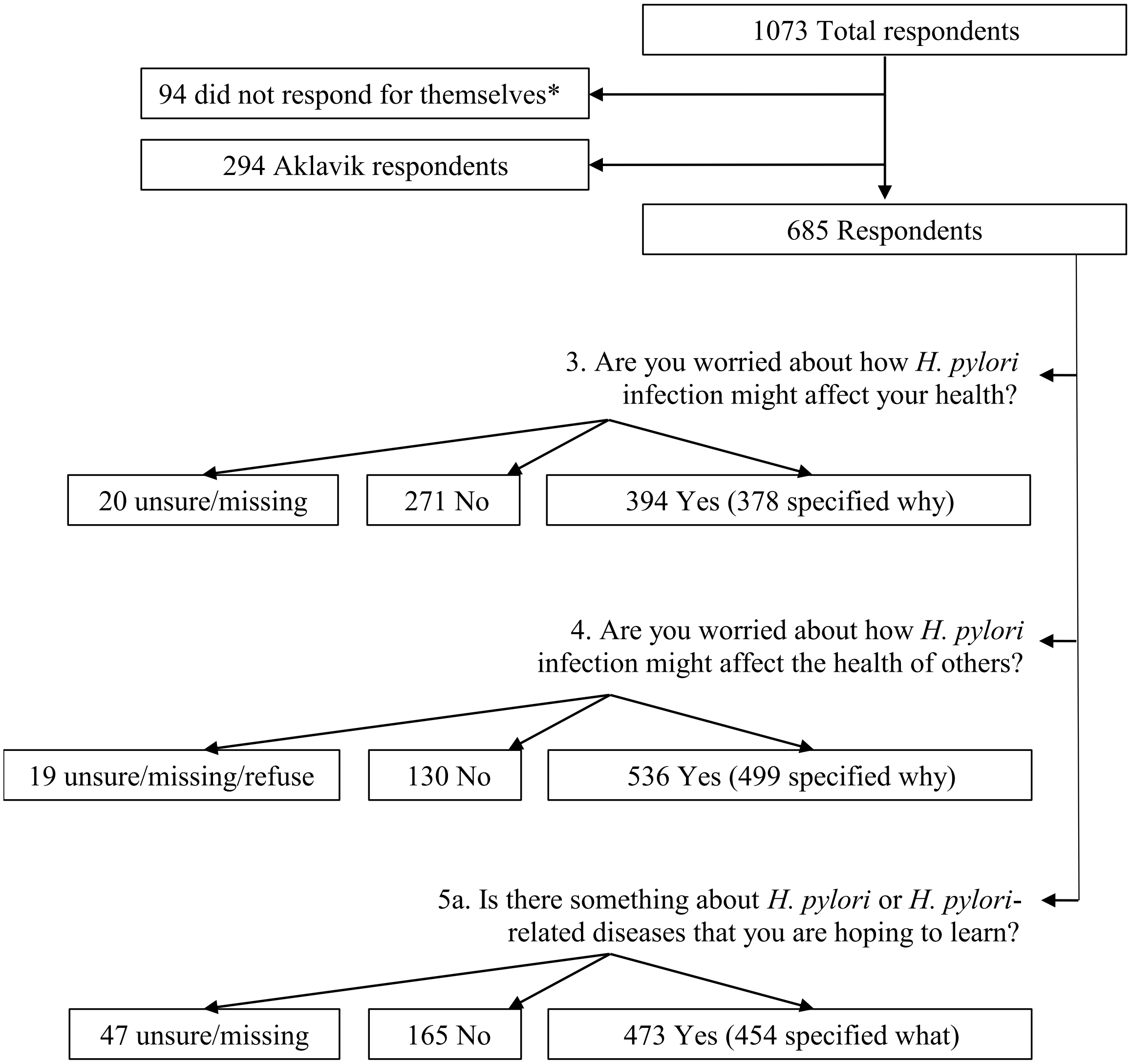
6.2. Supplement 1: Structured interviews

Figure S6.2.1: Flow chart of CAN*Help* Working Group Health Questionnaire respondents who answered questions 2, 2a, and 2b; western Canadian Arctic communities; 2007-2017



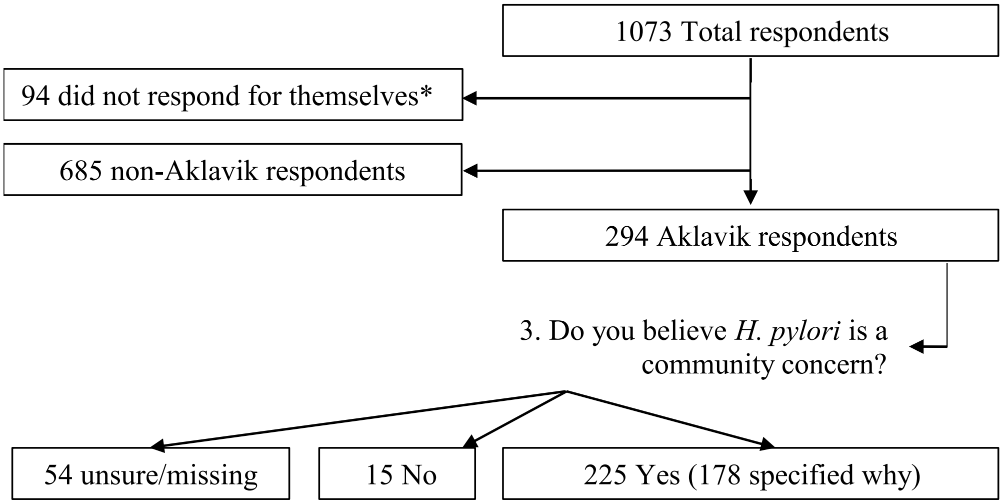
*Median age 9 years old, range <1 year old to 97 years old.

Figure S6.2.2: Flow chart of CAN*Help* Working Group Health Questionnaire respondents who answered questions 3, 4, and 5a; western Canadian Arctic communities excluding Aklavik; 2010-2017



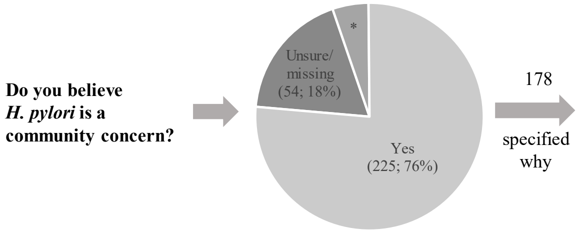
*Median age 11 years old; range 2 to 97 years old.

Figure S6.2.3: Flow chart of CAN*Help* Working Group Health Questionnaire respondents who answered question 3, Aklavik, 2007-2010



*Median age 6 years old; range <1 year old to 50 years old.

Figure S6.2.4: Distribution (number and proportion) of responses to questions about concerns related to *H. pylori* infection regardless of whether respondents had heard of *H. pylori* infection, Aklavik, 2007-2010 (n=294)



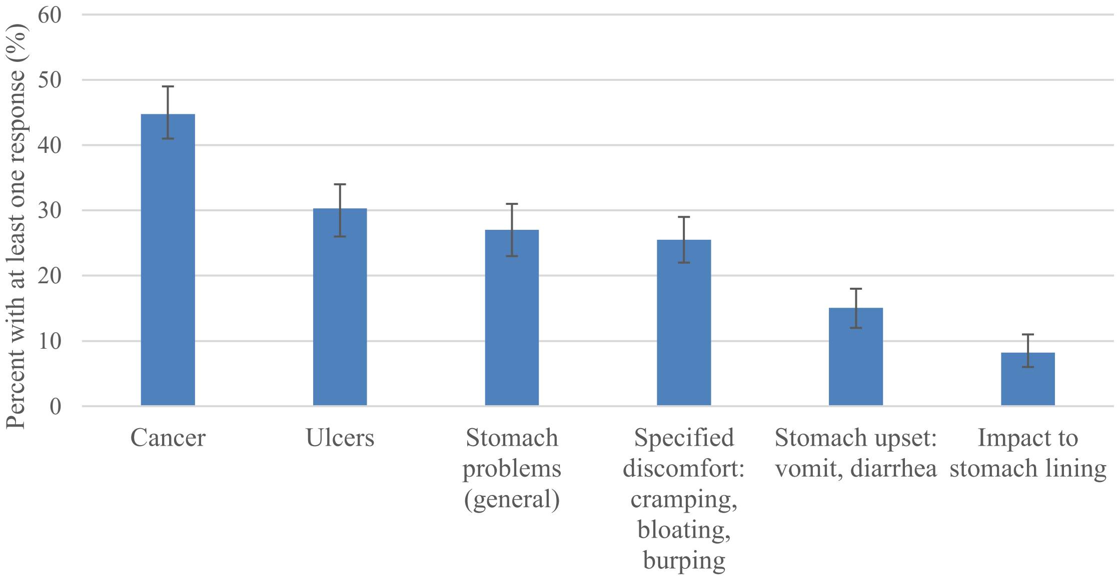
Main response categories	n	%	95% CI
Many people infected	44	25	(19, 32)
Link with cancer	41	23	(17, 30)
Causes illness	23	13	(7, 17)
Link with water	21	12	(8, 19)
Matter of health/safety	18	10	(6, 15)
Impacts the community	17	10	(6, 15)
Others worried/want answers	13	7	(4, 12)

Percent (%) in the table refers to the proportion who gave that response among those who indicated that they believe *H. pylori* infection is a community concern. Note that these are the most frequent response categories (responses mentioned by <5% of respondents are not presented). Individuals may have mentioned more than one response and, as a result, may be included in multiple categories.
* = no; 5% of respondents

Table S6.2.1: Distribution (number and proportion) of responses to questions about what kind of illness *H. pylori* causes, western Canadian Arctic communities, 2007-2017 (n=525)

Main response categories	**n**	**Percent total (%)**	**95% CI**
Cancer	235	45	(41, 49)
Ulcers	159	30	(26, 34)
Stomach problems (general)	142	27	(23, 31)
Specified discomfort: cramping, bloating, burping	134	26	(22, 29)
Stomach upset: vomit, diarrhea	79	15	(12, 18)
Impact to stomach lining	43	8	(6, 11)

Figure S6.2.5: Distribution (proportion) of responses to questions about what kind of illness *H. pylori* causes, western Canadian Arctic communities, 2007-2017 (n=525)

