

IMPROVING THE RISK COMMUNICATION OF CANCER

**EXPERT AND NON-EXPERT PERCEPTIONS OF RISK: IMPROVING THE RISK
COMMUNICATION OF CANCER**

by

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LAY ABSTRACT

Cancer clusters constitute geographical areas where the frequency of cancer diagnoses during a given period of time occur more frequently than expected by chance. Cancer clusters can generate significant anxiety in communities and influence perceptions of personal safety and health. As cluster investigations rarely yield the answers citizens seek around a definitive cause of cancer, health officials may appear to be withholding information and not doing enough to address public concerns. The objectives of this dissertation were to summarize key issues with the communication of and investigation of cancer clusters in Canada; test the impact of different types of cancer information on risk perceptions; and explore whether individual characteristics, expertise and skills were linked to positive attitudes about coping with cancer risks. This work provides insights into the diverse ways that people interpret cancer information and perceive risk and identifies improved methods of conducting cancer risk communication and risk education.

ABSTRACT

Cancer clusters constitute geographical areas where the frequency of cancer diagnoses during a given period of time occur more frequently than expected by chance. Cancer clusters can impact perceptions of risk and generate significant anxiety in communities. Unfortunately, cluster investigations rarely yield the answers citizens seek around a definitive cause of cancer due to the long latency of cancer and other factors. As a result, health officials may appear to be withholding information and not doing enough to address public concerns. Effective cancer risk communication may also be hindered by other stakeholders such as the media, who sometimes sensationalize risks from environmental hazards, which can distort the public's perceptions of risks. The result may be a community dissatisfied with a cluster investigation's results, or worse, a community that distrusts local leaders and doesn't understand the information reported by expert officials.

The four studies comprising this dissertation aimed to summarize key issues with the communication of and investigation of cancer clusters in Canada; test the impact of different types of cancer information on risk perceptions; and explore whether individual characteristics and skills were linked to positive attitudes about coping with cancer risks. An analysis of cancer news coverage and interviews with Canadian public health officials revealed that communities may be receiving inadequate and inconsistent information about cancer risks during cluster investigations. In addition, an experiment and survey revealed information trustworthiness and individuals' numeracy and health literacy to be important factors shaping cancer risk perceptions and attitudes. This work has significant implications for risk communicators and educators seeking improved methodologies of cancer risk communication and risk education to

(1) manage differences in cancer risk perceptions between experts and non-experts (2) enhance public trust in institutions and perceptions of expert competence and (3) inform future educational interventions that promote cancer coping beliefs.

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PREFACE

This doctoral dissertation may be read as a complete summary of the research conducted in fulfillment of the Doctor of Philosophy degree at McMaster University. However, it contains four chapters (Chapters 2-5) that were originally prepared for submission as stand-alone articles for publication in various peer-reviewed journals. Therefore, there is some overlap in their content, specifically in their reviews of the relevant literature and in their summaries of the data sources (for Chapters 4 and 5). This dissertation begins with the first chapter, which serves as an introduction to the research subject and provides an overview of each of the four chapters that form the basis of the ‘meat’ of this sandwich thesis. The sixth and final chapter of this work serves as a conclusion to the research and outlines some of the implications of the research summarized in the four substantive chapters.

As the supervisor and mentor to this research, Dr. Niko Yiannakoulias, is a co-author on all four papers. His contributions include assistance with the development of research ideas, guidance on research methodologies, data collection and data analysis techniques, critical appraisal of each chapter as well as editorial reviews. The co-authors on the third and fourth papers, Dr. Robert Wilton and Dr. Fran Scott, who also served as committee members during the course of the doctoral research, provided substantial feedback on earlier drafts of these works in addition to editorial reviews. As the primary author on all four chapters, I made significant original contributions to each work. My contributions included conducting all literature reviews, leading the collection and analysis of all data, interpreting statistical analyses and writing each chapter. The four research papers included in this dissertation include:

Chapter 2: Slavik, C.E. & Yiannakoulias, N. (2021). Cancer risk communication in the news coverage of suspected cancer clusters in Ontario: Contrasting media messaging on cancer by geography. *The Canadian Geographer / Le Géographe canadien*, 65(3), 333-345. <https://doi.org/10.1111/cag.12661>

Chapter 3: Slavik, C.E., & Yiannakoulias, N. (2021). Cancer cluster investigations in Canada: a qualitative study of public health communication practices and investigation procedures. *Health Promotion and Chronic Disease Prevention in Canada* (Submitted June 2021).

Chapter 4: Slavik, C.E., Yiannakoulias, N., Wilton, R., Scott, F. (2022). Investigating the impacts of communication source and format on perceptions of information trustworthiness and cancer risk. *Health Communication* (Submitted March 2022).

Chapter 5: Slavik, C.E., Yiannakoulias, N., Wilton, R., Scott, F. (2022). Impacts of numeracy, health literacy and health information-seeking on cancer risk management beliefs: A cross-sectional study. *Health Education & Behavior* (Submitted April 2022).

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1 INTRODUCTION

In 2016, reports of a cancer cluster in Hamilton among teachers and staff emerged at a local high school, drawing considerable media attention and public concern (Paddon, 2016). The cluster of 23 cases at Cathedral High School diagnosed over the course of about 20 years led to air quality testing inside the school, an environmental site assessment and initiated more than a dozen teacher requests for job transfers to other schools – despite testing revealing an absence of harmful exposures. Although the concerns expressed seemed like overreactions to some in the public health community, it wasn't the first time that high rates of cancer made headlines in the city (Prokaska, 1996). In fact, residents of Hamilton frequently cite the risk of cancer due to pollution from local industries as a significant cause of worry (Carter, 2019) and they are not alone. Numerous cancer cluster investigations are launched in jurisdictions around the world every year, though specific cluster causes are rarely identified due to the difficulties of measuring exposures to hazards years after the onset of the disease (Goodman et al., 2012). As a result, public health officials are often skeptical of the value that a cluster investigation can yield despite the public's repeated calls for them (Thun & Sinks, 2004).

Variations in perceived cancer risk between different stakeholders during an investigation – particularly between experts and non-experts – are largely what inspired this doctoral research. This dissertation begins by providing a snapshot of the issues pertaining to the communication of and investigation of cancer clusters in Canada. Then, the results of an experimental survey used to examine the impact of communications and individual skills and expertise on cancer risk perceptions and attitudes are presented. Although the focus of much of the research undertaken for this doctoral thesis is related to cancer clusters, the findings that will be discussed and the lessons drawn have broader implications for how researchers and health educators ought to

interpret public perceptions of cancer and how to communicate the risks of cancer more effectively.

1.1 BACKGROUND

Cancer clusters constitute geographical areas where the frequency of a cancer diagnosis during a given period of time occurs more frequently than would be expected by chance. Though most suspected cancer clusters are not considered to be a threat to public health after taking into account age-specific cancer rates and other factors (Assunção, 2013), they can create anxiety in communities and influence perceptions of personal safety and health. Compared to death from other diseases, the public often ranks cancer death as the worst, suggesting it is among the most dreaded and feared health outcomes for a large proportion of the population (Sunstein, 2002). Concerns over industrial pollution and hazardous contaminants in the environment often fuel worries about cancer because risks that are perceived as involuntarily imposed or highly uncertain are among the most dreaded by citizens (Slovic, 1997). Cancer is also a complex health condition consisting of a multitude of different types of diseases linked to numerous hypothesized causes, and it can sometimes take decades to develop cancer following exposure to a carcinogen (Neutra et al., 1992). These factors can make it difficult for health officials to craft messages explaining the risk of cancer and carry out effective risk communication that would quell citizen fears.

Effective cancer risk communication may also be hindered by stakeholders such as the media, a common source of health information that many citizens rely on. News agencies frequently report about cancer and strongly influence the public's knowledge and perceptions of cancer risks through their coverage of cancer events and studies. However, the media has been found to sometimes sensationalize risks from environmental hazards and mischaracterize

uncertain risk information as overly certain, which can distort the public's perceptions of cancer risks (Jensen et al., 2014).

Perceptions of cancer risk also depend on people's comprehension of risk information, which is influenced by an individual's education, skills and expertise. Although numeric formats of risk communication can lead to more accurate perceptions of risk compared to verbal probability phrases that are less precise (Gurmankin, Baron & Armstrong, 2004), they require competencies in numeracy that are not universal. For example, people who have difficulty interpreting numerical information have been found to overestimate risks when contextual verbal probability information is omitted (Klein & Stefanek, 2007). Therefore, employing appropriate information formats (e.g. numeric, verbal, visual) to conduct risk communication is an important step in improving risk comprehension and forming more accurate perceptions of risk. This is especially critical during cluster investigations when health officials are expected to convey information about cancer probabilities to citizens that compare observed versus expected rates of the disease. If health officials disseminate data on cancer rates that is confusing or seems inconsistent with the level of disease risk that citizens believe to be present in their community, then the official response to the suspected cluster may be considered inadequate. Unfortunately, this type of scenario can also lead to an erosion of public trust in government institutions and expert knowledge (Fjelland, 2016; Johnson & Waishwell, 2014).

A decline in institutional and expert trust is not only problematic for the impacts it would have on social, political and scientific stakeholders trying to lead a community out of a crisis, but also because of the role that trust plays in shaping perceptions of risk. When people trust an information source, they tend to believe the information that is being shared and frame their beliefs and risk judgments around that trusted reference point (Weaver et al., 2017). However,

becoming a trusted source is a complex process. The philosopher Onora O'Neill suggested that levels of trust fluctuate based on the circumstances in which people gauge a stakeholder's *trustworthiness* (2013). That is, trust can be gained when stakeholders actively demonstrate their trustworthiness, for example, by being competent, honest and reliable communicators. This raises important questions for risk educators about how to design communications that influence perceptions of both trustworthiness and risk when educating citizens about cancer risks.

Although cancer clusters have been studied for decades in the United States (Caldwell, 1990; Goodman et al., 2012), where a national set of guidelines for investigations exists, it is not known how many cancer clusters have been reported in Canada because they are not tracked and no investigation protocols exist at a national level. As a result, there are also no consistent guidelines in place to direct cancer risk communication activities during cluster investigations. This research sought to address these knowledge gaps by examining current cancer cluster investigation procedures and communication practices in Canada and exploring how knowledge about cancer risk is received and transferred by various expert and non-expert stakeholders. A major overarching goal of this research project was to gain new insights into the diverse ways that people interpret and engage with cancer information and perceive cancer risk, and to identify improved methods of conducting cancer risk communication and risk education.

1.2 CHAPTER OBJECTIVES AND CONTENTS

This dissertation includes four substantive chapters, which each contribute to the overarching goal of this research project. The first research paper (Chapter 2) set out to establish how cancer risk was communicated by the media during cancer cluster investigations. The objective of this chapter was to investigate the media's risk communication practices during Canadian cancer cluster investigations and characterize their role as disseminators of information on cancer risk

between expert and non-expert audiences. To achieve this, 84 news articles on cancer clusters in the province of Ontario that were published between 1990-2017 were retrieved from news databases and a media content analysis of the newspaper coverage followed. In this chapter, we summarized linguistic trends in the media's reporting of cancer risk after quantifying the frequency of select words that described risk qualitatively (e.g. serious, concerning), quantitatively (e.g. rate per 100,000), and discussed cancer risk factors (e.g. tobacco, pollution). This work revealed key differences in the way that news agencies communicated cancer risk. For example, it was found that news coverage of cancer clusters in urban areas of Ontario used more precise quantitative risk language and discussed key cancer risk factors more frequently than articles reporting on rural clusters. The findings highlighted issues surrounding communication inequality, whereby not all members of the public have access to effective cancer risk communication. This unequal access could lead to differences in people's awareness of and perceptions of cancer risk as well as varied views about the danger that cancer poses. Importantly, the absence of certain types of risk information in news articles we identified would suggest that communication interventions such as collaborative knowledge dissemination tools between health experts and the media may be required to ensure adequate levels of health risk literacy across populations.

Chapter 3 builds on many of the themes of Chapter 2 and summarizes the risk communication practices and cancer cluster investigation procedures undertaken by health officials from jurisdictions across Canada. The objective of this chapter was to compare and contrast the risk communication practices and cluster investigation procedures of various Canadian public health experts and agencies. This paper also utilized content analysis methods to compare various jurisdictions' cluster investigation policy documents, as well as a thematic

analysis of transcripts from 13 telephone interviews conducted with 15 health officials. This work revealed that a variety of approaches are being used to investigate cancer clusters with considerable procedural variations across Canadian jurisdictions. It also revealed a clear need for risk communication activities to be conducted alongside cluster investigations, as health officials consistently cited the need for more supports, training and face-to-face opportunities to engage in public outreach and cancer education with community members.