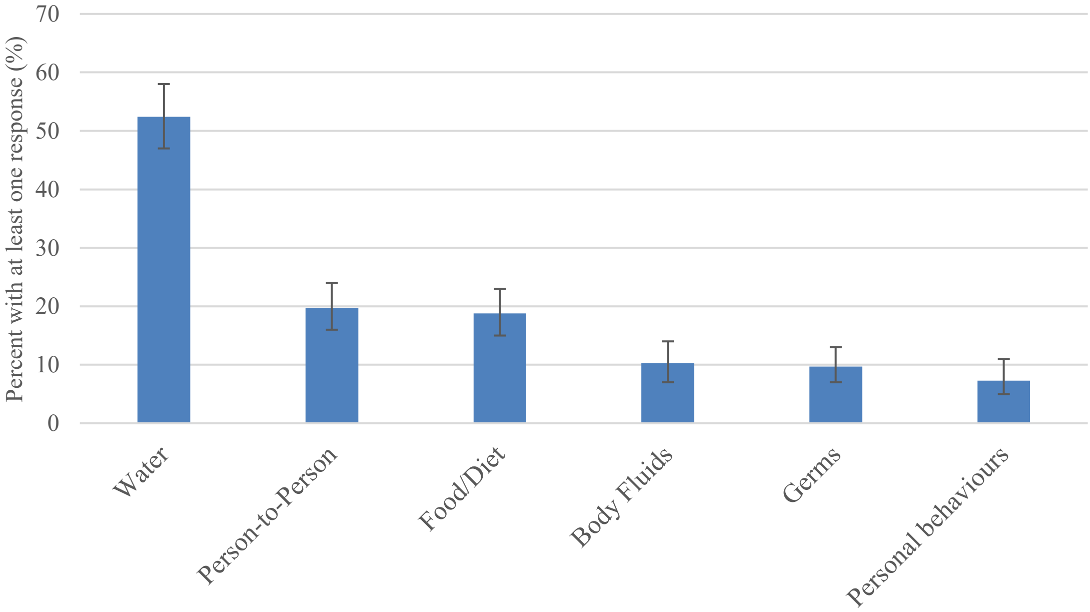


Percent refers to the proportion who gave that response among those who indicated that they knew what kind of illness *H. pylori* causes. Note that these are the most frequent response categories (responses mentioned by <5% of respondents are not presented). Individuals may have mentioned more than one response and, as a result, may be included in multiple categories.

Table S6.2.2: Distribution (number and proportion) of responses to questions about how people may get infected by *H. pylori*, western Canadian Arctic communities, 2007-2017 (n=330)

Main response categories	**n**	**Percent total (%)**	**95% CI**
Water	173	52	(47, 58)
Person-to-Person	65	20	(16, 24)
Food/Diet	62	19	(15, 23)
Body Fluids	34	10	(7, 14)
Germs	32	10	(7, 13)
Behaviour-related	24	7	(5, 11)

Figure S6.2.6: Distribution (proportion) of responses to questions about how people may get infected by *H. pylori*, western Canadian Arctic communities, 2007-2017 (n=330)

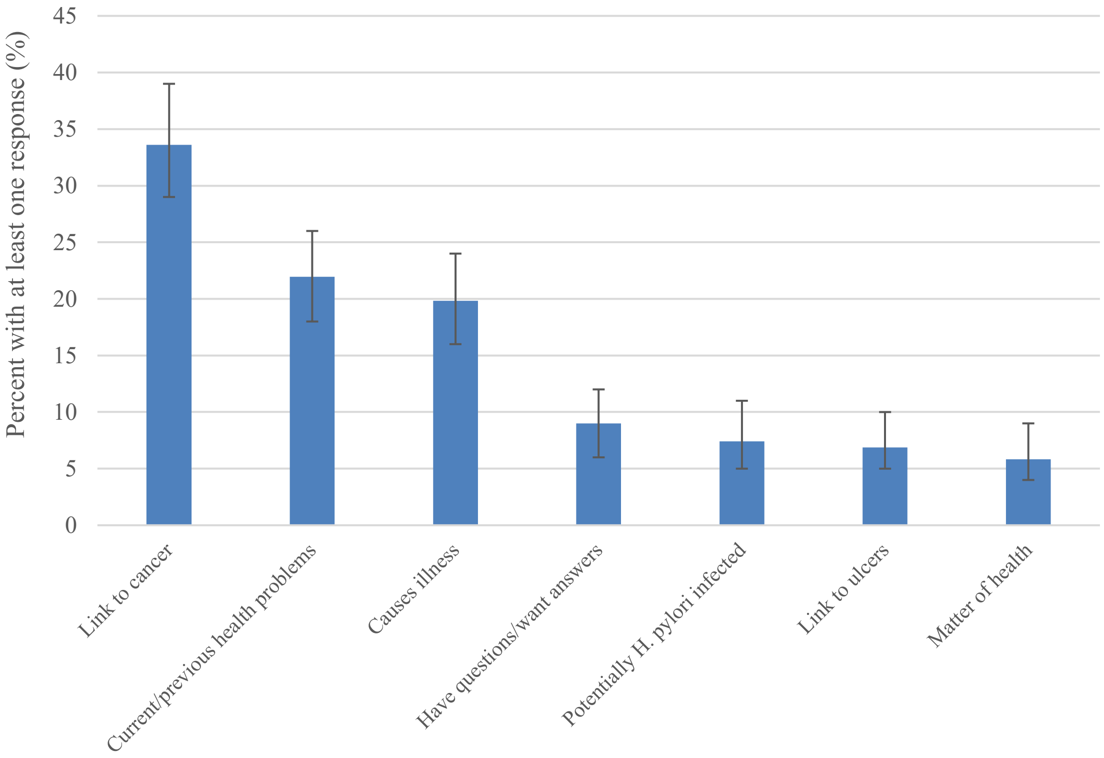


Percent refers to the proportion who gave that response among those who indicated that they knew or had an idea about how people get *H. pylori*. Note that these are the most frequent response categories (responses mentioned by <5% of respondents are not presented). Individuals may have mentioned more than on response and, as a result, may be included in multiple categories.

Table S6.2.3: Distribution (number and proportion) of responses to questions about why respondents are worried about how *H. pylori* might affect their health, western Canadian Arctic communities excluding Aklavik, 2010-2017 (n=378)

Main response categories	**n**	**Percent total (%)**	**95% CI**
Link to cancer	127	34	(29, 39)
Current/previous health problems	83	22	(18, 26)
Causes illness	75	20	(16, 24)
Have questions/want answers	34	9	(6, 12)
Potentially *H. pylori* infected	28	7	(5, 11)
Link to ulcers	26	7	(5, 10)
Matter of health	22	6	(4, 9)

Figure S6.2.7: Distribution (proportion) of responses to questions about why respondents are worried about how *H. pylori* might affect their health, western Canadian Arctic communities excluding Aklavik, 2010-2017 (n=378)

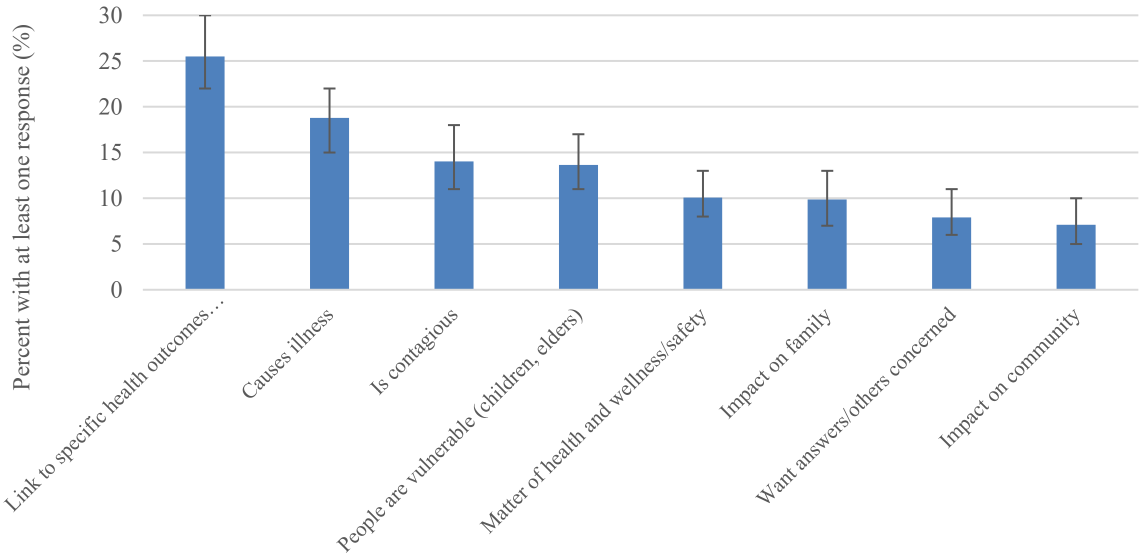


Percent refers to the proportion who gave that response among those who indicated that they are worried about how *H. pylori* infection might affect their health. Note that these are the most frequent response categories (responses mentioned by <5% of respondents are not presented). Individuals may have mentioned more than on response and, as a result, may be included in multiple categories.