While the objectives of Chapter 2 and Chapter 3 centered around identifying and summarizing the cancer risk communication practices of the media and public health officials in Canada, Chapter 4 set out to investigate the impacts of their communications on cancer risk perceptions. This chapter's objective was to test whether the portrayal of a cancer cluster event that differed by information source and information format would influence people's perceptions of the information's trustworthiness and their concerns about cancer. Using a randomized experiment, participants were assigned to view different types of information about a fictional community cancer cluster. The information treatments were designed to either look like a news story or a government report, which either included contextual information about the cluster and/or personal stories from community members or neither. Participants were then surveyed about their perceived trust in the information and cancer concerns. This chapter will show that certain message sources and formats are perceived as more or less trustworthy and may influence perceptions of cancer risk differently. The work also revealed through stratified analyses that the impacts of the information treatments on perceptions of cancer risk varied by participants' education level, suggesting that this could be an important variable to explore further.

In the fifth chapter, the impacts of education and expertise on cancer risk beliefs were examined. Using the data from the same survey that were analysed for the paper in Chapter 4,

this study set out to explore whether skills and competencies (e.g. numeracy, literacy) would be associated with individuals' beliefs related to cancer risk management. Since this chapter leveraged the same dataset as the prior chapter (Chapter 4), there is some overlapping content in both of their methods sections, particularly as it pertains to data collection approaches. However, as these two chapters focused on analyzing different variables and presenting distinct results, different conclusions were drawn. The objective of Chapter 5 was to investigate associations between participant skills/expertise, health information seeking, risk perceptions and beliefs related to coping with cancer risk. A major research finding discussed in this chapter was that participants with higher levels of health expertise and health literacy appeared more likely to report that they believed they had the capabilities to self-manage their risk of cancer. As some cancer coping beliefs have been linked to increased intentions of adopting cancer-preventive behaviours, understanding which competencies may be connected to these beliefs has practical implications for risk educators designing learning tools and health education interventions that aim to motivate healthier decision-making across populations.

Finally, in the sixth chapter, this dissertation's research contributions are discussed in the context of three subjects that were the focus of this work: cancer risk communication, cancer risk perceptions and cancer risk education. This chapter ends with a discussion of the implications of this project on policies and procedures related to cluster investigations and risk communication, as well as possible directions for future research. Thus, Chapter 6 will highlight how this dissertation has significantly worked to advance our knowledge across multiple disciplines.

1.3 REFERENCES

- Assunção, R. (2013). Commentary: Statistical assessment of cancer cluster evidence—in search of a middle ground. *International Journal of Epidemiology*, 42(2), 453-455.
- Bell, B. S., Hoskins, R. E., Pickle, L. W., & Wartenberg, D. (2006). Current practices in spatial analysis of cancer data: Mapping health statistics to inform policymakers and the public. *International Journal of Health Geographics*, 5(1), 49.
- Caldwell, G. G. (1990). Twenty-two years of cancer cluster investigations at the Centers for Disease Control. *American Journal of Epidemiology*, 132(supp1), 43-47.
- Carter, A. (2019, May). Study finds high levels of deadly blood cancer in Ontario industrial cities. CBC News. <https://www.cbc.ca/news/canada/hamilton/cancer-study-1.5153973>
- Fjelland, R. (2016). When laypeople are right and experts are wrong: Lessons from Love Canal. *HYLE—International Journal for Philosophy of Chemistry*, 22, 105-125.
- Goodman, M., Naiman, J. S., Goodman, D., & LaKind, J. S. (2012). Cancer clusters in the USA: what do the last twenty years of state and federal investigations tell us?. *Critical reviews in toxicology*, 42(6), 474-490.
- Gurmankin, A. D., Baron, J., & Armstrong, K. (2004). The effect of numerical statements of risk on trust and comfort with hypothetical physician risk communication. *Medical Decision Making*, 24(3), 265-271.
- Jensen, J. D., Scherr, C. L., Brown, N., Jones, C., Christy, K., & Hurley, R. J. (2014)..Public estimates of cancer frequency: Cancer incidence perceptions mirror distorted media depictions. *Journal of Health Communication*, 19(5), 609-624.
- Johnson, B. B., & Waishwell, L. (2014). Public response to official information on cancer and cancer clusters. *Human and Ecological Risk Assessment: An International Journal*, 20(3), 839-871.
- Klein, W. M., & Stefanek, M. E. (2007). Cancer risk elicitation and communication: Lessons from the psychology of risk perception. *CA: A Cancer Journal for Clinicians*, 57(3), 147-167.
- Levy, A. G., Weinstein, N., Kidney, E., Scheld, S., & Guarnaccia, P. (2008). Lay and expert interpretations of cancer cluster evidence. *Risk Analysis: An International Journal*, 28(6), 1531-1538.
- Neutra, R., Swan, S., & Mack, T. (1992). Clusters galore: Insights about environmental clusters from probability theory. *Science of the Total Environment*, 127(1-2), 187-200.
- O'Neill, O. (2013, June). What we don't understand about trust. TEDxHousesOfParliament. https://www.ted.com/talks/onora_o_neill_what_we_don_t_understand_about_trust
- Paddon, M. (2016, December). Union: Cathedral high school staff concerned about cancer. The Hamilton Spectator. <https://www.thespec.com/news/hamilton-region/2016/12/15/union-cathedral-high-school-staff-concerned-about-cancer.html>
- Prokaska, L. (1996, September). Another case of cancer: Cluster of 11 cases troubles Bell Canada employees. The Hamilton Spectator. Retrieved from Factiva on January 30, 2018.

Slovic, P. (1997). Public perception of risk. *Journal of Environmental Health*, 59(9), 22.

Sunstein, C.R. (2002). Chapter 3: Are experts wrong? In *Risk and reason: Safety, law, and the environment* (pp. 53-77). Cambridge, UK: Cambridge University Press.

Taekema, D. (2016, September). Remington Park residents question cancer cluster study at town hall. *The Windsor Star*. Retrieved from: <https://windsorstar.com/news/local-news/remington-park-cancer-cluster-town-hall-630-to-9-p-m>

Thun, M. J., & Sinks, T. (2004). Understanding cancer clusters. *CA: A Cancer Journal for Clinicians*, 54(5), 273-280.

Weaver, S. R., Jazwa, A., Popova, L., Slovic, P., Rothenberg, R. B., & Eriksen, M. P. (2017). Worldviews and trust of sources for health information on electronic nicotine delivery systems: Effects on risk perceptions and use. *SSM - Population Health*, 3, 787–794. <https://doi.org/10.1016/j.ssmph.2017.09.003>

Yiannakoulias, N. (2011). Understanding identifiability in secondary health data. *Canadian Journal of Public Health/Revue Canadienne de Sante Publique*, 291-293.

CHAPTER 2

Cancer risk communication in the news coverage of suspected cancer clusters in Ontario: Contrasting media messaging on cancer by geography

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2.1 INTRODUCTION

Risk communication is a valuable tool used to disseminate information that can lead to more accurate perceptions of health risks in a population and ultimately influence individual decision making towards adopting certain health-promoting behaviours.

Disseminating information on health risks that is accurate and easy to understand may therefore foster health literacy in a population, and help ensure individuals are sufficiently informed about health risks and benefits. Among the numerous communication channels that people receive information from, the news media can play an important role in shaping the public's perception of a health risk, particularly when media coverage of an event is frequent (Wilson et al. 2004). A recent poll has found that Canadian news readership is high, with about 9 out of 10 Canadians having reported reading a newspaper (either online, in-print, or both) at least once a week (Totum Research 2019). This can present either a unique opportunity to leverage this communication channel to influence and improve perceptions of health risks among Canadians, or raise the potential for ineffective health communication transmission or the spread of misinformation.

The social amplification of risk is a framework that helps describe how risk perceptions and public concern are transmitted from social and institutional actors (e.g., government, news media, etc.) and augmented by individuals' interpretations and responses to information following an adverse event (Kasperson et al. 1988). Key mechanisms that contribute to the

amplification of risk perceptions include the volume of information about a risk event, and the dramatization of facts (Kasperson and Kasperson 1996). Therefore, the style in which the media reports a health risk (e.g., tone, diction, syntax, themes, etc.) and the frequency of reporting may be instrumental in how media consumers will perceive and interpret that risk. For example, previous studies have found that media outlets tend to report health hazards and health risks by presenting risks as either overly certain or highly controversial, even if the risks are unconfirmed (Tang and Rundblad 2015), or report highly sensationalized content (Dahlstrom et al. 2012), which can lead to distorted perceptions of a health risk. However, not all media are created equal. Differences in geographic settings, such as whether a newspaper is based in an urban or rural community, may determine how a given newspaper or media outlet will report on various health topics (Young et al. 2015) or the level of resources and expertise that can be expended when covering specific health issues like cancer (MacDonald and Hoffman-Goetz 2001). Different geographic contexts can also shape how the same health risk event is covered by different news outlets. For example, Humphries et al. (2017) found that the content of news coverage of the 2014 Ebola outbreak varied considerably at a national scale when comparing news articles published in Canada and Nigeria.

There are many reasons why there could be differences in the frequency and content of health-related news reports in different geographies. Media organizations serving urban centres are generally larger and are more likely to have the resources to support journalists with specialized health or science backgrounds (MacDonald and Hoffman-Goetz 2001). Reporters may also be tailoring their writing to the characteristics or demographics of the communities reading their work. For example, the reporting of cancer risks in Indigenous and ethnic newspapers has been found to focus on particular cancer types and tends to utilize more non-

numeric descriptions of cancer risk (Hoffman-Goetz et al. 2003; Stryker et al. 2009). In addition, rural and remote communities often rely on the news media as a primary source of health information since populations that are geographically dispersed may face barriers accessing information through other channels (Ramírez et al. 2017). In comparison, individuals in urban areas are more likely to use the Internet as their primary health information source (Befort et al. 2013), while older individuals, as well as those with fewer Internet skills, are more likely to use traditional news media as a primary source of health information (Jacobs et al. 2017). Individuals with a medical history of cancer have also been found to spend more time reading newspapers compared to people without a diagnosis (Tian and Robinson 2008), which could suggest that in places with higher incidences of a disease, the local residents may seek out more news related to that specific disease.

Cancer clusters constitute a unique health risk event that attract considerable interest and concern from the public, the media, and government officials when they are reported. Disease clusters are geographically meaningful areas where the frequency of a disease diagnosis, like cancer, during a given period of time is higher than is expected (Yiannakoulias 2009). Often some suspected exposure to industrial pollutants or environmental contaminants will trigger a community's concern over a perceived cancer cluster (Robinson 2002), which can evoke strong responses from the public. However, the health risks of many pollutants remain unknown or poorly understood, and what constitutes a significant environmental risk to health can be difficult to assess by non-experts.

Despite advances in how disease clusters are statistically detected in populations, addressing public concerns about perceived cancer clusters and understanding how to effectively communicate health risk remains a serious challenge for risk communicators (Trumbo et al.

2008). While most public health officials view cancer clusters as chance occurrences, many community members become convinced that they are environmentally-caused and pose an immediate threat to their health (Johnson and Waishwell 2014). Unfortunately, cancer cluster investigations rarely point to a specific pollution point source nor yield the answers that members of a community are seeking; in fact, when the press leaves and the investigations end, many community members are left with increased feelings of uncertainty and concern about their community, and perceptions of expert incompetence or distrust may arise (Goodman et al. 2014). However, these investigations may still offer public health departments a useful opportunity to educate the public on cancer risk (Trumbo 2000). Key to the goal of public education is ensuring that cancer risk communication is conducted effectively and accurately by news outlets in a way that eases public concerns by leveraging the media's coverage of such a salient news event.

Many studies have attempted to answer the question of what constitutes effective health risk communication in order to produce accurate perceptions of risk in those receiving the information. Central to that question has been examining the role of various information formats, such as qualitative verbal and textual expressions of risk compared to quantitative numerical expressions of risk, and how each format may differently influence an individual's perception of the probability of that risk (Hendrickx et al. 1989; Gurmankin et al. 2004). Evidence from some studies would suggest that the communication of risks related to cancer is most effectively achieved when presented in formats using both words and numbers in order to accommodate individuals with all levels of numeracy skills (Janz et al. 2017; Carey et al. 2018). Therefore, striking the balance between the right amount of quantitative and qualitative risk information is an important piece in the effective communication of cancer risk and examining the risk

language used in the media's coverage of events like cancer clusters can be useful to study how cancer risk is likely to be perceived by the public.

Our study reports on the findings of a media content analysis of cancer news coverage in Ontario. Textual analyses of media content rarely draw from one methodological tradition, though inspiration is taken from other established methodologies common in research rooted in semiotics, linguistics, and post-structuralism, which stress the importance of language in understanding social relations, cultural practices, and human decision making (Fürsich 2009). Using cancer clusters as a case study of reporting on cancer risks, the goal of this study was to examine how cancer risk is communicated by the news media during suspected cancer cluster investigations in Ontario. Since cancer risk in Ontario varies by geography (Canadian Partnership Against Cancer 2014), and health-related news reports have been found to vary by geography, we hypothesized that differences in geographical contexts would reveal differences in the ways that the media communicate cancer risk in Ontario. Specifically, we sought to examine these differences by comparing cancer risk language in articles on urban versus rural cancer clusters, clusters occurring at different geographic scales (e.g., by region, on First nations reserves, and in neighbourhood settings), and clusters that were either environmental or occupational in nature.