Table S6.2.4: Distribution (number and proportion) of responses to questions about worries related to how *H. pylori* infection might affect the health of others, western Canadian Arctic communities excluding Aklavik, 2010-2017 (n=499)

Main response category	**n**	**Percent total (%)**	**95% CI**
Link to specific health outcomes (cancer, ulcer, death)	127	25	(22, 30)
Causes illness	92	18	(15, 22)
Is contagious	71	14	(11, 18)
People are vulnerable (children, elders)	69	14	(11, 17)
Matter of health and wellness/safety	51	10	(8, 13)
Impact on family	49	10	(7, 13)
Want answers/others concerned	40	8	(6, 11)
Impact on community	36	7	(5, 10)

Figure S6.2.8: Distribution (proportion) of responses to questions about worries related to how *H. pylori* infection might affect the health of others, western Canadian Arctic communities excluding Aklavik, 2010-2017 (n=499)

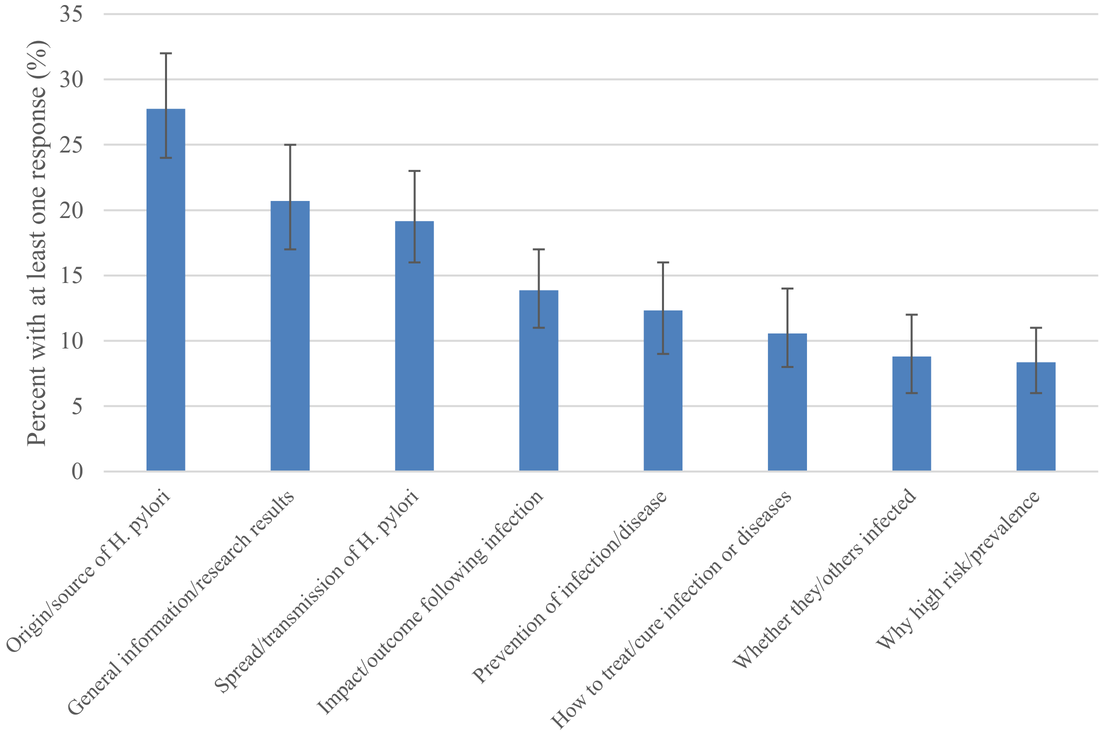


Percent refers to the proportion who gave that response among those who indicated that they are worried about how *H. pylori* infection might affect the health of others. Note that these are the most frequent response categories (responses mentioned by <5% of respondents are not presented). Individuals may have mentioned more than on response and, as a result, may be included in multiple categories.

Table S6.2.5: Distribution (number and proportion) of responses to questions about what respondents would like to learn about *H. pylori*-related topics, western Canadian Arctic communities excluding Aklavik, 2010-2017 (n=454)

Main response category	**n**	**Percent total (%)**	**95% CI**
Origin/source of *H. pylori*	126	28	(24, 32)
General information/research results	94	21	(17, 25)
Spread/transmission of *H. pylori*	87	19	(16, 23)
Impact/outcome following infection	63	14	(11, 17)
Prevention of infection/disease	56	12	(9, 16)
How to treat/cure infection or diseases	48	11	(8, 14)
Whether they/others infected	40	9	(6, 12)
Why high risk/prevalence	38	8	(6, 11)

Figure S6.2.9: Distribution (proportion) of responses to questions about what respondents would like to learn about *H. pylori*-related topics, western Canadian Arctic communities excluding Aklavik, 2010-2017 (n=454)

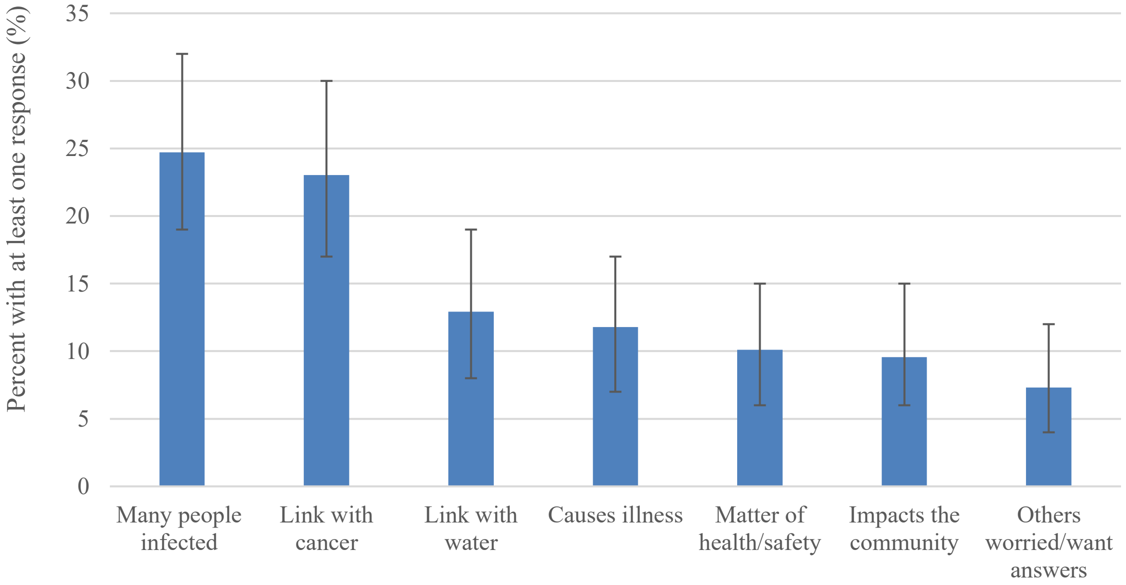


Percent refers to the proportion who gave that response among those who indicated that there was something about *H. pylori* or *H. pylori*-related diseases that they were hoping to learn. Note that these are the most frequent response categories (responses mentioned by <5% of respondents are not presented). Individuals may have mentioned more than on response and, as a result, may be included in multiple categories.

Table S6.2.6: Distribution (number and proportion) of responses to questions about why respondents believe *H. pylori* is a community concern, Aklavik, 2007-2010 (n=178)

Main response category	**n**	**Percent total (%)**	**95% CI**
Many people infected	44	25	(19, 32)
Link with cancer	41	23	(17, 30)
Causes illness	23	13	(7, 17)
Link with water	21	12	(8, 19)
Matter of health/safety	18	10	(6, 15)
Impacts the community	17	10	(6, 15)
Others worried/want answers	13	7	(4, 12)

Figure S6.2.10: Distribution (proportion) of responses to questions about why respondents believe *H. pylori* is a community concern, Aklavik, 2007-2010 (n=178)



Percent refers to the proportion who gave that response among those who indicated that they believe *H. pylori* infection is a community concern. Note that these are the most frequent response categories (responses mentioned by <5% of respondents are not presented). Individuals may have mentioned more than on response and, as a result, may be included in multiple categories.

6.2. Supplement 2: Semi-structured interviews

Choice of Methods

While outlining a philosophical or theoretical foundation is not typical for epidemiologic descriptions of research approaches, such an omission masks the philosophical or theoretical influences on how research is designed and how these influences constrain correct interpretations of what flows from the research. As Krieger (2011) notes, "…without explicit and transparent theory…we are likely to pose poorly-conceived hypotheses, inadequately interpret our findings, and potentially generate dangerously incomplete or wrong answers" (p. viii). Rather than choose an existing philosophy or theory, I have drawn on my own philosophy to set research goals and select methods that permit the most effective assessment of research questions to achieve my goals. As noted by Mayan (2009), "what is fundamental is making wise, thoughtful decisions through the course of the research so that at the end you will have something to conclude" (p. 32). Acknowledging my own philosophy allows me to be transparent about how my perspectives influence each aspect of my research, including which methods are selected, how data are collected and analyzed, and how results are communicated: see Chapter 2 for information on my key relevant influences.

In particular, it is useful to note that one of my guiding principles is the potential for practical application of research outcomes. While methods such as embedded ethnography, which maximize academic researcher engagement in communities, could offer an in-depth understanding of a given phenomenon, these methods may be restricted in their ability to provide practical solutions for considering public health questions. Similarly, methods such as ethnography, grounded theory, and phenomenology also permit what has been described as "free floating theorizing," a term used to describe the identification of new conceptualizations that are removed from practical application (Thorne, Kirkham, & O'Flynn-Magee, 2004, p. 7). Given my interest in utilitarian contributions, I found it useful to draw from methods borne out of the nursing sciences where the potential for application is also relevant (Sandelowski, 2000; Thorne, Kirkham, & MacDonald-Emes, 1997).

In particular, interpretive description, which "acknowledges the constructed and contextual nature of much of the health-illness experience" (Thorne et al., 1997, p. 172) aims to move beyond a description of a phenomenon to explanations that have implications for practice (Thorne et al., 1997, 2004). The end result of an interpretive description is “a coherent conceptual description that taps thematic patterns and commonalities believed to characterize the phenomenon that is being studied and also accounts for the inevitable individual variations within them” (Thorne et al., 2004, p. 7). Ultimately, this conceptualization “will make sense of something that clinicians ought to understand” (Thorne et al., 2004, p. 8).

To facilitate this, data analysis strategies in interpretive description recognize “the nature and shape of the preliminary theoretical scaffolding that has been used to construct the study” (Thorne et al., 2004, p. 10) and, within this framework, explore arising concepts. Here, I found this methodological perspective useful in how it permits entering into analyses with some sense of where to look while also permitting the exploration of themes that may lead to conceptualizations not previously apparent. Using this method in conjunction with quantitative assessments of structured questionnaires, labeled by some as a concurrent mixed methods approach (Creswell, 2009), permitted me to draw inferences from information obtained in various ways. Taken together, I believe this provides a rich understanding of community perspectives while also facilitating pragmatic approaches that yield potential application.

Interview guide 1 (Fort McPherson)

I asked respondents if they would be willing to answer a few questions about their thoughts on topics related to the research and gave them the choice of having the conversation recorded or not. Questions were semi-structured and involved probing, clarification, or follow-up questions as appropriate. In general, the questions were structured as follows:

1) Please describe *H. pylori* in your own words.