2.2 METHODS

We used Factiva and LexisNexis to draw our sample of news articles, which constitute traditional print, online news, and wire services that covered suspected cancer clusters in Ontario. There were nine instances of an article being published both in a newswire and by a newspaper; in these cases both articles were retained in our study on the basis that their word

counts differed (on average newswires were longer) and the location of their readership would differ. The first search using Factiva was limited to Canada and the years 1990 to 2017, included the words “cancer” and “cluster,” and yielded 2,029 articles. After both an earlier scoping review of Canadian reports and government documents on cancer clusters and the search using Factiva yielded mostly content about clusters in Ontario, a decision was made by the researchers to focus on news articles reporting on cancer clusters from that province. Articles were screened by their title and the context around the word “cluster” in the article’s text. Since cancer clusters are defined as cancer risk events where the observed incidence rate in a population is higher than would be expected to occur in that population within a defined space and time (Yiannakoulias 2009), this led to the inclusion of articles only covering particular events where it was reported that multiple people had been diagnosed with cancer both in a defined geographic area and during a particular period of time, not just one or the other. This search yielded 67 articles that reported on suspected cancer clusters in Ontario. The process was repeated using LexisNexis, which yielded an additional 10 articles on cancer clusters in Ontario, after removing duplicates. An additional 7 articles were retrieved with a general search of “cancer cluster Ontario” using the Google search engine. There was a total of 84 articles analyzed in this study, reporting on 24 unique cancer cluster events.

We classified each article based on characteristics of the cancer cluster covered in that article, using two binary cluster type categories. First, we classified a suspected cancer cluster as occurring in either urban or rural settings based on the population and density of the location of the cluster. We applied Statistics Canada’s (2016) definition of urban areas as population centres with a population of at least 1,000 and a population density of 400 persons or more per square kilometre, with all other areas classified as rural. Second, we examined whether the cluster in the

article was reported in the context of some hypothesized exposure occurring in the environment or in the workplace, and clusters were classified as either environmental or occupational based on the context of the exposure or hazard discussed in the article. For example, if an article mentioned an exposure to a cancer-causing substance that took place in a workplace or the cluster of cancer cases involved group of workers, it was coded as occupational.

In addition, we classified each article based on the news outlets that published the articles, using binary news agency type categories. News agencies were coded as either local or non-local depending on whether the reporting agency was based in the community where the cluster took place. The agencies were also coded as having a high or low readership based on whether the news outlet cited a daily (or weekly for some weekly newspapers) readership of more than or less than 100,000 readers.

We also included a 6-category variable for geographic scale; articles were coded as reporting on a cluster that occurred either in a city, neighbourhood, entire region, school, workplace, or First Nations reserve. The coding for this variable was based on the spatial extent of cancer cases and the finest level of spatial resolution described in the article. As is common in geography, scales with a similar spatial extent and granularity (e.g., a neighbourhood, workplace, or First Nations reserve), can be distinguished from one another by the local population's characteristics, social behaviours, and dynamics, and by governmental jurisdiction (Lloyd 2014). Additionally, as Canada moves towards recognizing the injustices brought about by settler colonialism, including the disproportionate levels of industrial pollution on and around reserves (Basu and Lanphear 2019), it was important to consider First Nations reserves as a separate scale category in support of the resurgence of Indigenous-led governance of lands and their rights to self-determination.

All articles were analyzed textually in the open-source statistical software R 3.4.4 using the Stringr & Quanteda packages (R Core Team 2018). Research utilizing corpus linguistic procedures, which examine the construction of discourses by analyzing occurrences of linguistic phenomena (e.g., word frequencies) (Baker 2006), are becoming more commonplace in media content analyses which have traditionally focused more on thematic analyses and message framing (Karlsson and Sjøvaag 2016). The authors of this paper, however, came across a limited number of studies applying corpus linguistic procedures to quantify language on risk. Of the studies that have explored what language is used to describe risk, most characterize differences in the level of contextual precision of various words used to describe risk consequence and probability. For example, when examining articles about the West Nile virus, Roche and Muskavitch (2003) defined qualitative risk words (e.g., “dangerous”) as non-numerical phrases, and considered quantitative risk words (e.g., “percent”) as numerator/denominator information about risk probability. Qualitative and quantitative risk can therefore be thought of as measurements of risk precision using either qualitative descriptors of risk severity or quantitative descriptors of risk probability, respectively. We calculated measures of three risk word variables: qualitative risk, quantitative risk, and cancer risk factors. Measures for these three categories were calculated using specific word frequencies, a method consistent with other linguistic analyses of risk communication (Tang and Rundblad 2015). The word frequencies were summed for each measure by article and divided by the total word count of each article to control for total number of words.

To select words representative of qualitative risk and quantitative risk, the authors selected a random sample of 10 articles for manual analysis to examine what terminology was commonly used in news articles to describe risk; additionally, relevant words identified from

other media content analyses on risk were included (Musso and Wakefield 2009; Dahlstrom et al. 2012; Birnbauer et al. 2017). For qualitative risk, the frequency of the following words was calculated for each article: “serious,” “danger,” “dangerous,” “hazard,” “hazardous,” “toxic,” “fear,” “scared,” “worry,” “concerning,” and “concern.” To obtain measures of quantitative risk, the frequency of the following numerical and statistical words or phrases was calculated for each article: “prevalence,” “prevalent,” “incidence,” “rate,” “more risk,” “greater risk,” “average,” “cases,” “percent,” “of every,” “per year,” “proportion,” and “per 100,000.”

In addition to how risk is qualitatively or quantitatively communicated in cancer cluster reporting, we also examined whether cancer risk factors were discussed in the articles since it has been suggested that inclusion of risk factors can impact health risk perceptions by contextualizing risk with other causes of morbidity and mortality (Russell 1999). To obtain measures of cancer risk factors discussed in the study articles, the frequency of the following words associated with common cancer risk factors (WHO 2020) was calculated for each article: “tobacco,” “smoking,” “radon,” “pollution,” “radiation,” “virus,” “alcohol,” “diet,” “obesity,” “obese,” “genetic,” and “family history.”

We calculated the mean word frequencies for qualitative risk, quantitative risk, and cancer risk factors for articles reporting on urban versus rural clusters, environmental versus occupational clusters, published by local versus non-local news agencies and those with high versus low readership. To test whether the word frequencies from each binary cluster type and agency type variable significantly differed from one another (i.e., came from different populations), the non-parametric Mann-Whitney-Wilcoxon Test was applied as our data was not normally distributed. We used the non-parametric Kruskal Wallis one-way ANOVA to assess

differences in the mean word frequencies for qualitative risk, quantitative risk, and cancer risk factors for the geographic scale category.

2.3 RESULTS

The locations of the suspected cancer clusters in Ontario from this study are found in Figure 2-1.

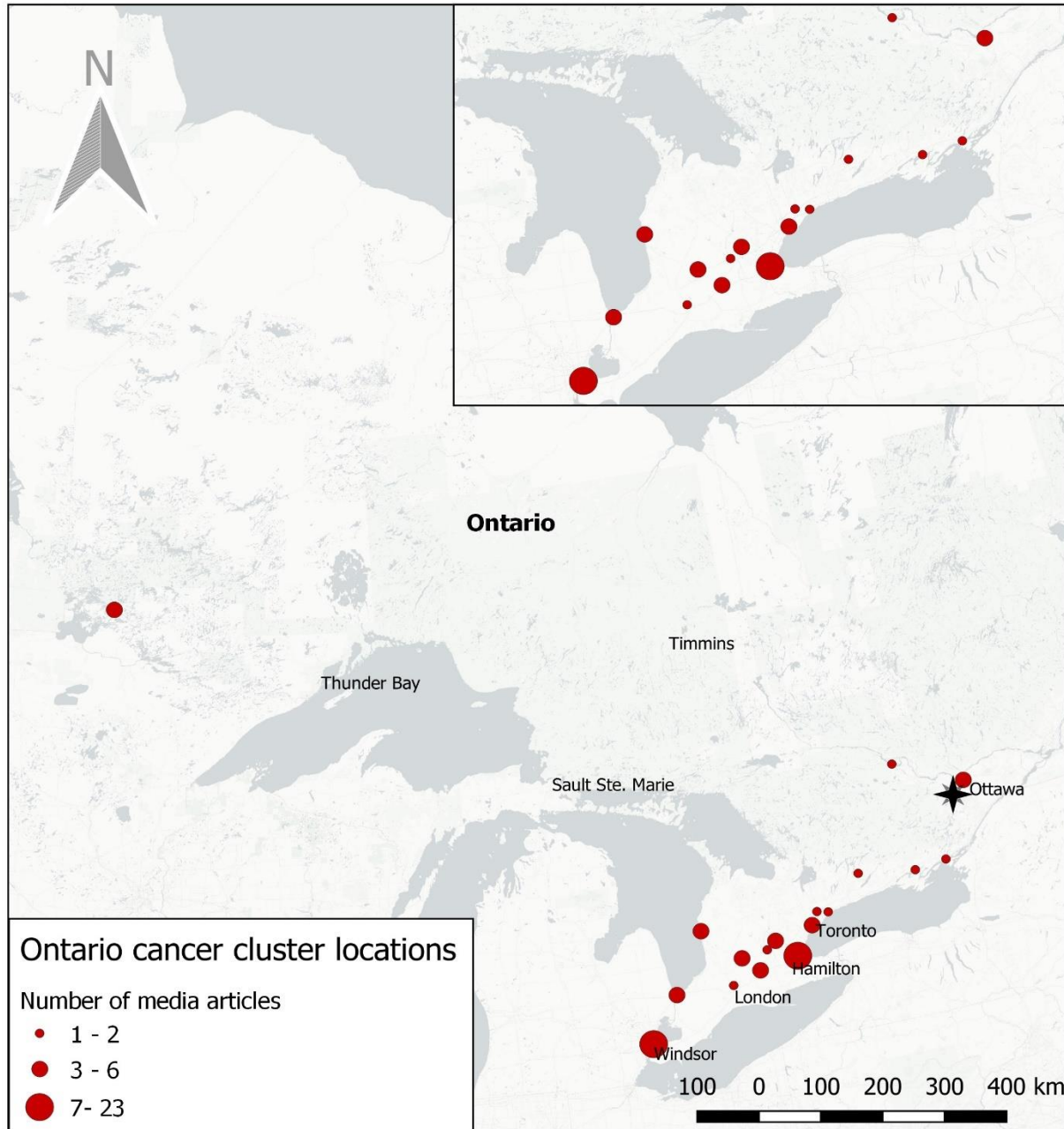


Figure 2-1. Map of the locations of cancer clusters in Ontario, Canada that were reported by the media and the number of articles per location, 1990–2017.

The majority of clusters that were reported by the media were located in southern Ontario. The most widely reported cancer clusters were located in Hamilton and Windsor, with 17 and 23 news articles, respectively (Figure 2-1). There were 3 news articles each documenting cancer clusters in Toronto and Ottawa.

Frequencies of news articles by various cluster type and news agency type categories are summarized in Table 2-1.

Table 2-1. Frequency of news articles (n=84) analyzed by cancer cluster characteristics and news agency characteristics, across various geographic scales.

Geographic Scale	Cancer Cluster Characteristics				News Agency Characteristics			
	Environmental	Occupational	Urban	Rural	Local	Non-local	High Readership	Low Readership
City	6	0	6	0	4	2	2	4
Neighbourhood	31	0	26	5	21	10	25	6
Region	5	0	0	5	4	1	1	4
Reserve	7	0	0	7	2	5	3	4
School	0	5	5	0	5	0	5	0
Workplace	0	30	30	0	20	10	23	7
TOTAL	49	35	67	17	56	28	59	25

Of the 84 articles analyzed, most reported on environmental clusters (n=49) compared to occupational (n=35), and most articles reported on clusters in urban communities (n=67). When comparing cluster characteristics across geographic scales, most environmental clusters that were reported were observed to be at a neighbourhood level (n=31), followed by First Nations reserves (n=7). All occupational clusters (n=35) occurred either at the workplace (n=30) or school (n=5) scale. Two-thirds of clusters were reported by articles published by local news agencies (n=56) compared to non-local (n=28), and 70% were reported by agencies with a high readership (n=59) compared to low readership (n=25). Approximately twice as many local news agencies covered rural (n=11) and urban clusters (n=45) compared to non-local agencies (n=6 and n=22, respectively). Articles covering clusters at the neighbourhood scale and workplace

scale were mostly published by local agencies (68%) and agencies with high readership (81%). The frequency of articles covering clusters at other geographic scales was more spread out among non-local agencies and agencies with low readership.

On average, word frequencies for terms describing quantitative risk and cancer risk factors were higher for cancer clusters located in urban settings compared to rural (Figure 2-2). For terms describing quantitative risk, the mean word frequency was 7.34 words per 1,000 for rural clusters, compared to approximately 10.24 words per 1,000 in urban. Articles on urban cancer clusters also contained on average more than four times as many cancer risk factor terms compared to articles on rural clusters (Figure 2-2).