2) Do you think *H. pylori* is a problem in Fort McPherson?
   If follow-up questions or probing appropriate:
   a. How long has it been a problem here?
   b. What do you think may have caused the problem?
   c. Do you have any idea how to fix the problem?
   d. Is there anything you'd like to learn about *H. pylori*?

3) What do you think are the biggest health problems in Fort McPherson?
   If follow-up questions or probing appropriate:
   a. How long has it been a problem here?
   b. What do you think may have caused the problem?
   c. Do you have any idea how to fix the problem?

Notes on interviews: These interviews were conducted immediately after participants gave t consent to participate in the Fort McPherson *H. pylori* Project and immediately before participation in additional research components. For this reason, it was necessary to balance the time devoted to the interview and the time necessary to complete other project components. Furthermore, as this was done in the context of the overarching research project, questions related specifically to *H. pylori* were asked first in case the interview was cut short. While the ordering of the questions did not appear to impact responses about general health issues in the community, there is the possibility that discussions about *H. pylori* prior to Question 3 above affected responses.

Interview guide 2 (Ross River and Teslin)

Interview Tool:

CAN*Help* Working Group: Community members'
perspectives on *H. pylori* infection - Interview Guide

Name: ____________________________ DOB:
____

[Participant Name], thank you for coming in today. Before we begin, I would like to give a brief introduction about the purpose and nature of our conversation today. I am having conversations with different individuals from **[Community]** to learn about people's perspectives on *H. pylori* and about how *H. pylori* has affected individuals' lives and their community. Today, I will be asking you questions about *H. pylori* and how it has affected your life. I am going to be asking you to think about those questions, describe your experiences, and offer your opinion. Anything you tell me in our conversation will stay confidential**.** I will be recording our conversation, which I will transcribe at another date, to ensure the accuracy the information. Your participation is important and we thank you for taking the time to talk to us today. The interview should take approximately 30 minutes, maybe more maybe less, depending on how much you want to share with me. Do you have any questions before we begin?

General prompts to gather depth and encourage dialogue
- Can you explain what you mean?
- Tell me more about that.
- How so?
- Don't worry about being right or wrong, just tell me what comes to mind.
- Can you explain why?
- How did that make you feel?

1. **A.** *When you hear to the term "H. pylori," what is the first thing that comes to your mind? It can be words or images.*
   B. *Please tell me about "H. pylori" in your own words.*
   Probes:
   a. How do you think someone gets *H. pylori*?
   b. What symptoms do you associate with *H. pylori*?
   c. Can you tell me what you know about the potential long term risks of *H. pylori* infection?

2. *Please describe how H. pylori has affected <u>your life</u>.*
   Probes as necessary:
   a. Has *H. pylori* affected you well-being/health?
   b. Can you tell me if you have made any changes to your life since learning about *H. pylori*?

   c. Is *H. pylori* a topic of discussion among your friends, family, and/or broader community?

3. *Please describe how H. pylori has affected <u>your friends or family</u>.*
   Probes as necessary:
   a. In your opinion, has *H. pylori* affected their well-being/health?
   b. Do you think they've made any changes to their life since learning about *H. pylori*?

4. **A.** *Do you think H. pylori is an important health issue in this community? If so, how has it impacted the community?*
   a. If yes:
      i. How do you know it is problem?
      ii. Has it always been health concern/issue?
      iii. How would your community be different if *H. pylori* did not exist?
   b. If no:
      i. Can you tell me why *H. pylori* is not a concern?

   B. *Are there other health issues or concerns that are important to your community?*

5. *Is there anything you think it is important for me to know about any of topics we have discussed that I didn't ask about or you want to share?*

6. *Would you like any specific information about H. pylori?*

Reflections and audit trail

The concept of rigor in a qualitative research study is often described broadly as ‘trustworthiness’, the elements of which include concepts such as credibility, transferability, dependability, and confirmability as outlined by Lincoln and Guba (1985) (restated in Mayan (2009)). To support the assessment of trustworthiness, I highlight here some of the methodological choices made throughout this work.

I have described key methodological considerations elsewhere: the research setting and collaborative nature of the work (Chapter 6.2), decisions related to the choice of methods and key influences (Appendix II, Supplement 2). Also, I described recruitment and data collection processes, including the use of interview guides in Chapter 6.2 and Appendix II, Supplement 2. Here, I outline some key decisions made during analyses. The aim is to record main coding decisions so that someone else may be able to follow the rationale.

- Initial codes identified categories that directly corresponded to research questions; these are repeated below:
    1) How do research participants describe *H. pylori*, and what do they know and think about it?
    2) To what extent are research participants concerned about *H. pylori* or believe it is a problem in their community?
    3) How, in their view, does *H. pylori* infection and *H. pylori*-associated diseases impact research participants, their families and friends, and community?
- These questions drove the initial coding of transcripts. For example, I identified particular language that participants used to describe the *H. pylori* bacterium: what it is, how it is transmitted, and how it might impact the health of research participants or others. I initially selected codes without understanding how they might relate to the research questions or to other codes. Upon repeated assessment, I then re-grouped initial codes to facilitate the application of emergent themes. Some key examples of coding changes that occurred throughout analyses and the rationale for implementing these changes are outlined below:

- Water
    - I initially coded water separately by the type of water being referred to: water from lakes, rivers, or tap water available in homes. Upon repeated assessment, I then grouped these into the overarching concept of water.
    - After continued review, I noticed that, while some participants referred to one source of water as more problematic than another, there was a connection between each: the idea of placing something contaminated into one's body is what increased risks related to *H. pylori*, regardless of the source.
    - Further, each of the sources mentioned shared an underlying factor related to change: industry modified the natural land so as to make it dangerous; pipes bringing water places somehow impacted the quality of available water; chemicals used to treat water that is available in peoples' homes are impacting health over time.
- Food
    - I initially coding food according to the types of food mentioned by participants. For example, they might have described the impact of processed foods, fish, country foods like caribou, or store-bought food.
    - Upon repeated assessment, I noticed that, as with concepts of water, the issue participants were typically referring to was the placement of something contaminated or unnatural into one's body, regardless of the food source.
    - Similarly, participants referred to some foods when describing healthy behaviours in general; these, too, did not necessarily require a stratification of food type as it also depended on the context within which the food item was being described.
- Contaminants
    - I initially coded contaminants separately by the exact contaminant mentioned: sewage, chemicals, chlorine, cleaning supplies, and oil.
    - Much like for water and food, continued examination revealed that the precise nature of the contaminant was not as relevant as the concept of

something unnatural or unwanted being present in something that might be consumed.

- Through these assessments, I developed an understanding of how these concepts were connected; as a result, I was able to test and re-test whether emergent themes fit the developing frameworks.
- Throughout these processes, it was essential for me to repeatedly question what I was learning, acknowledging that my perspectives and, in turn, the identification of codes and themes, could be driven by the selected research questions and previous work on structured interviews.

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Appendix IV: Supplemental material for Chapter 7.1

Table 7.1.1: Proportion positive for *H. pylori* infection (prevalence) among tested individuals by age group, Indigenous status, and year; Northwest Territories, 2009-2016

	0-24 year olds				25-49 year olds				50-74 year olds				75 years of age and older			
	Number Tested*	Prevalence per 100	95%CI		Number Tested*	Prevalence per 100	95%CI		Number Tested*	Prevalence per 100	95%CI		Number Tested*	Prevalence per 100	95%CI	
Indigenous																
2009	63	40	28	55	184	63	55	70	145	66	58	74	23	44	23	66
2010	58	40	27	53	174	60	53	68	133	59	50	67	15	60	32	84
2011	64	28	18	41	171	63	55	70	129	67	58	75	23	48	27	69
2012	45	27	15	42	174	63	55	70	125	54	45	63	20	45	23	68
2013	41	49	33	65	149	56	48	64	112	65	56	74	21	52	30	74
2014	56	38	25	51	162	57	48	64	147	57	49	65	12	58	28	85
2015	38	50	33	67	143	59	50	67	129	63	54	71	19	47	24	71
2016	50	36	23	51	141	57	48	65	113	68	59	77	31	45	27	64
non-Indigenous																
2009	35	11	3	27	152	18	13	26	112	19	12	27	6	50	12	88
2010	28	14	4	33	160	18	12	24	135	13	8	19	7	14	0.4	58
2011	27	4	0.1	19	140	16	11	24	129	21	14	29	11	36	11	69
2012	35	11	3	27	179	16	11	22	155	21	15	28	11	18	2	52
2013	30	10	2	27	131	13	8	20	136	14	9	21	18	29	10	53
2014	27	4	0.1	19	123	16	10	24	139	19	13	26	13	7.7	0.2	36
2015	30	20	8	39	144	16	10	23	137	19	13	27	8	13	0.3	53
2016	34	18	7	35	151	15	9	22	114	22	15	31	17	24	7	50

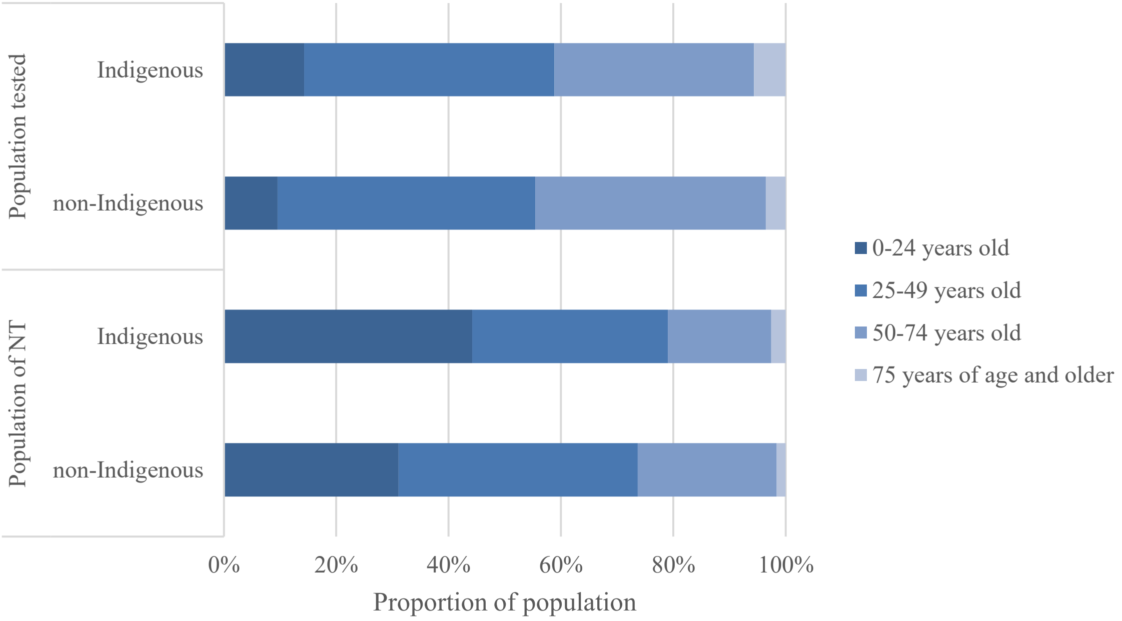
*Individuals tested more than once or testing positive more than once within a year were counted only once within that year; individuals tested in multiple years were counted once in each year tested.