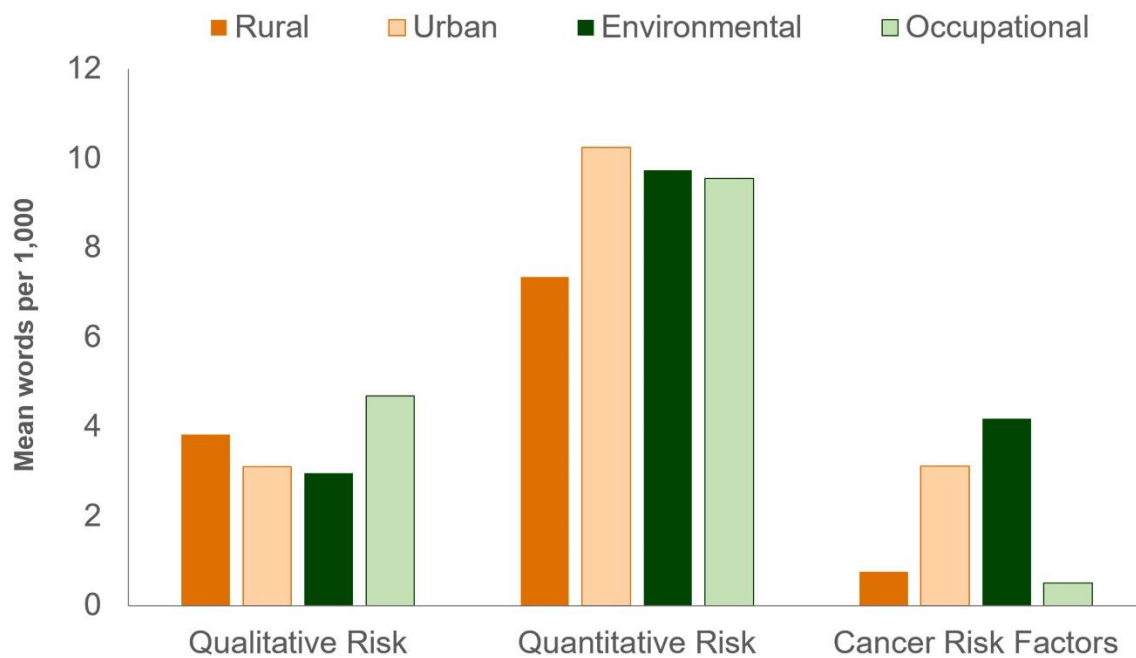


Figure 2-2. Mean frequency of words per 1,000 describing qualitative risk, quantitative risk, and cancer risk factors in articles reporting on cancer clusters by cluster characteristics.

Among cancer clusters that were environmental or occupational, the frequency of terms used to describe quantitative risk were very similar with 9.73 words per 1,000 and 9.54 words per 1,000, respectively (Figure 2-2). More qualitative risk words were associated with articles

reporting on occupational clusters compared to environmental ($p=0.04$); however, more words describing cancer risk factors were present in articles reporting on environmental cancer clusters compared to occupational ($p<0.001$).

For the news agency characteristics variables, there was little apparent difference in word frequencies for all categories of risk terms between local and non-local news agencies covering cancer clusters (Figure 2-3). However, articles published by news agencies with higher readership on average used words of every risk category more frequently compared to news agencies with lower readership. Among cancer risk factor terms, word frequencies were four times higher in articles published by news agencies with high readership compared to low readership ($p=0.01$).

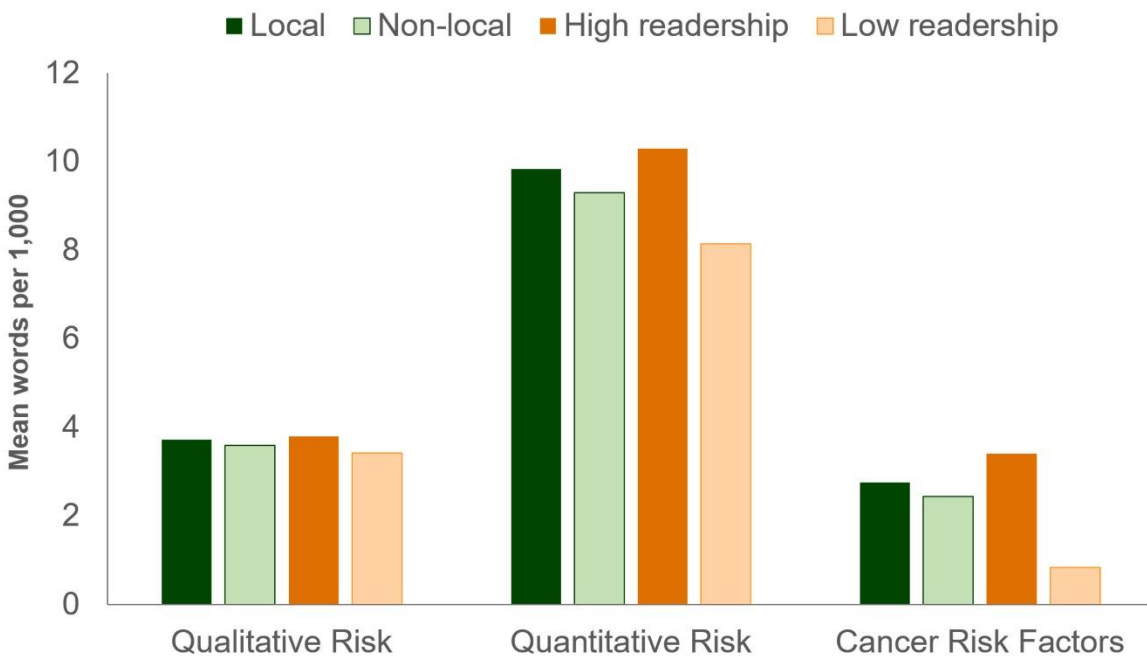


Figure 2-3. Mean frequency of words per 1,000 describing qualitative risk, quantitative risk, and cancer risk factors in articles reporting on cancer clusters by news agency characteristics.

Qualitative risk, quantitative risk, and cancer risk factor word frequencies for the 6-category geographic scale variable are summarized in Figure 2-4. On average, qualitative risk word frequencies were highest for articles that reported on cancer clusters that occurred at school and workplace settings and lowest for articles reporting cancer clusters that took place at the city scale (Figure 2-4). The differences in mean qualitative risk word frequencies were not statistically significant ($p=0.21$). Among quantitative risk terms, the average word frequency was highest for articles reporting on cancer clusters that took place at the school scale and city scale and lowest for cancer clusters that occurred within a workplace or on a First Nations Reserve (Figure 2-4). These differences were statistically significant ($p=0.008$). Average word frequencies describing cancer risk factors were largest for articles that reported cancer clusters that occurred at the neighbourhood scale followed by the city scale, whereas word frequencies of cancer risk factors were similar and low at the other geographic scales ($p<0.001$).

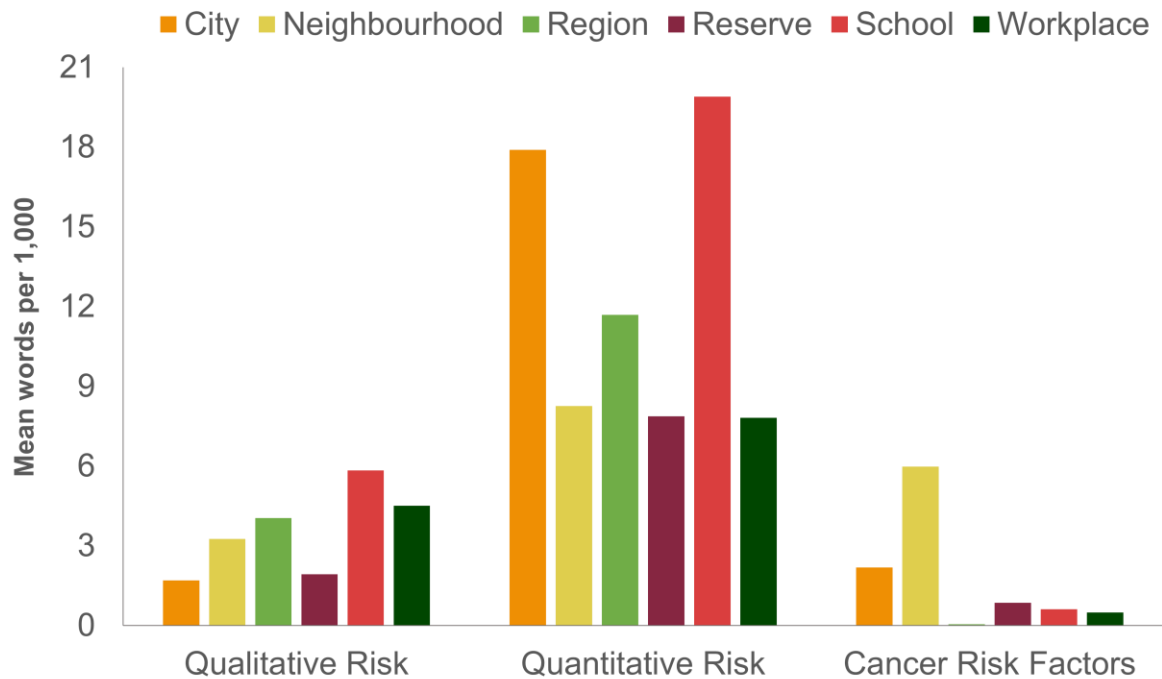


Figure 2-4. Mean frequency of words per 1,000 describing qualitative risk, quantitative risk, and cancer risk factors in articles reporting on cancer clusters by geographic scale.

2.4 DISCUSSION

The reporting of health events, such as cancer clusters, has important public health implications with regard to providing information to the public on leading health issues. How the messaging in the news report is presented and framed, in context with other key information that may be highlighted or omitted, plays a role in how the public will interpret that health issue and any risks associated with it (Gollust et al. 2019). In this study of news articles on cancer clusters, we observed that newspaper coverage of cancer clusters located in urban areas on average tended to use more quantitative risk language compared to coverage of cancer clusters in more rural areas. Qualitative risk word frequencies were slightly higher in articles on rural cancer clusters compared to urban clusters, but this relationship was not significant. While quantitative risk information offers the public more precise information about the risk of cancer, it often lacks comparative context, and differences in individuals' numeracy skills to interpret this information can make this approach to risk communication less effective (Rothman and Kiviniemi 1999).

A balanced approach to risk communication, which draws equally on quantitative and qualitative risk descriptions and contextualizes the risk of cancer from many different risk factors (Russell 1999), should also present different categories of risk language more equally across different geographies and populations. Yet our study found differences in the frequency of risk language used in articles about urban compared to rural clusters, particularly among quantitative and cancer risk factor terms. Interestingly, there was little difference in the frequency of risk language among articles reporting on local versus non-local cancer clusters, suggesting the location of the cluster and the community itself is a more important factor in the news coverage of clusters than the location of the reporting news agency. What is unclear is whether the difference in urban-rural language use is a function of editorial decisions or consumer demand,

but this finding does suggest that more could be done to ensure that there is balanced risk communication in articles about both urban and rural communities.

When Hinnant et al. (2016) interviewed health journalists, they found that they experienced challenges balancing readable content with necessary technical health information, and tended to see the latter as the responsibility of public health agencies. However, as the media remains a key health information disseminator, especially in rural communities (Friedman et al. 2014), the level of precision they use in their language about health risks has to accommodate a readership with varied health literacy levels. More research gathering insights from health journalists about their writing practices and what considerations are made when reporting on particular populations should be undertaken in the future to address these types of geographic discrepancies in article content.

The results from this study also suggest an absence of information on cancer risk factors in the media's reporting of cancer clusters in rural areas (Figure 2-2), and at most geographic scales (Figure 2-4). As discussed above, the explanation for this difference in language use is unclear, and may be caused by or reinforce differences in perceptions of health risk across geographic areas. Nevertheless, language around cancer risk factors provides useful context for understanding the complexity of health risks, and helps communicate the combined role of structure and agency in explaining the emergence of apparent cancer clusters. A previous study on the media's coverage of cancer clusters in the United States also found that very little background information about cancer rates, confounders, and other contextual information was provided to readers (Greenberg and Wartenberg 1991). In the absence of these important contextual descriptors, the public is left to form its own opinions about cancer risk (Wählberg and Sjöberg 2000). In addition, since other modes of health information communication (e.g.,

direct physician communication, Internet searches) may be less easily accessible in rural areas (Spencer and Real 2019) or on First Nations reserves, there may be added value and demand for access to accurate and effective news coverage of health risks in these geographies.

More qualitative risk words were associated with articles reporting on occupational clusters; however, more words describing cancer risk factors were present in articles reporting on environmental cancer clusters. Articles covering occupational cancer clusters were also on average longer than articles on environmental clusters (915 words compared to 723 words), suggesting that the media's coverage of occupational clusters may employ more descriptive reporting approaches. We also observed low mean word frequencies describing cancer risk factors in articles reporting on occupational cancer clusters. This is likely due to those articles focusing their coverage on hazardous occupational exposures relevant to that particular workplace rather than discussing other potential cancer risk factors.