Table S7.1.2: Age-specific rates of *H. pylori* diagnostic testing* by age group, Indigenous status, and year; Northwest Territories, 2009-2016

	0-24 year olds				25-49 year olds				50-74 year olds				75 years of age and older			
	Population	Age-specific rate per 1,000	95%CI		Population	Age-specific rate per 1,000	95%CI		Population	Age-specific rate per 1,000	95%CI		Population	Age-specific rate per 1,000	95%CI	
Indigenous																
2009	10,210	6.2	4.7	7.7	7,628	24	21	28	3,538	41	34	48	530	43	26	61
2010	10,191	5.7	4.2	7.2	7,693	23	19	26	3,656	36	30	43	536	28	14	42
2011	10,134	6.3	4.8	7.9	7,788	22	19	25	3,821	34	28	40	516	45	26	63
2012	9,927	4.5	3.2	5.9	7,802	22	19	26	3,972	31	26	37	555	36	20	52
2013	9,711	4.2	2.9	5.5	7,722	19	16	22	4,177	27	22	32	570	37	21	53
2014	9,591	5.8	4.3	7.4	7,663	21	18	24	4,343	34	28	39	593	20	9.0	32
2015	9,460	4.0	2.7	5.3	7,657	19	16	22	4,524	29	24	33	616	31	17	45
2016	9,055	5.5	4.0	7.1	7,694	18	15	21	4,632	24	20	29	632	49	32	66
non-Indigenous																
2009	6,419	5.5	3.7	7.3	9,728	16	13	18	4,819	23	19	28	277	22	4.3	39
2010	6,294	4.5	2.8	6.1	9,659	17	14	19	4,942	27	23	32	307	23	5.9	40
2011	6,246	4.3	2.7	6.0	9,503	15	12	17	5,165	25	21	29	328	34	14	53
2012	6,367	5.5	3.7	7.3	9,313	19	16	22	5,316	29	25	34	342	32	13	51
2013	6,428	4.7	3.0	6.3	9,243	14	12	17	5,570	24	20	29	365	49	27	72
2014	6,431	4.2	2.6	5.8	9,141	13	11	16	5,742	24	20	28	385	34	15	52
2015	6,554	4.6	2.9	6.2	9,094	16	13	18	5,932	23	19	27	407	20	6.0	33
2016	9,872	5.0	3.3	6.6	9,153	17	14	19	6,010	19	15	22	421	19	15	22

*Individuals tested more than once or testing positive more than once within a year were counted only once within that year; individuals tested in multiple years were counted once in each year tested.

Figure 7.1.1: Age distribution of the population tested for *H. pylori* infection and of the Northwest Territories population by Indigenous status; Northwest Territories, Canada; 2009-2016



Appendix V: Supplemental material for Chapter 7.2

7.2 Supplement 1: country-specific estimates

Table S7.2.1: Estimated age-standardized incidence rates (ASR) per 100,000 person-years and estimated number of cases (N) of cardia and non-cardia gastric cancer by country and sex in 2012 (Note: country-specific estimates should be regarded as rough approximations)

	Males				**Females**			
	Cardia		**Non-cardia**		**Cardia**		**Non-cardia**	
	ASR	**N**	**ASR**	**N**	**ASR**	**N**	**ASR**	**N**
Sub-Saharan Africa								
Angola	0.1	6	3.9	167	0.1	5	3.5	173
Benin	0.1	3	3.8	89	0.1	3	3.5	91
Botswana	0.0	0	1.3	9	0.0	0	0.5	4
Burkina Faso	0.1	3	3.0	96	0.1	3	2.8	131
Burundi	0.2	4	5.4	111	0.1	2	2.7	67
Cameroon	0.1	5	2.6	147	0.1	3	2.0	122
Cape Verde	0.1	0	4.0	7	0.1	0	3.8	8
Central African Republic	0.1	1	3.0	36	0.0	1	1.6	22
Chad	0.1	2	2.4	69	0.1	1	1.6	50
Comoros	0.1	0	1.5	3	0.0	0	0.6	1
Congo, Democratic Republic of	0.2	28	4.9	841	0.2	29	5.5	956
Congo, Republic of	0.1	1	3.7	41	0.0	1	1.6	20
Cote d'Ivoire	0.2	12	5.6	364	0.1	4	2.7	160
Djibouti	0.1	0	3.1	8	0.1	0	2.3	7
Equatorial Guinea	0.1	0	2.6	7	0.0	0	2.0	5
Eritrea	0.1	1	3.0	30	0.1	1	2.0	28
Ethiopia	0.1	23	3.0	705	0.1	19	2.9	731
France, La Reunion	0.5	2	14.1	65	0.2	1	5.9	34

Gabon	0.1	0	3.0	15	0.0	0	1.7	10
Ghana	0.1	10	3.8	302	0.1	4	1.8	147
Guinea	0.1	3	3.6	97	0.1	2	2.6	75
Guinea-Bissau	0.1	1	4.1	17	0.1	0	2.6	13
Kenya	0.4	31	10.5	922	0.3	26	8.2	832
Lesotho	0.1	0	1.6	10	0.0	0	0.7	6
Liberia	0.2	1	4.6	45	0.1	1	2.7	30
Madagascar	0.2	12	6.2	353	0.1	5	2.9	173
Malawi	0.1	3	2.8	92	0.1	3	2.5	105
Mali	0.3	10	10.2	310	0.2	8	8.0	323
Mauritania	0.1	1	4.0	36	0.1	1	2.9	30
Mauritius	0.4	2	10.5	69	0.2	2	5.7	48
Mozambique	0.0	2	1.3	68	0.0	1	0.5	30
Namibia	0.1	0	2.1	14	0.0	0	1.2	11
Niger	0.1	4	2.2	105	0.1	2	1.5	56
Nigeria	0.1	28	1.9	847	0.1	27	2.0	987
Rwanda	0.2	6	6.2	183	0.3	9	9.4	276
Senegal	0.2	6	6.9	189	0.1	4	5.3	179
Sierra Leone	0.2	2	4.7	60	0.1	1	2.6	43
Somalia	0.2	5	6.8	147	0.2	4	5.6	140
South African Republic	0.3	42	7.7	1266	0.1	23	3.0	698
South Sudan	0.2	5	5.6	157	0.1	4	4.0	124
Swaziland	0.1	0	3.1	10	0.0	0	1.2	5
Tanzania	0.1	14	3.5	423	0.1	9	2.5	306
The Gambia	0.1	0	2.5	9	0.0	0	0.8	2
Togo	0.2	4	6.6	110	0.1	3	4.9	95
Uganda	0.2	16	7.2	476	0.1	7	2.9	221
Zambia	0.2	4	4.7	136	0.1	4	3.9	132

Zimbabwe	0.3	9	7.7	266	0.3	11	7.7	314
Northern Africa and Western Asia								
Algeria	2.4	329	5.1	715	1.1	166	3.4	507
Armenia	7.6	139	16.1	290	2.3	65	6.9	197
Azerbaijan	5.9	248	12.3	526	2.2	118	6.6	358
Bahrain	1.5	6	3.0	13	0.8	2	2.3	8
Egypt*	1.1	354	1.8	599	0.6	202	1.7	634
Georgia	4.3	133	8.9	273	1.7	76	5.3	229
Iraq	2.1	157	4.5	335	1.1	110	3.3	334
Israel*	4.0	201	5.7	279	1.5	87	3.5	210
Jordan	2.1	42	4.4	89	1.3	26	4.0	80
Kuwait	0.9	9	1.9	19	0.5	3	1.6	9
Lebanon	2.1	45	4.3	92	1.2	30	3.6	90
Libya	1.5	33	3.0	68	0.7	16	2.1	47
Morocco	1.7	224	3.5	481	0.7	116	2.3	355
Oman	2.1	18	4.3	37	1.0	6	2.9	18
Qatar	2.0	9	4.0	21	1.4	2	4.2	7
Saudi Arabia*	1.4	123	2.5	213	0.7	58	1.7	137
State of Palestine	1.8	21	4.0	47	1.3	13	3.9	38
Sudan	0.9	85	1.9	181	0.2	24	0.7	73
Syrian Arab Republic	2.1	144	4.4	308	1.2	90	3.6	276
Tunisia*	1.4	73	4.0	214	0.5	28	2.7	155
Turkey*	4.5	1478	13.4	4460	2.3	895	8.6	3287
United Arab Emirates	1.9	22	3.7	51	0.9	7	2.6	23
Western Sahara	2.3	5	4.8	10	1.4	2	4.3	8
Yemen	1.9	92	3.9	187	0.6	35	1.9	108
Central Asia								
Afghanistan	7.1	478	9.9	691	3.5	246	5.1	366

Bangladesh	3.1	1659	4.4	2396	1.6	1003	2.5	1525
Bhutan	9.5	26	13.5	38	4.4	11	6.4	17
India*	3.3	16415	5.3	26971	1.4	7541	2.3	12170
Iran, Islamic Republic of*	13.4	4314	7.2	2326	5.4	1670	4.3	1350
Kazakhstan	14.6	944	20.6	1366	5.2	546	7.6	794
Kyrgyzstan	14.7	250	21.0	366	4.2	93	6.1	138
Maldives	2.7	3	3.8	5	0.3	0	0.4	1
Nepal	3.0	278	4.2	397	1.5	180	2.3	271
Pakistan	1.5	975	2.3	1433	0.9	569	1.3	863
Sri Lanka	2.7	319	3.8	446	2.1	286	3.1	419
Tajikistan	12.6	219	17.5	312	6.1	137	8.9	203
Turkmenistan	9.8	164	14.1	244	5.5	118	8.1	175
Uzbekistan	6.9	635	9.9	926	3.6	401	5.3	599
Eastern/Southeastern Asia								
Brunei	1.2	2	8.6	12	0.5	1	5.0	8
Cambodia	0.9	34	6.7	276	0.3	16	3.0	181
China*	12.0	103233	20.8	180254	3.4	31390	9.7	90119
Indonesia	0.5	442	3.4	3369	0.2	186	1.7	2014
Japan*	4.7	7714	41.0	66256	1.3	2644	15.2	31284
Korea, Democratic Republic of	2.5	319	19.6	2490	0.7	137	8.0	1457
Korea, Republic of*	3.6	1242	58.6	20096	1.1	425	23.6	9506
Lao PDR	0.3	6	2.6	51	0.1	3	1.6	39
Malaysia	1.2	135	8.7	1042	0.5	61	5.3	662
Mongolia	5.3	47	42.1	384	1.7	18	18.5	197
Myanmar	1.7	341	13.6	2768	0.6	148	7.1	1656
Philippines*	2.0	627	2.8	781	0.9	297	2.0	710
Singapore*	3.2	118	7.7	284	1.3	55	4.5	190
Thailand*	1.4	581	2.4	1029	0.8	398	1.7	833

Timor-Leste	0.3	1	2.4	6	0.2	0	1.7	6
Viet Nam	2.6	1007	21.1	8399	0.8	393	9.3	4404
Central/Southern America and Caribbean								
Argentina*	2.8	676	7.1	1698	0.7	234	3.5	1130
Bahamas	2.8	5	6.8	11	0.8	2	3.9	8
Barbados	2.9	6	7.0	14	0.7	2	3.2	12
Belize	2.1	2	5.2	6	0.7	1	3.4	4
Bolivia	2.4	80	5.8	197	1.3	51	6.2	253
Brazil*	4.3	4108	8.8	8498	1.2	1376	4.8	5708
Chile*	7.4	779	15.9	1670	2.0	281	7.2	982
Colombia*	6.9	1345	12.0	2343	2.2	536	6.8	1673
Costa Rica*	4.7	111	16.8	402	1.5	39	12.2	322
Cuba	2.2	198	5.3	484	0.7	75	3.6	369
Dominican Republic	2.4	112	5.9	273	1.1	51	5.4	260
Ecuador*	3.5	234	17.2	1147	1.0	72	12.5	948
El Salvador	5.7	148	13.8	361	2.3	81	11.7	398
France, Guadeloupe	4.0	14	9.7	33	1.2	6	5.8	30
France, Martinique	3.9	13	9.4	33	1.0	5	4.9	26
French Guyana	2.2	2	5.3	5	0.7	1	3.6	3
Guatemala	7.0	318	17.1	776	3.9	202	19.5	1013
Guyana	1.9	5	4.6	11	0.4	1	1.9	6
Haiti	2.7	85	6.5	206	1.1	42	5.4	212
Honduras	5.5	140	13.4	342	2.5	71	12.8	355
Jamaica	3.6	49	8.7	120	1.0	17	5.1	83
Mexico	2.3	1192	5.6	2912	1.0	592	5.0	2984
Nicaragua	4.1	80	10.0	194	1.4	31	7.1	158
Panama	4.0	70	9.8	170	1.3	24	6.3	119
Paraguay	2.5	65	6.1	158	0.7	19	3.4	94

Peru	4.8	620	11.8	1516	2.5	371	12.5	1834
Puerto Rico*	1.4	39	3.9	113	0.5	18	2.6	100
Suriname	2.2	5	5.3	13	0.6	2	2.7	7
Trinidad and Tobago	2.2	13	5.3	32	0.4	4	2.0	18
Uruguay*	7.6	181	6.8	162	2.1	81	4.6	153
Venezuela	3.9	497	9.5	1212	1.0	149	5.2	744
Northern America								
Canada*	3.3	1006	3.7	1181	0.8	299	2.3	856
United States of America*	2.6	6336	2.7	6813	0.7	1960	2.0	6046
Eastern Europe								
Belarus*	3.4	205	25.8	1564	1.0	92	11.3	1100
Bulgaria*	2.7	181	11.8	809	0.9	86	6.1	588
Czech Republic*	2.8	258	7.4	686	0.8	95	4.5	556
Hungary	2.7	220	11.0	895	0.9	113	5.6	723
Poland*	7.9	2340	5.3	1596	2.1	915	2.9	1254
Republic of Moldova	3.6	81	14.7	330	0.9	27	5.6	171
Romania	3.2	535	13.1	2176	0.8	185	5.0	1179
Russian Federation*	4.7	4216	19.7	17621	1.6	2481	9.2	14099
Slovakia*	3.4	131	10.5	403	0.9	51	5.7	316
Ukraine*	4.4	1333	18.0	5502	1.3	647	7.9	3891
Northern and Western Europe								
Austria*	4.9	391	4.3	369	1.4	161	3.4	393
Belgium*	5.0	529	3.1	355	1.4	181	2.5	352
Denmark*	5.8	300	2.5	140	1.3	75	1.8	110
Estonia*	3.0	30	16.5	166	1.0	17	9.3	157
Finland*	4.9	263	1.9	105	2.1	150	1.9	123
France (metropolitan)*	3.0	1811	3.9	2450	0.5	360	2.3	1886
Germany*	3.8	3519	6.8	6562	1.0	1114	4.4	4820

Iceland	3.1	8	3.2	9	1.1	3	2.6	8
Ireland*	3.6	126	5.2	180	1.4	60	3.0	121
Latvia*	5.0	81	18.1	302	0.9	29	7.7	228
Lithuania*	3.0	71	19.8	467	0.6	25	7.4	304
Luxembourg	5.2	21	5.2	21	1.6	7	3.6	18
Norway*	2.4	111	3.2	156	0.9	50	2.9	158
Sweden	2.4	241	2.4	256	0.8	94	1.9	220
Switzerland*	2.2	166	2.8	209	0.9	74	2.7	234
The Netherlands*	3.4	535	4.2	693	1.0	185	2.9	540
United Kingdom*	3.9	2440	2.6	1729	1.5	1124	1.7	1391
Southern Europe								
Albania	7.0	137	18.4	364	2.2	47	13.0	288
Bosnia Herzegovina	2.9	85	7.5	226	0.9	31	5.2	187
Croatia*	7.5	301	7.0	287	2.4	153	3.9	225
Cyprus	2.1	17	5.6	46	0.5	4	2.8	27
FYR Macedonia	6.3	95	17.2	259	1.5	26	9.1	162
Greece	2.0	234	5.4	669	0.5	79	3.1	496
Italy*	2.4	1634	8.5	5915	0.6	571	5.3	4881
Malta*	6.1	23	5.0	20	1.2	5	4.3	20
Montenegro	3.4	15	8.9	38	1.0	5	6.0	30
Portugal*	5.4	542	12.8	1292	1.6	215	7.2	969
Serbia*	6.7	525	5.3	404	2.9	277	2.8	256
Slovenia*	5.0	96	10.4	196	1.0	27	5.4	149
Spain*	2.9	1251	8.1	3615	0.7	374	4.5	2570
Oceania								
Australia*	3.4	672	3.3	668	1.0	223	2.2	486
Fiji	0.9	3	1.0	3	0.9	4	2.1	8
French Polynesia	4.7	7	4.5	6	1.7	2	3.9	6

Guam	1.7	1	1.7	2	0.0	0	0.0	0
New Caledonia	5.5	8	5.4	8	1.5	3	3.5	6
New Zealand*	3.3	115	3.4	125	0.9	36	2.9	117
Papua New Guinea	4.3	72	4.3	66	1.7	36	4.1	87
Samoa	7.4	5	6.9	4	1.7	1	4.1	3
Solomon Islands	1.1	2	1.0	1	0.6	1	1.4	3
Vanuatu	1.5	1	1.1	1	1.2	1	2.8	3

*Estimated using country-level data; other country estimates were based on a regional average for the proportion of cardia/non-cardia gastric cancers (see Methods)

7.2 Supplement 2: sensitivity analyses

We conducted sensitivity analyses by redistributing CI5X country- and sex-specific NOS cases (C16.8-9) to CGC (C16.0) or NCGC (C16.1-6) categories using a variety of different methods (Figure S7.2.1). This process permitted us to evaluate the outcome of each potential scenario on the final distribution of CGC and NCGC cases and to test the robustness of each method when using data from different registries and countries. These methods included:

(i) Redistributing all NOS cases to CGC cases.
(ii) Redistributing all NOS cases to NCGC cases.
(iii) Using the proportion of CGC and NCGC cases to redistribute NOS cases to CGC or NCGC (applied in main paper).
(iv) Using the regional proportion of CGC and NCGC cases to redistribute country-level NOS cases to CGC or NCGC.
(v) Using the global proportion of CGC and NCGC cases to redistribute country-level NOS cases to CGC or NCGC.
(vi) Using the proportion of oesophageal adenocarcinoma and oesophageal squamous cell carcinoma (proportions derived as in Arnold et al. 2015[1]) to redistribute gastric cancer NOS cases to CGC and NCGC cases, respectively.

Method (i) is likely to overestimate the number of CGC and method (ii) overestimate the number of NCGC cases for most populations. For many countries, the results obtained through Method (iv) offer a reasonable approximation of the country-specific CGC/NCGC estimates obtained in (iii); however, results differ from those obtained through country-level estimates for a few populations. For some countries, the results obtained through Method (v) differ substantially from results obtained directly from country-level information. Method (vi) is theory-driven; the results obtained from this method differ substantially across some populations. Method (iii) maximizes the information available and is data-driven. This method is equivalent to using the proportion of CGC and NGC directly, and was selected for estimating CGC and NCGC cases (Figure S7.2.2).

[1] Arnold, M., Söerjomataram, I., Ferlay, J., & Forman, D. (2015). Global incidence of oesophageal cancer by histological subtype in 2012. *Gut*, *64*(3), 381–387.