The higher mean word frequencies describing cancer risk factors among articles reporting on cancer clusters at the neighbourhood scale were likely driven by the reporting of one particular cluster event that occurred in the neighbourhood of one city. This single event was highly reported by 23 articles over the course of two years, compared to the average of 4 articles per cluster event (range: 1 to 11 articles per cluster). Therefore, it is possible that these reporters may have had more time to report more in-depth content related to other cancer risk factors during this cluster event. In comparison, other cancer cluster events that did not prompt as much news coverage may not have provided as much of an opportunity for reporters to investigate and report on potential cancer causes. Cancer risk factor terms also appeared significantly more frequently in articles published by news agencies with higher readership, which could suggest

that the perceived number of readers of an article is an important factor in journalistic writing practices that should be explored more in future research.

Articles reporting on cancer clusters on First Nations reserves all constituted environmental clusters (n=7), which could be partially explained by the ongoing issues with environmental pollution due to industrial contamination on hundreds of First Nations reserves in Canada (Indigenous and Northern Affairs Canada 2016). This underscores the need to conduct effective risk communication in these communities where legitimate concerns and perceptions of risk related to environmental health issues are likely to arise. In fact, cancer incidence is increasing more quickly among members of Ontario's First Nations compared to other Ontarians (Kewayosh et al. 2015), representing a significant health inequity that will need to be addressed in part with improved cancer education and communication. Consistent with previous work in this area (Hoffman-Goetz et al. 2003), we found that cancer risk factors were reported significantly less frequently in our sample of articles on Indigenous communities, despite the growing disease burden of cancer in Canadian Indigenous communities. Going forward, the media and public health officials have a shared responsibility to supply Indigenous communities with relevant information on health risks, which may allow individuals from these communities to play a more active role in promoting their health and preventing disease (Rempel et al. 2016). While improving the health literacy of populations does not necessarily lead to full empowerment of marginalized community members, it is a necessary step in starting to address some of these health inequities and ensuring that these communities are given the tools to form accurate perceptions of risks relevant to their health.

The results of this study can be contextualized by past research examining the role that communication inequality plays in exacerbating rural health disparities due to differential access

to health information, as well as characteristics more typical of rural populations who tend to have difficulty retrieving or understanding health information (Estrada et al. 2018).

Communication infrastructure theory can provide a useful framework for examining how community communication structures differ by geographic contexts and how to address these differences to improve health communication. Geographic features such as the built environment and cultural, social, or political structures influence a community's communication structure, which is composed of multiple actors (e.g., government organizations, the media, societal institutions, social networks, and individuals), by influencing individuals' exposure to information (Wilkin 2013). Improving the communication structure between communication creators and users requires identifying what the information needs of those users are and recognizing trusted sources of information in the community (Estrada et al. 2018).

This theory has led to research into various health communication interventions based on participatory community-based and person-centred frameworks. Some examples from the literature that should be explored further in future research include establishing participatory news websites with contributions by local residents, community organizations, and traditional media (Chen et al. 2012), and developing written content that meets the information needs of the population by involving patients and those impacted as co-designers (Smith et al. 2017), rather than treating the community as mere study subjects or interviewees for a news segment.

Collaborating with local community organizations in the production and dissemination of health materials in communities with particular cultural or linguistic needs is also important (Li et al. 2019). Increasingly, researchers are looking at the use of social media forums such as Q&As on Twitter involving health officials, local news reporters, and community members during health crises (Young et al. 2018) and how this engagement with the public could be leveraged.

However, determining the best approach will depend on the geographic and social context of the local community and their existing communication dynamics (Villanueva et al. 2016). Future improvements in the risk communication of news articles covering health risk events should be framed by participatory-based communication principles involving collaboration between public health departments, journalists, and local community leaders. Such collaboration would help meet the particular community's information needs, leverage the news media's ability to reach a wide audience, and ensure that accurate and balanced health risk communication is conducted effectively to empower local community members with information.

The findings from our study are limited by the relatively small sample of articles (n=84) analyzed. There is some evidence to suggest that environmental and occupational cancer risk factors, which tend to fuel the public's fascination with cancer clusters (Robinson 2002), may be underreported in the media; this could explain why only 84 news articles on cancer clusters in Ontario were found. The true number of cancer clusters investigated in the province, beyond those that have been reported by the media, is unknown. Another limitation of this study is the focus on analyzing content from news in textual format since risk reporting and information dissemination to the public also occurs through other means, such as televised media. However, Driedger (2007) found little difference in the content and information presented in media coverage when comparing televised versus print coverage of a given health risk event, therefore, it is unlikely that expanding this research to other media forms would have resulted in vastly different conclusions.

As far as the authors are aware, this is the first study to examine risk communication in the news coverage of cancer clusters in Canada, and the first to contrast differences in risk

communication between urban and rural communities and across different geographic scales.

While researchers have suggested that the communication of risk is most effectively conducted when both quantitative and qualitative risk communication approaches are leveraged (Cheng 2016; Roslyng and Eskjær 2017), our study suggests that both approaches are not equally utilized in the media's coverage of cancer clusters in Ontario.

There is a fundamental need to better understand the language used in news reporting and whether or not the patterns in communication method reveal patterns that could be improved, or whether they reveal a systematic problem in the way cancer information is communicated to the public. A lack of balanced risk reporting can distort readers' perceptions of cancer risk (MacDonald and Hoffman-Goetz 2001), which can impact an individual's ability to make informed decisions regarding their health. The reporting of cancer information relevant to distinct geographic areas could be a way to inform the public of local cancer risk factors during a cancer cluster event. This study has proposed that the news media could be leveraged to serve as one of those communication channels for information dissemination.

The media's reporting of accurate and effective information on cancer risk is important for informing the public about cancer and fostering a level of health literacy in the population. Consistent with the social amplification of risk framework, the media can be thought of as message transmitters between public health officials and the public, thereby intensifying or weakening signals that make up the information that the public receives about health risks from government officials. The research has implications for the roles that both the media and public health departments have in communicating health risks when responding to disease events like cluster investigations and how geography may impact the communication of those risks. Going forward, increased collaboration between expert risk communicators at public health agencies,

journalists, and local community leaders and members could help address some of the disparities in access to health information and maximize the reach of this information to a broader audience. More input from various stakeholders in the creation and development of health-related messages may also produce journalistic content that informs the readers about health risks in ways that are more understandable, relevant, and tailored to the local community, while still providing accurate information to promote healthy behaviours and choices and improve population health outcomes.

2.5 REFERENCES

- Baker, P. 2006. *Using corpora in discourse analysis*. London, UK: Continuum.
- Basu, N., and B. P. Lanphear. 2019. The challenge of pollution and health in Canada. *Canadian Journal of Public Health* 110(2): 159–164.
- Befort, C. A., N. Nazir, K. Engelman, and W. Choi. 2013. Fatalistic cancer beliefs and information sources among rural and urban adults in the USA. *Journal of Cancer Education* 28(3): 521–526.
- Birnbrauer, K., D. O. Frohlich, and D. Treise. 2017. Inconsistencies in reporting risk information: A pilot analysis of online news coverage of West Nile Virus. *Global Health Promotion* 24(3): 14–22.
- Canadian Partnership Against Cancer. 2014. *Examining disparities in cancer control: A system performance special focus report*. Toronto, ON: Canadian Partnership Against Cancer. <https://www.systemperformance.ca/report/examining-disparities-in-cancer-control/>.
- Carey, M., A. Herrmann, A. Hall, E. Mansfield, and K. Fakes. 2018. Exploring health literacy and preferences for risk communication among medical oncology patients. *Plos One* 13(9): 1–12.
- Chen, N. T. N., F. Dong, S. J. Ball-Rokeach, M. Parks, and J. Huang. 2012. Building a new media platform for local storytelling and civic engagement in ethnically diverse neighborhoods. *New Media & Society* 14(6): 931–950.
- Cheng, W. M. E. T. 2016. Radon risk communication strategies: A regional story. *Journal of Environmental Health* 78(6): 102–106.

- Dahlstrom, M. F., A. Dudo, and D. Brossard. 2012. Precision of information, sensational information, and self-efficacy information as message-level variables affecting risk perceptions. *Risk Analysis* 32(1): 155–166.
- Driedger, S. M. 2007. Risk and the media: A comparison of print and televised news stories of a Canadian drinking water risk event. *Risk Analysis* 27(3): 775–786.
- Estrada, E., A. S. Ramirez, S. Gamboa, and P. Amézola de Herrera. 2018. Development of a participatory health communication intervention: An ecological approach to reducing rural information inequality and health disparities. *Journal of Health Communication* 23(8): 773–782.
- Friedman, D. B., A. Tanner, and I. D. Rose. 2014. Health journalists' perceptions of their communities and implications for the delivery of health information in the news. *Journal of Community Health* 39(2): 378–385.
- Fürsich, E. 2009. In defense of textual analysis: Restoring a challenged method for journalism and media studies. *Journalism Studies* 10(2): 238–252.
- Gollust, S. E., E. F. Fowler, and J. Niederdeppe. 2019. Television news coverage of public health issues and implications for public health policy and practice. *Annual Review of Public Health* 40: 167–185.
- Goodman, M., J. S. LaKind, J. A. Fagliano, T. L., Lash, J. L. Wiemels, D. M. Winn, C. Patel, et al. 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.
- Greenberg, M., and D. Wartenberg. 1991. Newspaper coverage of cancer clusters. *Health Education Quarterly* 18(3): 363–374.
- Gurmankin, A. D., J. Baron, and K. Armstrong. 2004. Intended message versus message received in hypothetical physician risk communications: Exploring the gap. *Risk Analysis* 24(5): 1337–1347.
- Hendrickx, L., C. Vlek, and H. Oppewal. 1989. Relative importance of scenario information and frequency information in the judgment of risk. *Acta Psychologica* 72(1): 41–63.
- Hinnant, A., J. Jenkins, and R. Subramanian. 2016. Health journalist role conceptions: Existing and emerging professional identities. *Journalism Practice* 10(6): 763–781.
- Hoffman-Goetz, L., C. Shannon, and J. N. Clarke. 2003. Chronic disease coverage in Canadian Aboriginal newspapers. *Journal of Health Communication* 8(5): 475–488.
- Humphries, B., M. Radice, and S. Lauzier. 2017. Comparing “insider” and “outsider” news coverage of the 2014 Ebola outbreak. *Canadian Journal of Public Health* 108(4): 381–387.

- Indigenous and Northern Affairs Canada. 2016. *Evaluation of the contaminated sites on-reserve (south of the 60th parallel) program*. Ottawa, ON: Indigenous and Northern Affairs Canada. <https://www.rcaanc-cirnac.gc.ca/eng/1511365606141/1542218278768>.
- Jacobs, W., A. O. Amuta, and K. C. Jeon. 2017. Health information seeking in the digital age: An analysis of health information seeking behavior among US adults. *Cogent Social Sciences* 3(1): 1302785.
- Janz, N. K., Y. Li, B. J. Zikmund-Fisher, R. Jagsi, A.W. Kurian, L.C. An, M. C. McLeod, K. L. Lee, S. J. Katz, and S. T. Hawley. 2017. The impact of doctor–patient communication on patients’ perceptions of their risk of breast cancer recurrence. *Breast Cancer Research and Treatment* 161(3): 525–535.
- Johnson, B. B., and L. Waishwell. 2014. Public response to official information on cancer and cancer clusters. *Human and Ecological Risk Assessment: An International Journal* 20(3): 839–871.
- Karlsson, M., and H. Sjøvaag. 2016. Content analysis and online news: Epistemologies of analysing the ephemeral Web. *Digital Journalism* 4(1): 177–192.
- Kasperson, R. E., and J. X. Kasperson. 1996. The social amplification and attenuation of risk. *The Annals of the American Academy of Political and Social Science* 545(1): 95–105.
- Kasperson, R. E., O. Renn, P. Slovic, H. S. Brown, J. Emel, R. Goble, J. X. Kasperson, and S. Ratick. 1988. The social amplification of risk: A conceptual framework. *Risk Analysis* 8(2): 177–187.
- Kewayosh, A., L. Marrett, U. Aslam, R. Steiner, M. M. Lum-Kwong, J. Imre, and A. Amartey. 2015. Improving health equity for First Nations, Inuit and Metis people: Ontario’s Aboriginal cancer strategy II. *Healthcare Quarterly* 17: 33–40.
- Li, M., Y. L. Yeh, H. Sun, B. Chang, and L. S. Chen. 2019. Community-based participatory research: A family health history-based colorectal cancer prevention program among Chinese Americans. *Journal of Cancer Education*. doi: 10.1007/s13187-019-1486-1.
- Lloyd, C. D. 2014. *Exploring spatial scale in geography*. West Sussex, UK: John Wiley & Sons.
- MacDonald, M., and L. Hoffman-Goetz. 2001. Cancer coverage in newspapers serving large and small communities in Ontario. *Canadian Journal of Public Health* 92(5): 372–375.
- Musso, E., and S. E. L. Wakefield. 2009. ‘Tales of mind over cancer’: Cancer risk and prevention in the Canadian print media. *Health, Risk & Society* 11(1): 17–38.
- R Core Team. 2018. *R: A language and environment for statistical computing*. <http://www.R-project.org/>.