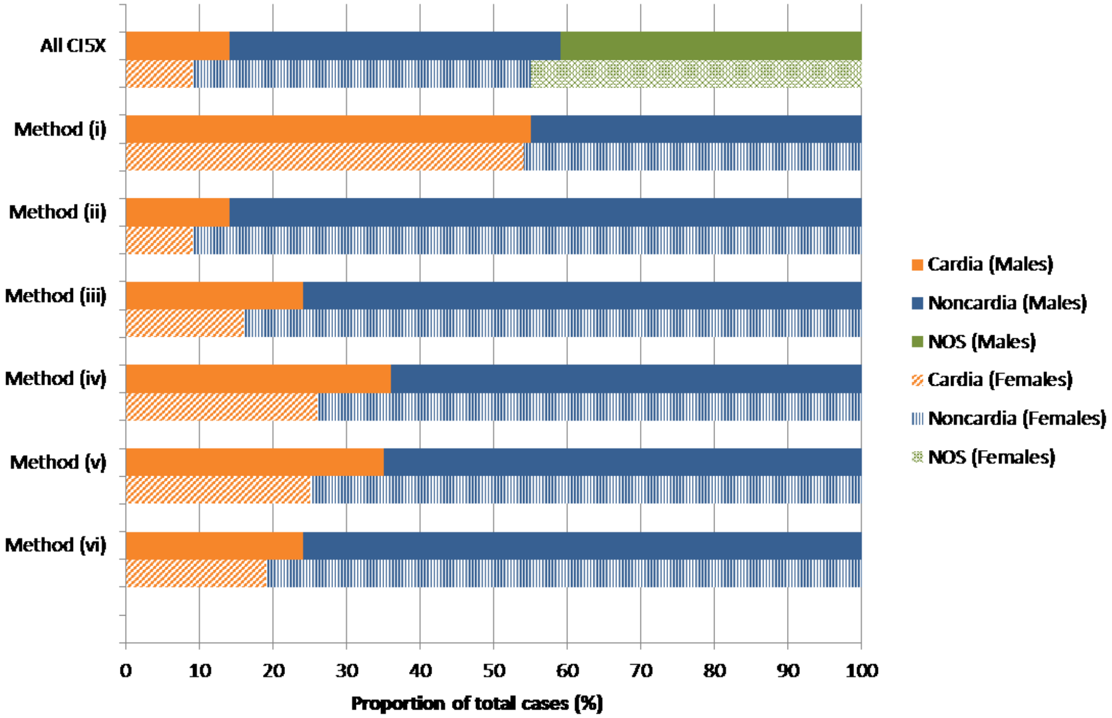


Figure S7.2.1: Proportions of CGC and NCGC cases derived using six different methods to reclassify NOS cases in CI5X countries, all CI5X countries, 2012

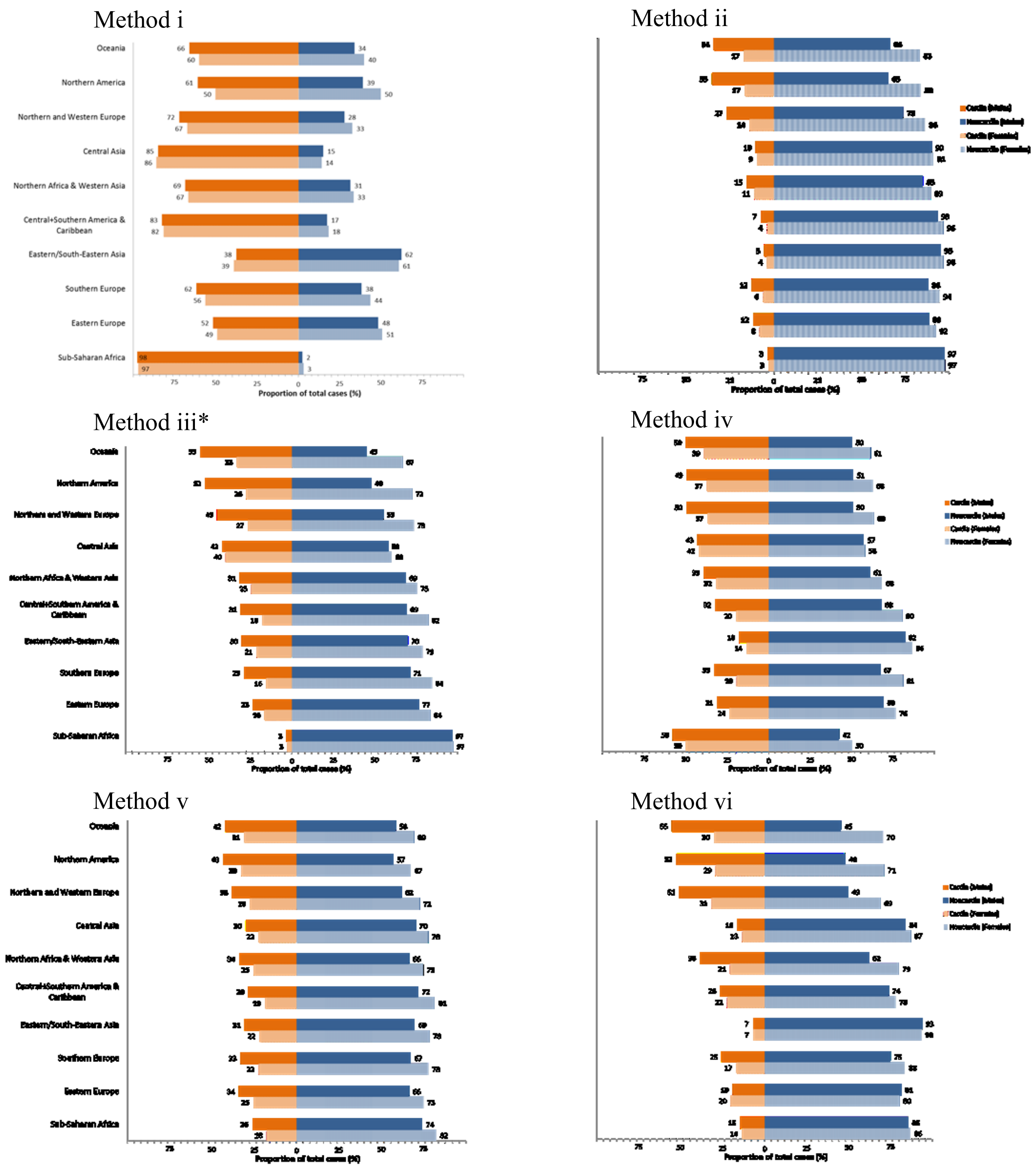


Figure S7.2.2: Proportion of gastric cancer cases identified as cardia and non-cardia by region and sex, 2012. *Method used in main paper

Appendix VI: Supplemental material for Chapter 7.3

7.3 Supplement 1: Gastric cancer subsites

As noted in Chapter 7.2, gastric cancer may be further categorized into two broad topographical subsites: cardia and non-cardia. Cardia gastric cancers (CRC) are those occurring in the stomach at the esophageal-gastric junction where the stomach connects with the esophagus. Non-cardia gastric cancers (NCGC) are those occurring in the remaining regions of the stomach. In general, gastric cancer cases classified as C16.0 are considered CRC and those classified as C16.1-6 are considered NCGC (Table S7.3.1). The remaining topographical categories, C16.8-9, are not typically attributed to either gastric cancer category without further analytical consideration (see 7.3 Supplement 2).

Table S7.3.1: International Classification of Diseases for Oncology, Third Edition (ICD-O-3), topographical codes for gastric cancer (“International Classification of Diseases for Oncology,” n.d.)

ICD-O-3 Code*	Topography Description
C16.0	Cardia gastric cancer, NOS
C16.1	Fundus of stomach
C16.2	Body of stomach
C16.3	Gastric antrum
C16.4	Pylorus
C16.5	Lesser curvature of stomach, NOS
C16.6	Greater curvature of stomach, NOS
C16.8	Overlapping lesion of stomach
C16.9	Stomach, NOS

*synonymous with the International Classification of Diseases – 10th revision (ICD-10)
NOS = not otherwise specified

7.3 Supplement 2: Choice of case definitions

In Chapter 7.2, cases defined as ‘other or not otherwise specified’ (C16.8-9) were redistributed to gastric cancers of the cardia (C16.0) or non-cardia (C16.1-6) by applying the sex and age-specific proportions of CGC and NCGC cases within a country or region to country-specific C16.8-9 cases (see Chapter 7.2 for more details). Here, I assessed the possibility of redistributing C16.8-9 cases in a similar manner. Two challenges inhibited this form of redistribution:

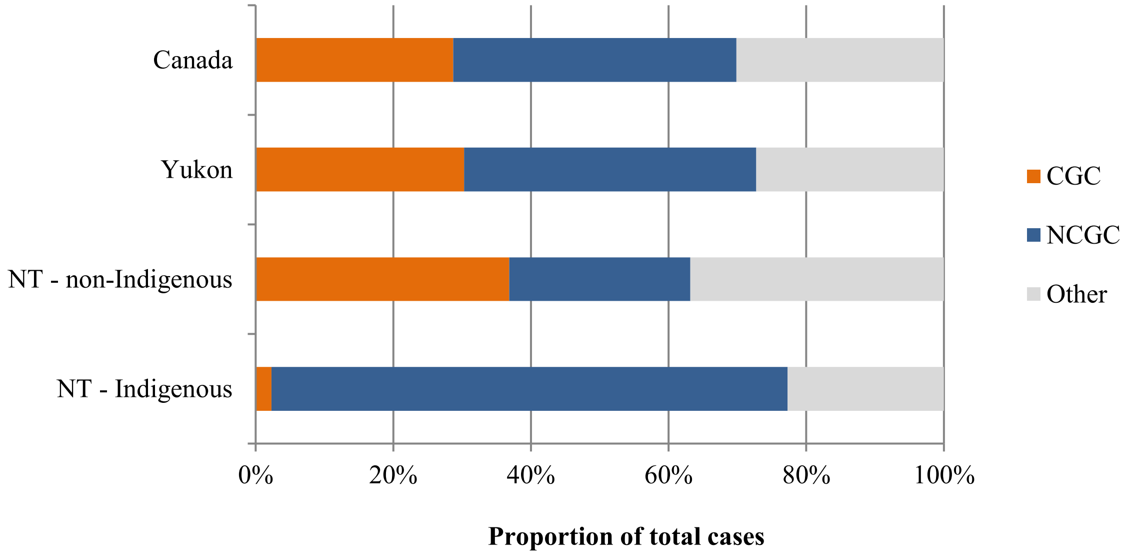
1) CI5X datasets available online group C16.5-6 together with C16.8-9. As a result, known NCGC cases available by age-group and sex could not be readily distinguished from ‘other or not otherwise specified’ (see Table S7.3.2 for the level of data disaggregation available by population).
2) Where C16.5-6 could be distinguished from C16.8-9, either the levels of disaggregation presented limitations (a.) or the numbers of cases were too small to adequately determine the proportion of cases within each sex and age category (b.):
    a. For both YT and Canada, data on C16.5-6 was not available separately from C16.8-9 except for all ages combined; as a result, it was not possible to disaggregate based on age group to permit age-adjustments for rate estimations (see Table S7.3.2).
    b. In Chapter 7.2, if a dataset for a country contained fewer than two cases of CGC or NCGC within any sex and age group stratification, information at a regional level was applied to that country. Here, the numbers of cases in the NT were too small to apply sex and age group proportions to reallocate C16.8-9 cases and regional information from Canada was unavailable (see a.).

As a result, all cases classified as C16.8-9 were considered NCGC cases. This approach is consistent with the analytical choices made in Chapter 7.2. Specifically, in Sub-Saharan Africa there were fewer than 5 reported gastric cancer cases in any sex and age group category and redistribution was based on information from a small number of cases. My co-authors and I decided that allocating all C16.8-9 cases to NCGC would be the most reasonable solution in this region, particularly given the high incidence of infectious disease in the area. Given the relatively small number of cases in northern Canada and apparent high prevalence of *H. pylori* infection in these regions (Goodman, Jacobson, & van Zanten, 2008), this seemed like a reasonable assumption here as well. To investigate the extent to which this may have over-estimated cases of NCGC, I also performed a sensitivity analysis in which NCGC cases were defined as C16.1-4, acknowledging that this would be an underestimate due to exclusion of C16.5-6 gastric cancer cases (see Tables S7.3.3 and S7.3.4).

Table S7.3.2: Gastric cancer data available as of January 2018 by population

Population	Gastric cancer	Level of disaggregation available (Subsites: C16.1-9)	Available level of disaggregation by age and sex	Year(s) available	Source
World and Regions	All	-	Sex	2012	Colquhoun et al., 2015
	Subsites	C16.8-9 redistributed to C16.0 and C16.1-6	Sex	2012	Colquhoun et al., 2015
Canada	All	-	Age group, sex	2003-2012	CI5X, CI5XI registry summaries (Forman et al., 2013; Bray et al., 2017)
	Subsites	C16.1,2,3,4,5,6 and C16.8-9	Sex	2003-2012	CI5X, CI5XI registry summaries (Forman et al., 2013; Bray et al., 2017)
	Subsites	C16.1,2,3,4 and C16.5-9	Age group, sex	2003-2007	CI5X data tables (Forman et al., 2013)
Yukon	All	-	Age group, sex	2003-2012	CI5X, CI5XI registry summaries (Forman et al., 2013; Bray et al., 2017)
	Subsites	C16.1,2,3,4,5,6 and C16.8-9	Sex	2003-2012	CI5X, CI5XI registry summaries (Forman et al., 2013; Bray et al., 2017)
	Subsites	C16.1,2,3,4 and C16.5-9	Age group, sex	2003-2007	CI5X data tables (Forman et al., 2013)
Northwest Territories	All	-	Age group, sex	1997-2015	Northwest Territories Government (Epidemiology and Surveillance Unit, Population Health, 2017)
	Subsites	Each subsite separately	Age group, sex	1997-2015	Northwest Territories Government (Epidemiology and Surveillance Unit, Population Health, 2017)

Figure S7.3.1: Proportional incidence of CGC, NCGC and other stomach cancer sites population; northern territories and Canada; various years*



* Canada and Yukon based on data from 2003-2012; Northwest Territories (NT) based on data from 1997-2015. Cardia gastric cancer (CGC) defined as C16.0; non-cardia gastric (NCGC) defined as C16.1-6; other and not otherwise specified (Other) defined as C16.8-9.

7.3 Supplement 3: Sensitivity analyses

Table S7.3.3: Comparison of the number of cases and estimated standardized incidence ratios (SIRs) using two different definitions of non-cardia gastric cancer by population and sex; Northwest Territories and Yukon; various years*

	Non-Cardia Gastric Cancer	Men				Women			
		Cases	SIR*	95% CI		Cases	SIR*	95% CI	
Yukon	C16.1-9	14	1.3	0.62	2.0	9	1.6	0.54	2.6
	C16.1-4	7	1.6	0.40	2.7	3	1.3	0.00	2.7
NT - non-Indigenous	C16.1-9	9	0.94	0.33	1.6	3	0.62	0.00	1.3
	C16.1-4	3	0.75	0.00	1.6	0	0	0.00	0.04
NT - Indigenous	C16.1-9	25	2.7	1.6	3.7	18	3.1	1.7	4.5
	C16.1-4	14	3.6	1.7	5.5	12	4.9	2.1	7.7

*Reference population for Standardized Incidence Ratios (SIR) based on Canada 2003-2007; Yukon includes cases diagnosed during 2003-2012; Northwest Territories (NT) includes cases diagnosed during 1997-2015.

Table S7.3.4: Comparison of the number of cases and estimated age-standardized incidence rates (ASRs per 100,000) using two different definitions of non-cardia gastric cancer by population and sex, northern territories and Canada; various years*

	Non-Cardia Gastric Cancer	Men				Women			
		Cases	ASR*	95% CI		Cases	ASR*	95% CI	
Canada	C16.1-9	6,489	6.0	4.8	5.1	4,544	2.8	2.7	2.8
	C16.1-4	2,702	2.1	2.0	2.1	1,884	1.1	1.1	1.2
Yukon	C16.1-9	6	6.1	1.2	11.1	4	4.5	0.0	9.1
	C16.1-4	1	0.3	0.0	0.9	2	0.8	0.0	1.9
NT - non-Indigenous	C16.1-9	9	5.8	1.5	10.1	3	2.0	0.0	4.3
	C16.1-4	3	1.7	0.0	3.7	0	0	0.0	0.0
NT - Indigenous	C16.1-9	25	13.3	8.0	18.6	18	7.7	4.1	11.2
	C16.1-4	14	7.8	3.7	11.9	12	5.2	2.2	8.1

*Age-standardized incidence rates (ASRs) per 100,000, standardized to the World Population; Canada and Yukon include data for 2003-2007; Northwest Territories (NT) includes data for 1997-2015.

Table S7.3.5: Estimated gastric cancer age-standardized incidence rates (ASRs per 100,000) by subsite, population, and sex using two different standard populations; northern territories and Canada; various years*

	Gastric Cancer	Men				Women			
		Cases	ASR*	95% CI		Cases	ASR*	95% CI	
Standard population: World (Segi)									
Canada	All	16,872	7.0	6.9	7.1	9,510	3.2	3.2	3.3
	CGC	3,151	2.5	2.5	2.6	857	0.6	0.5	0.6
	NCGC	6,489	5.0	4.8	5.1	4,544	2.8	2.7	2.8
Yukon	All	9	9.2	5.2	13.2	5	5.8	2.4	9.2
	CGC	3	3.3	0.0	7.3	1	0.9	0.0	2.8
	NCGC	6	6.1	1.1	11.1	4	4.5	0.0	9.1
NT - non-Indigenous	All	16	8.8	3.9	13.7	3	2.0	0.0	4.3
	CGC	7	3.0	0.6	5.3	0	0.0	0.0	0.1
	NCGC	9	5.8	1.5	10.1	3	2.0	0.0	4.3
NT - Indigenous	All	26	13.8	8.4	19.2	18	7.7	4.1	11.2
	CGC	1	0.5	0.0	1.4	0	0.0	0.0	0.0
	NCGC	25	13.3	8.0	18.6	18	7.7	4.1	11.2
Standard population: Canada 2011									
Canada	All	16,872	14.2	13.9	14.4	9,510	6.4	6.3	6.5
	CGC	3,151	4.8	4.7	5.0	857	1.1	1.0	1.2
	NCGC	6,489	10.4	10.1	10.7	4,544	5.6	5.4	5.8
Yukon	All	9	16.4	9.0	23.8	5	9.3	3.6	14.9
	CGC	3	5.7	0.0	12.4	1	3.6	0.0	10.7
	NCGC	6	11.1	1.8	20.5	4	5.6	0.0	11.4
NT - non-Indigenous	All	16	20.6	6.6	34.7	3	5.0	0.0	11.1
	CGC	7	5.6	0.7	10.5	0	0.0	0.0	0.0
	NCGC	9	15.1	1.9	28.2	3	5.0	0.0	11.1
NT - Indigenous	All	26	25.3	14.7	35.9	18	14.8	7.4	22.1
	CGC	1	0.6	0.0	1.9	0	0.0	0.0	0.0
	NCGC	25	24.6	14.1	35.2	18	14.8	7.4	22.1

*For Canada, all gastric cancer cases combined include cases diagnosed during 2003-2012; gastric cancer subsites include cases diagnosed 2003-2007. Yukon includes cases diagnosed during 2003-2007. Northwest Territories (NT) includes cases diagnosed during 1997-2015. Cardia gastric cancer (CGC) defined as C16.0; non-cardia gastric (NCGC) defined as C16.1-9.

7.3 Supplement 4: Time trends

I assessed the possibility of describing changes over time in the incidence of gastric cancer among northern populations, particularly among the NT population where counts and person-years were available by year. The relatively small number of cases of gastric cancer prevented an effective assessment of time trends, especially when attempting to describe differences across time by gastric cancer subsite.

For example, among the YT population, there were a total of 14 gastric cancer cases in 2003-2007 and 19 in 2007-2012. Further disaggregation by other relevant characteristics such as subsite and sex would have prevented a meaningful assessment of differences over time.

Similarly, for the NT population when disaggregated by sex, there were 5 cases of gastric cancer or fewer each year between 1997 and 2015. For 7 of the study years, there were no cases observed among women and only 1 case observed among men. Attempts to adjust for these small annual counts, such as the use of 3- or 5-year moving average rate estimates, would still have resulted in estimates that fluctuate over time and would have made time trends difficult to interpret.

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