- Ramírez, A. S., E. Estrada, and A. Ruiz. 2017. Mapping the health information landscape in a rural, culturally diverse region: Implications for interventions to reduce information inequality. *The Journal of Primary Prevention* 38(4): 345–362.
- Rempel, E., L. Donelle, and A. Kothari. 2016. Exploring the health literacy of First Nations young adult women. *Journal of Communication in Healthcare* 9(1): 11–21.
- Robinson, D. 2002. Cancer clusters: Findings vs feelings. *Medgenmed: Medscape General Medicine* 4(4): 16–16.
- Roche, J. P., and M. A. Muskavitch. 2003. Limited precision in print media communication of West Nile virus risks. *Science Communication* 24(3): 353–365.
- Roslyng, M. M., and M. F. Eskjær. 2017. Mediatized risk culture: News coverage of risk technologies. *Health, Risk & Society* 19(3–4): 112–129.
- Rothman, A. J., and M. T. Kiviniemi. 1999. Treating people with information: An analysis and review of approaches to communicating health risk information. *Journal of the National Cancer Institute Monographs* 1999(25): 44–51.
- Russell, C. 1999. Living can be hazardous to your health: How the news media cover cancer risks. *Journal of the National Cancer Institute Monographs* 1999(25): 167–170.
- Smith, F., C. Wallengren, and J. Öhlén. 2017. Participatory design in education materials in a health care context. *Action Research* 15(3): 310–336.
- Spencer, E. A., and K. Real. 2019. ‘Health care coverage is the toughest beat to cover’: A multi-method analysis of rural newspaper coverage of county health rankings. *Kentucky Journal of Communication* 38(1): 4–27.
- Statistics Canada. 2016. *Population Centre and Rural Area Classification 2016*.
<https://www.statcan.gc.ca/eng/subjects/standard/pcrac/2016/introduction#s3> .
- Stryker, J. E., J. Fishman, K. M. Emmons, and K. Viswanath. 2009. Cancer risk communication in mainstream and ethnic newspapers. *Preventing Chronic Disease* 6(1): 1–11.
- Tang, C., and G. Rundblad. 2015. When safe means ‘dangerous’: A corpus investigation of risk communication in the media. *Applied Linguistics* 38(5): 666–687.
- Tian, Y., and J. D. Robinson. 2008. Incidental health information use and media complementarity: A comparison of senior and non-senior cancer patients. *Patient Education and Counseling* 71(3): 340–344.
- Totum Research. 2019. *Newspapers 24/7: 2019 Edition*. Toronto, ON: News Media Canada.
<https://nmc-mic.ca/ad-resources/presentations/presentation-newspapers-24-7-2019-edition-pdf-and-powerpoint/>.

- Trumbo, C. W. 2000. Public requests for cancer cluster investigations: A survey of state health departments. *American Journal of Public Health* 90(8): 1300–1302.
- Trumbo, C. W., K. A. McComas, and J. C. Besley. 2008. Individual-and community-level effects on risk perception in cancer cluster investigations. *Risk Analysis* 28(1): 161–178.
- Villanueva, G., G. M. Broad, C. Gonzalez, S. Ball-Rokeach, and S. Murphy. 2016. Communication asset mapping: An ecological field application toward building healthy communities. *International Journal of Communication* 10: 2704–2724.
- Wählberg, A. A. F., and L. Sjöberg. 2000. Risk perception and the media. *Journal of Risk Research* 3(1): 31–50.
- WHO (World Health Organization). 2020. *Cancer prevention*. <https://www.who.int/cancer/prevention/en/>.
- Wilkin, H. A. 2013. Exploring the potential of communication infrastructure theory for informing efforts to reduce health disparities. *Journal of Communication* 63(1): 181–200.
- Wilson, K., C. Code, C. Dornan, N. Ahmad, P. Hébert, and I. Graham. 2004. The reporting of theoretical health risks by the media: Canadian newspaper reporting of potential blood transmission of Creutzfeldt–Jakob disease. *BioMed Central Public Health* 4(1): 1–9.
- Yiannakoulias, N. 2009. Using population attributable risk to understand geographic disease clusters. *Health and Place* 15(4): 1142–1148.
- Young, R., M. Tully, and K. E. Dalrymple. 2018. # Engagement: Use of Twitter chats to construct nominal participatory spaces during health crises. *Information, Communication & Society* 21(4): 499–515.
- Young, R., E. Willis, J. Stemmler, and S. Rodgers. 2015. Localized health news releases and community newspapers: A method for rural health promotion. *Health Promotion Practice* 16(4): 492–500.

CHAPTER 3

Cancer cluster investigations in Canada: a qualitative study of public health communication practices and investigation procedures

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3.1 INTRODUCTION

Public health officials play a vital role investigating and responding to community reports of space-time disease clustering. Although clusters of various health outcomes including birth defects¹, neurological diseases like multiple sclerosis² and cancers³ have been reported in numerous Canadian communities in recent years, cancer clusters attract an exceptional level of enduring public concern and extensive media interest for a couple of reasons. First, cancer clusters occur when a greater-than-expected number of cases of cancer occur in a group of individuals in a specific geographic area during a particular period of time⁴ and despite cancer constituting a multitude of diseases with numerous causes, cancer clusters tap into a common anxiety that toxic industrial exposures or environmental pollutants in a geographic location may be to blame⁵. Second, the long latency of cancer makes it particularly challenging to investigate exposures that may no longer be present and reassure community members that their concerns will be addressed⁶.

These challenges present difficulties for public health officials communicating and engaging with a fearful and distrustful public⁷, in addition to statistical challenges officials face when investigating a small number of cases using analyses with low statistical power⁸.

Consequently, the overwhelming majority of cancer cluster investigations cannot rule out the role of chance from explaining an increase in observed cases of cancer relative to what would be

expected, and fewer still will be able to link the cancer cases to a specific cause⁹. Nonetheless, cancer cluster investigations remain an important practice for public health officials, who often consider them to be a way of addressing community concerns about cancer incidence¹⁰ and educating citizens on risk factors and known carcinogenic exposures¹¹; therefore, they are still viewed as a public service regularly undertaken by public health agencies and officials in Canada and all over the world¹².

The success of a cancer cluster investigation in achieving these goals and satisfying local community members may be partly determined by the approaches that public health officials take in responding to the community's cancer complaints. For one, incorporating effective risk communication at all stages of a cancer cluster investigation and supplying concerned citizens with adequate information is viewed as essential in fostering accurate perceptions of risk¹³. Indeed, Trumbo (2000) noted that although very few of the thousands of cancer cluster complaints in the US end up leading to significant investigations, the interactions with community members that take place during the process provide an opportunity for meaningful public education about cancer. In addition, transparency and communication around cancer cluster investigation procedures has been shown to be important in promoting beliefs around procedural fairness, which in turn increases citizen satisfaction with the results of investigations and trust in authorities¹⁴. Furthermore, confusion around the methodologies used in cluster investigations and perceived flaws in the investigation procedure can influence beliefs around expert competency and credibility¹⁵. For these reasons, the United States and other nations have developed guidelines for investigating cancer clusters to provide public health officials with a systematic methodology for their analysis and to guide their response to citizen concerns¹⁶⁻¹⁸.

Researchers have twice studied the state of cancer cluster investigations in the US, once in the 1990s¹⁹ and most recently a decade ago⁹, and each time recommended changes to investigation approaches and priorities. In the absence of national guidelines for investigating cancer clusters in Canada, it is not currently known what cancer cluster investigation procedures are used by public health officials across Canadian jurisdictions. In this study, we aim to examine the experiences of public health officials who have investigated cancer clusters, particularly with respect to their approaches in communicating the results of investigations and the risk of cancer. Although provincial/territorial jurisdictions are responsible for the provision of most services related to health, there exist considerable divergences in the administration and organization of public health policies and practices between the various Canadian provinces and territories due to their local population and geographic characteristics. Some employ a regionalized approach for the delivery of public health programs and services, while others have opted for a top-down centralized approach²⁰. Therefore, we hypothesized that the primary agencies and officials responsible for conducting cancer cluster investigations would vary significantly across Canada.

3.2 METHODS

3.2.1 Interviews

The participants selected for interviews for this research project were public health officials from various Canadian jurisdictions who either had had experience conducting a cancer cluster investigation in a community or who would be tasked with investigating one should a cancer cluster concern arise. Between the fall of 2019 and summer of 2020, a total of 13 telephone interviews were conducted and recorded with 15 public health officials across Canada

(two interviews had two participants present). The average interview length was 45 minutes (range: 30-65). Ethics approval for this research was obtained from McMaster University in the summer of 2019 (MREB#: 1763). Key informants to interview for this project were identified using two approaches to achieve representation from most Canadian provinces and one territory. In jurisdictions where the authors had no prior connections or knowledge of cancer cluster investigations, an email was sent to the province's primary health ministry (or public health agency) through their general inquiry webpage to receive the contact information for public health officials responsible for such investigations. In other jurisdictions where known and/or well-reported cancer clusters had been investigated, the authors contacted the lead public health official in charge of the investigation directly according to publicly available reports or news articles. Interviews were semi-structured and carried out by one researcher, C.S. Interviewees received the questions prior to the interview. Questions covered four broad topics: the interviewee's jurisdiction's cancer cluster investigation methodologies, the outcomes of the investigations, the challenges public health officials encountered with risk communication, and communication approaches and goals. This research followed a constructivist framework whereby the data gathered from interviews is recognized as personally and socially constructed knowledge reflective of the participants' individual contexts, while the researchers' interpretation of this data merely attempts to elucidate the participants' particular realities²¹.

3.2.2 Analysis

3.2.2.1 Thematic analysis

Interviews were transcribed using Otter, a speech to text transcription software (Otter.ai, Los Altos, California), with occasional corrections to words transcribed manually by one researcher (C.S.) to remedy errors in the automatic transcription process. Transcripts were read

several times and a thematic analysis of the interview transcripts was carried out using NVivo 12 (QSR International, Burlington, Massachusetts). Thematic analyses are a common qualitative analytic method to help identify themes from an extensive set of text-based data and this study used a semantic approach to analyze participant responses, therefore, responses were analyzed as they were recorded in the interviews²². One researcher (C.S.) coded text segments in each interview transcript and categorized codes into common themes that emerged for each question posed to participants to allow for comparisons across interviews. These codes were discussed with the secondary researcher to assess how well the identified themes related to the research questions of this study and their relation to the dataset. The coding process followed an inductive approach²³, whereby dominant themes in the data were used to summarize general similarities and differences in investigative practices across Canadian jurisdictions.

3.2.2.2 Content analysis

In addition to the interview data collected, some officials shared documents summarizing the cancer cluster investigation guidelines or practices used in their jurisdiction. A content analysis of these documents was undertaken using the same coding framework that was used for the interview transcripts to supplement the information that was not already captured in the interviews. The coded themes identified in the thematic analysis of the interview transcripts and the content analysis of the procedural documents were organized and analyzed in an electronic spreadsheet.

3.3 RESULTS

Thirteen interviews were conducted with 15 public health officials whose cancer cluster investigations spanned seven out of ten Canadian provinces and one out of three Canadian northern territories. Additionally, one interview was conducted with a public health official who had investigated a cancer cluster in a northern Canadian territory while employed under the federal Canadian Public Health Agency's field epidemiology program, which occasionally deploys epidemiologists to investigate cancer clusters when a provincial or territorial government requests assistance. Four interviews were conducted with participants who had investigated cancer clusters in Ontario, Canada's most populated province, two in Manitoba, and one each in Alberta, British Columbia, Saskatchewan, Quebec, New Brunswick, Northwest Territories and federally. The job titles of the participants interviewed for this research varied; five were senior epidemiologists at a public health department or agency, five were medical officers of health or chief medical officers at a municipal/regional/provincial/territorial level, four held senior management roles in cancer data analytics departments at a public health agency and one was a specialist in environmental health at a local public health department. The findings from this study are summarized according to three main themes: cancer cluster investigation procedures, investigation characteristics and communication approaches.

3.3.1 Cancer cluster investigation procedures

Cancer cluster investigation procedures by Canadian jurisdiction are summarized in Table 3-1. Three out of nine jurisdictions (New Brunswick, Northwest Territories and Canada) did not strictly adhere to any one protocol and did not design their own guidelines for investigating cancer clusters. Another three jurisdictions (British Columbia, Alberta and Manitoba) had produced their own procedural guidelines to use for investigating cancer clusters.

Table 3-1. Characteristics of cancer cluster investigation procedures and methodologies by Canadian jurisdiction (n=9).

Jurisdiction	Lead investigating agency	Other agencies and actors that may be involved in the investigation	Document type consulted	Year produced	Procedural authoring agency	Other guidelines referenced in procedures	Steps defined	Risk communication included in procedure
Ontario	Local public health department	Provincial Public Health Agency; Provincial Cancer Agency; Provincial Ministry of Environment; Provincial Ministry of Labour	Guideline	2013	US CDC	None	1. Initial contact and response 2. Assessment 3. Determining feasibility of conducting an epidemiologic study 4. Conducting an epidemiologic investigation	Yes - at every stage
British Columbia	Cancer Control Research Unit of Provincial Cancer Agency	Local Medical Health Officer; Provincial Ministry of Health; Regional First Nations Health Authority	Guideline	1998	British Columbia Cancer Agency	None	1. Initial contact and response 2. Assessment and case evaluation 3. Determine feasibility of epidemiological study 4. Etiologic investigation	No
Alberta	Not defined - Guidelines state the lead may be whichever initial agency was contacted,	Provincial Ministry of Health Service Delivery; Provincial Ministry of Health; Regional Medical Officer of Health; Federal Health	Guideline	2011	Alberta Health and Wellness; Alberta Health Services	US CDC; New Zealand; Europe	1. Primary evaluation and collection of data from requestor 2. Secondary evaluation and	Yes - at every stage

	the regional Medical Officer of Health, the Cancer Surveillance Department at Alberta Health Services or the Surveillance Unit of Alberta Health and Wellness	Ministry (for on-reserve investigations)					assessment of cases for further action 3. Tertiary evaluation involving ongoing surveillance or etiologic investigation	
Quebec	Regional Public Health Agency	Provincial Public Health Agency; Local health or public health professionals; Provincial Cancer Registry; Expert advisory committee consisting of medical and public health professionals and toxicologists; Provincial Ministry of Environment; Provincial Ministry of Labour	Guideline	2005	Institut de Veille Sanitaire (France), now part of the French National Public Health Agency	Laval University; US CDC; Netherlands; New Zealand	1. Evaluation of reported cases 2. Validation of cases and environmental exposure 3. In-depth descriptive study 4. Additional epidemiological work	Yes - at every stage
Manitoba	Medical Officer of Health from the Regional Health Authority	Provincial Cancer Agency; Provincial Cancer Registry; Provincial Ministry of Health; Provincial Ministry of Labour	Guideline	2015	Regional Health Authority	US CDC; Alberta Guidelines	1. Primary evaluation and information intake 2. Primary evaluation and assessment of	Yes - at some stages

							information 3. Secondary evaluation and analysis of data 4. Determine feasibility of epidemiologic study 5. Conduct epidemiologic study	
Saskatchewan	Provincial Cancer Agency	Regional Medical Health Officer; Provincial Health Authority; Provincial Ministry of Health; Provincial Ministry of Labour	Unknown	Early 2000s	Saskatchewan Cancer Agency	US CDC	NA	NA
New Brunswick	Cancer Department of Provincial Ministry of Health and/or Office of the Provincial Chief Medical Officer of Health	Provincial Department of Environment; Communications Branch at the Provincial Department of Health; Analytics Branch at the Provincial Department of Health; Regional Medical Health Officer	No formal protocol or guideline strictly followed	NA	NA	US CDC	NA	NA
Northwest Territories	Territorial Department of Health and	Academic researchers and/or expert scientists from other provinces;	No formal protocol or guideline	NA	NA	US CDC; Alberta Guidelines	NA	NA

	Social Services	PHAC Field Epidemiologist; Local Clinician	strictly followed					
Canada	Public Health Agency of Canada's Field Epidemiology Program	Provincial or Territorial Ministry of Health; Chief Medical Health Officer from province or territory; Provincial, territorial, regional and/or local health authority	No formal protocol or guideline strictly followed	NA	NA	US CDC	NA	NA

Abbreviations: US CDC, United States Centers for Disease Control

In two jurisdictions, Ontario and Quebec, cluster investigation guidelines from other nations (US' Centers for Disease Control and Prevention and France's National Public Health Agency) serve as the primary guidance that officials consult in those provinces to conduct an investigation. In Saskatchewan, a procedural document authored by the lead investigating agency was not shared with the researchers and could not be analyzed as part of this study, however, the interviewee there described guidelines that were based largely on those authored by the US Centers for Disease Control and Prevention (CDC). Of the jurisdictions that shared procedural documents (n=5), three (Ontario, British Columbia and Quebec) followed a four-step investigation procedure, while the remaining two (Alberta and Manitoba) followed a three- and five-step procedure, respectively. Only four jurisdictions followed guidelines that explicitly referenced risk communication in their procedures and of these four, three included risk communication at every step of their investigation.

Interviewees from each jurisdiction described a different lead investigating agency or individual responsible for investigating cancer cluster concerns. Some of these agencies included local/regional/territorial public health departments/agencies (Ontario, Quebec, Northwest Territories) and cancer-specific agencies or departments (British Columbia, Saskatchewan & New Brunswick), while in Manitoba, the medical officer of health from the regional health authority where the concern originated assumes primary responsibility over the investigation with support from provincial agencies. In one province's guidelines, Alberta, a lead investigating agency or individual is not specified and the procedures suggest that the initial agency contacted by the citizen may remain involved in either a lead or liaison role during the investigation, which is in contrast to the procedures followed in the other eight jurisdictions that have identified one main lead agency or individual in charge.

3.3.2 Cancer cluster investigation characteristics

Characteristics of the cancer cluster investigations carried out by the public health officials interviewed for this work are summarized in Table 3-2. Nearly all officials cited local non-expert citizens as the initiators of cancer cluster investigations due to concerns about local cancer cases. However, the official interviewed in one province, Quebec, identified clinicians and employers as the most frequent initiators of cancer cluster reports. In five interviews, officials cited investigating cancer clusters on an annual basis, whereas in seven interviews, officials reported that investigations occurred less frequently. Officials interviewed in one province, New Brunswick, had never launched a large-scale formal investigation but had frequently responded to more general inquiries about cancer rates from the public and other stakeholders.

All officials interviewed confirmed that environmental or occupational exposures were suspected and investigated in at least one of the cancer clusters they had investigated. In five interviews, officials reported not having had staff trained in risk communication or not having awareness of any such training, while in eight interviews officials either had direct access to staff with risk communication training (3 out of 13) or occasional access to this expertise through other governmental or non-governmental agencies (5 out of 13). Officials in four interviews perceived an overall positive response from the public after a cancer cluster investigation had concluded, while in eight others, officials perceived either a mostly negative response or a mix of positive and negative responses from the public. In five interviews, officials cited the need for ongoing community outreach after an investigation had concluded because either the community had requested further monitoring of cancer incidence rates or public health officials were gathering more data to observe trends.

Table 3-2. Characteristics of cancer cluster investigation(s) by interview with Canadian public health officials (n=13).

Interview	Jurisdiction	How cancer clusters were reported	Frequency of reports	Environmental or occupational hazards suspected	Involvement of officials trained in risk communication	Perceived public satisfaction with cluster response	Need for ongoing outreach or monitoring after investigation
1	Ontario	Citizen reported to local public health department;	Less than annual	Yes	Yes	Generally positive	No
2	Ontario	Citizen reported to local public health department; Employer reported to local Medical Officer of Health	Less than annual	Yes	Yes	Positive and negative	No
3	Ontario	Citizen reported to local public health department; Employer reported to local Medical Officer of Health	Less than annual	Yes	Yes - through other government agencies or departments	Positive and negative	No
4	Ontario	Citizen reported to local public health department	Less than annual	Yes	Yes - through other government agencies or departments	Generally negative	Yes
5	Manitoba	Healthcare professional reported to provincial cancer agency; Employer reported to provincial cancer agency; First Nations community reported to regional Medical Officer of Health	Annual	Yes	No or not known	Generally positive	No

6	Manitoba	Citizen reported to regional Medical Officer of Health	Annual	Yes	No or not known	Positive and negative	No
7	Alberta	Citizen reported to provincial Ministry of Health Services; Citizen reported to regional Medical Officer of Health; Healthcare professional reported to provincial Ministry of Health; Provincial Ministry of Health Services reported to provincial Ministry of Health; Employer reported to provincial Ministry of Health	Annual	Yes	Yes - through other government agencies or departments	Positive and negative	Yes
8	British Columbia	Citizen reported through online form to provincial cancer agency; Citizen reported to provincial Ministry of Health; Citizen reported to regional Medical Officer of Health	Annual	Yes	No or not known	Positive and negative	No
9	Saskatchewan	Citizen reported to regional Medical Officer of Health; Citizen reported to healthcare professional	Annual	Yes	Yes - through other government agencies or departments	Generally positive	No
10	Quebec	Healthcare professional reported to regional public health agency;	Less than annual	Yes	Yes	Generally negative	Yes

		Employer reported to regional public health agency					
11	New Brunswick ^a	Citizen requested information; Healthcare professionals requested information; News media requested information	Never; Respond to general requests for information on cancer on an annual basis	No	No or not known	N/A	N/A
12	Northwest Territories	Citizen reported to local health authorities; Local clinician reported to territorial Ministry of Health; Cluster discovered during routine surveillance of cancer data by territorial Health Ministry	Less than annual	Yes	Yes – through non-governmental organizations	Positive and negative	Yes
13	Canada	Provincial or territorial or regional lead of investigating agency reported to PHAC	Less than annual	Yes	No or not known	Generally positive	Yes

Abbreviations: PHAC, Public Health Agency of Canada.

^aInvestigators noted they had never launched an investigation and had never taken more action beyond responding to a citizen’s concerns about cancer with public education.

3.3.3 Communication approaches

The primary themes that emerged from our interviews with Canadian public health officials regarding communication approaches and challenges encountered during investigations are summarized in Table 3-3.

Table 3-3. Primary themes from interviews with Canadian public health officials about communication approaches and challenges during cancer cluster investigations (n=13).

Topic	Themes	Number of interviews with theme present (%)
Main messages communicated to community during/after investigation	Observed vs. expected incidence rates	8 (62%)
	Cancer risk factors	8 (62%)
	Why pursuing investigation or why not	3 (23%)
Key stakeholders for communication	Citizens/community	13 (100%)
	Other government agencies or ministries	13 (100%)
	Local elected officials	7 (54%)
	Employers	3 (23%)
	News media	3 (23%)
Challenges communicating risk	Non-governmental organizations	1 (8%)
	Complexity of information	10 (80%)
	Addressing public perceptions of risk	10 (80%)
	Crafting messages on risk	9 (70%)
	Language and/or cultural considerations	3 (23%)
Purpose of risk communication	Public education	11 (85%)
	Health behaviour change	5 (38%)
	Address public concerns	5 (38%)
	Improve transparency	3 (23%)
Communication formats used to share results or investigation conclusions	Printed texts (e.g. reports, brochures)	11 (85%)
	Face-to-face	10 (80%)
	Telephone or email	9 (70%)
	Presentations	6 (46%)
Role of the media in information sharing	Positive role	6 (46%)
	Negative role	5 (38%)
	Neutral	2 (15%)

Officials in eight interviews stated that the main messages communicated during and after a cancer cluster investigation consisted of explanations of the difference between observed versus expected cancer incidence rates and explaining various risk factors that are associated with increased rates of cancer (e.g. sun exposure, smoking, etc.). Officials in three interviews also discussed communicating with citizens why their agency was or was not pursuing further action investigating the cancer cluster as a primary theme. All officials interviewed identified the local community members and other government agencies as key stakeholders to communicate with about the progress of an investigation, however, there was less agreement about the importance of communicating with other stakeholders. In just over half of the interviews, officials identified local elected officials (e.g. city councillors, members of parliament, etc.) as key communication stakeholders, whereas the news media, employers, and non-governmental organizations were identified less frequently (in 23%, 23% and 8% of interviews, respectively).

In most interviews, officials perceived the biggest challenges with communicating risk to citizens to be as a result of the complexity of information related to statistics and cancer rates (80%), due to issues addressing public perceptions of cancer risk (80%) and due to difficulties with crafting effective messages on risk (70%). Another challenge to communicating risk effectively identified in three interviews included language barriers and special cultural considerations when communicating with citizens whose mother tongue was not one of Canada's two official languages (i.e. English and French) or with recent immigrants to Canada. In most interviews, officials saw the main purpose of conducting risk communication during cancer cluster investigations as a way to educate the public on cancer (85%). Other goals of risk communication identified less frequently in the interviews included promoting changes to health

behaviors (38%), addressing public concerns (38%) and improving public perceptions of government transparency (23%).

When discussing specific approaches to disseminating information and communicating results with stakeholders from cancer cluster investigations, officials discussed the use of printed text documents (e.g. reports, brochures) and face-to-face interactions with community members (e.g. town halls, one on one meetings) as the most common formats of information sharing (85% and 80%, respectively). In situations where the suspected cancer cluster was addressed at an early stage of the process without necessarily requiring the launch of a large-scale investigation, officials in most interviews stated that telephone or email correspondence with the individual(s) raising the concern was carried out (70%). In six interviews, officials also discussed presenting results from the cancer cluster investigation using visual tools (e.g. PowerPoint) to stakeholders. Officials interviewed had mixed experiences when it came to leveraging the news media as information disseminators during cancer cluster investigations. The media's role in assisting with information sharing during the investigation was perceived as positive by officials in six interviews, some of whom discussed collaborating with local news media report on the results of investigations. However, in seven interviews, officials discussed that the media played either a negative or neutral role in sharing information about cancer cluster investigations.

3.4 DISCUSSION

Despite past concerns raised about their overall value in other jurisdictions⁶ this research has found that cancer cluster investigations are regularly undertaken by Canadian public health officials for the purposes of educating the public about cancer and exploring whether observed

incidences of cancer in a community occur at levels that are higher than expected. While these goals were found to be consistent across Canada, the investigation procedures varied considerably across the provinces and territory included in this study. In the absence of national cancer cluster guidelines, each Canadian jurisdiction has taken a different approach to investigating clusters, whereby some have produced their own guidelines and others have opted to mostly follow the US CDC's procedures. This patchwork of approaches has resulted in little consistency in establishing lead agencies or individuals responsible for cancer cluster investigations across Canadian jurisdictions and may hinder some citizens' ability to identify the appropriate arena for raising concerns about cancer clusters.

In addition to ill-defined roles and responsibilities, the investigation procedures also appeared to utilize important steps inconsistently across Canadian jurisdictions. For example, although it is widely known that the public's interest in cancer clusters is highly influenced by perceived environmental hazards and harmful exposures⁹, only one jurisdiction included environmental exposure validation as a defined action in their investigation protocol. Further, only three jurisdictions explicitly specified a step for examining the feasibility of an epidemiologic study of the cancer cluster as a part of their procedural guidelines, which is surprising given the increasing reluctance of officials to pursue large-scale epidemiological studies of most cancer clusters – except for those that meet specific criteria to warrant an investigation due to limited time and resources²⁴. Interestingly, despite most officials having identified information on cancer risk factors as a primary message communicated during the course of investigations, only a third of the Canadian jurisdictions we studied included risk communication at every step of their investigation protocols. Establishing a national set of cancer cluster guidelines could provide public health officials as well as local citizens with more clarity

and uniformity in cluster investigation approaches to ensure citizens receive a consistent response from investigators regardless of where the cluster concern originates from.

However, the case for a national cancer cluster guideline goes beyond achieving procedural uniformity and aiding those provinces where guidelines currently do not exist; it would also benefit those provinces where an assortment of guidelines and procedures already exist, and the lack of consistency currently makes it difficult to make provincial comparisons and determine best practices. For example, by establishing a set of national cancer cluster guidelines with a consistent approach for screening cluster concerns raised, it would be possible to study whether discrepancies in the number of cancer clusters that get investigated across provinces was due to a true difference in the number of reports requiring investigation or due to differences in the way that the guidelines were being adopted. In addition, there are two significant scenarios where national guidelines for cancer clusters would be beneficial due to federal jurisdiction over health matters. The first involves clusters arising in Indigenous communities, where provincial and federal jurisdictional ambiguities remain and the need for national policy frameworks on health matters has previously been raised beyond cancer clusters²⁵. The second, involves clusters where a cross-boundary environmental exposure is suspected either across two provinces or across the Canadian and US border²⁶, whereby the federal government would also have jurisdiction over such matters.

Our study also discovered some experiences of cancer cluster investigators that were shared across Canadian jurisdictions. There was considerable agreement among the public health officials interviewed regarding the challenges they faced in communicating risk to stakeholders, which included communicating complex statistical information and addressing the public's perceptions of higher risks to health from environmental hazards. These challenges, coupled with

the fact that most officials interviewed cited they had no direct access to staff trained in risk communication in their department, would suggest that public health officials would benefit greatly from more support from specialized communications staff with this type of training. Indeed, these findings are consistent with those most recently published in a survey of US state health departments conducting cancer cluster investigations in which 75% of states stated they would benefit from more resources in risk communication²⁷. Fortunately, best practices for risk communication have been widely published²⁸⁻³⁰, however, in the absence of a national cluster reporting database with investigation resources that are easily accessible to public health officials alongside procedural guidelines, investigators may be missing out on a useful tool for conducting risk communication more effectively and cohesively.

A type of national cancer cluster reporting database, the Cancer Cluster Public Inquiry Triage System, as well as an electronic listserv were established by the US CDC's National Center for Environmental Health (NCEH) in 2002 to track the public's cancer cluster concerns and improve information sharing between federal, state and local public health agencies by providing a mechanism to share expertise and scientific methods³¹. Development of a Canadian cluster reporting database could also be used to establish a network for federal, provincial and local investigators to share knowledge about responding to initial reports of clusters and share methodological expertise should a formal cluster investigation be warranted after the initial concerns are validated and other criteria established by the investigators are met. Additionally, this kind of database would help public health officials study patterns of citizen expressions of concerns about cancer across provinces and nationally, which may help officials prioritize public education efforts about cancer in areas where there are demonstrated needs for it. For example,

the US NCEH used their database to study which types of cancers were most frequently cited by cluster inquirers to inform their development of additional targeted educational tools³¹.

Another interesting finding from this work was the agreement found among public health officials interviewed regarding the primary purpose of risk communication as a means to conduct public education on cancer risk. While this is an important objective of any public health agency during routine activities, this goal may fall short in addressing the expectations of a citizen reporting a cancer cluster whose primary objective is to seek answers for an unexplained pattern of cancer diagnoses. Other research has found that when a cluster investigation does not confirm the presence of a statistically-significant increase in cancer, concerned citizens often persist in believing that the cluster of cancer cases cannot be random largely due to a lack of trust in public health experts³². Therefore, addressing public concerns around the perceived threat from the cancer cluster and maintaining trust and credibility ought to be a primary goal of risk communication during an investigation and may require a different communications approach compared to one that centers around education alone. In fact, one official interviewed observed that being transparent with citizens about what steps were taken to come to the decision on whether to investigate their concerns or not contributed to the overall positive response they received from local community members despite the investigation not progressing to a full epidemiological study to identify the causes of cancer.

Using face-to-face two-way communication approaches has also been found to be an effective way to reduce tensions and address concerns during cancer cluster investigations³³, which was echoed by most of the officials interviewed in this work. Therefore, this method for communicating with public stakeholders should continue to be prioritized over other communication formats when it is feasible even though it may require some extra training or

resources targeted towards community engagement. Interestingly, one interviewee reflected on seeing noticeable improvements in public trust after hiring an external non-governmental organization to coordinate in-person meetings to share information and lead discussions with community members during a cancer cluster investigation, such that public health officials were *participants* of the discussion with local community members rather than leading the conversations. This kind of approach is rooted in participatory communication theory surrounding horizontal models of communication³⁴ and should continue to be explored by public health officials conducting any work with community stakeholders as a way to foster improved trust with local community members. Furthermore, the establishment of a cancer cluster reporting database that is publicly accessible could also be viewed as one way for public health officials to leverage participatory approaches to information sharing and improve public engagement.

This study has some important limitations. Firstly, although this research attempted to obtain a diverse sample of participants with various experiences conducting cancer cluster investigations across Canada, we did not interview an exhaustive list of public health officials who have investigated every cluster. Our participant recruitment approach instead centered on collecting detailed perspectives from a smaller sample of key experts. However, the broad regional coverage of procedural practices that was achieved using both a thematic analysis of expert interviews and a content analysis of text documents should be viewed as a major strength of a study of this kind. Another limitation of this study includes the challenges associated with comparing jurisdictions within and outside of Canada where public health agencies and departments vary widely with respect to their organization, administration of duties and resources. Future research examining the strengths and weaknesses of investigation approaches

in various jurisdictions globally could provide more context for comparisons. In addition, it is possible that responses from other investigators in each province/territory could have differed depending on the scope of knowledge and experience of the public health official interviewed. However, the experiences of officials interviewed in this study still provide a snapshot of the common challenges likely encountered by officials investigating cancer clusters in many other jurisdictions.

3.5 CONCLUSION

In summary, although this work has demonstrated the usability and accessibility of the CDC's cancer cluster guidelines as a great resource internationally, it has also highlighted the benefits of establishing national guidelines for investigating cancer clusters in countries like Canada where they do not currently exist. National guidelines would not only improve procedural consistency across local and provincial/territorial agencies and address important discrepancies in public health practices during cancer cluster investigations in Canada, but they are also warranted in situations where the federal government already has jurisdiction over environmental health matters.

In addition, this study has also discussed the benefits of developing a national database for clusters to serve as a reporting system to track citizen concerns and as a resource sharing platform for health officials responding to reports of clusters. Such a database would help local/provincial/federal agencies carry out their mandates around public health education, which may also address some citizen concerns around cancer without necessitating the launch of cluster investigations that are unlikely to reveal any definitive answers around the suspected causes of cancers. However, public education is carried out most effectively when health officials

responding to community concerns have the necessary skills and training in risk communication, which appears to be a key challenge area among the officials we interviewed.

Furthermore, for the rare instances where cluster investigators may proceed to move beyond the initial stages of a cluster response and towards a more formal investigation, we have proposed the inclusion of face-to-face participatory communication approaches when feasible, based on the views expressed by the public health officials we spoke to. Leveraging participatory communication practices may improve engagement with the public during investigations and, importantly, may help officials manage citizen expectations around the results of investigations with an open and transparent dialogue.

3.6 REFERENCES

1. Bassil KL, Yang J, Arbour L, et al. Spatial variability of gastroschisis in Canada, 2006–2011: An exploratory analysis. *Canadian journal of public health*. 2016 Jan;107(1):e62-7. <https://doi.org/10.17269/cjph.107.5084>
2. Torabi M, Green C, Yu N, et al. Application of three focused cluster detection methods to study geographic variation in the incidence of multiple sclerosis in Manitoba, Canada. *Neuroepidemiology*. 2014;43(1):38-48. <https://doi.org/10.1159/000365761>
3. Windsor-Essex County Health Unit. Remington Park Cancer Cluster Investigation. [Internet]. 2016 [cited 2021 Jun 4]. Available from: https://www.wechu.org/sites/default/files/reports-and-statistics/Remington_Park_Cancer_Cluster_Report_Sept_2016_WECHU_Final.pdf.
4. Centers for Disease Control and Prevention. About Cancer Clusters. [Internet]. 2019 [cited 2021 May 22]. Available from: <https://www.cdc.gov/nceh/clusters/about.htm>.
5. Goodie J. Toxic tort and the articulation of environmental risk. *Law Text Culture*. 2008;12:69.
6. Goodman M, LaKind JS, Fagliano JA, et al. Cancer cluster investigations: review of the past and proposals for the future. *International journal of environmental research and public health*. 2014 Feb;11(2):1479-99. <https://doi.org/10.3390/ijerph110201479>
7. McComas KA, Besley JC, Trumbo CW. Why citizens do and do not attend public meetings about local cancer cluster investigations. *Policy Studies Journal*. 2006 Nov;34(4):671-98. <https://doi.org/10.1111/j.1541-0072.2006.00197.x>
8. Coory MD, Jordan S. Assessment of chance should be removed from protocols for investigating cancer clusters. *International journal of epidemiology*. 2013 Apr 1;42(2):440-7. <https://doi.org/10.1093/ije/dys246>

9. Goodman M, Naiman JS, Goodman D, et al. Cancer clusters in the USA: what do the last twenty years of state and federal investigations tell us?. *Critical reviews in toxicology*. 2012 Jul 1;42(6):474-90. <https://doi.org/10.3109/10408444.2012.743505>
10. Department of Health and Human Services. The Chief Health Officer's investigation of cancer rates on the Bellarine Peninsula. State of Victoria. [Internet]. 2019 [cited 2021 May 22]. Available from: <https://www2.health.vic.gov.au/public-health/chief-health-officer/cho-publications/cancer-rates-bellarine-peninsula>
11. Black RJ, Sharp L, Finlayson AR, et al. Cancer incidence in a population potentially exposed to radium-226 at Dalgety Bay, Scotland. *British journal of cancer*. 1994 Jan;69(1):140-3. <https://doi.org/10.1038/bjc.1994.23>
12. Trumbo CW. Public requests for cancer cluster investigations: a survey of state health departments. *American Journal of Public Health*. 2000 Aug;90(8):1300. <https://doi.org/10.2105/ajph.90.8.1300>
13. Trumbo CW, McComas KA, Besley JC. Individual-and community-level effects on risk perception in cancer cluster investigations. *Risk Analysis: An International Journal*. 2008 Feb;28(1):161-78. <https://doi.org/10.1111/j.1539-6924.2008.01007.x>
14. Besley JC, McComas KA, Trumbo CW. Local newspaper coverage of health authority fairness during cancer cluster investigations. *Science Communication*. 2008 Jun;29(4):498-521. <https://doi.org/10.1177/1075547008316216>
15. McComas KA, Lundell HC, Trumbo CW, et al. Public meetings about local cancer clusters: exploring the relative influence of official versus symbolic risk messages on attendees' post-meeting concern. *Journal of Risk Research*. 2010 Sep 1;13(6):753-70. <https://doi.org/10.1080/13669870903551688>
16. Abrams B, Anderson H, Blackmore C, et al. Investigating suspected cancer clusters and responding to community concerns: guidelines from CDC and the Council of State and Territorial Epidemiologists. *Morbidity and Mortality Weekly Report: Recommendations and Reports*. 2013 Sep 27;62(8):1-24.
17. Fletcher T, Crabbe H, Close R. *Guidance for Investigating Non-infectious Disease Clusters From Potential Environmental Causes*. London: Public Health England. 2019:45.
18. New Zealand Ministry of Health. *Investigating Clusters of Non-communicable Disease: Guidelines for public health units*. [Internet]. 2015 [cited 2021 Jun 4]. Available from: <https://www.health.govt.nz/system/files/documents/publications/investigating-clusters-non-communicable-disease-guidelines-may15-v3.pdf>
19. Caldwell GG. Twenty-two years of cancer cluster investigations at the Centers for Disease Control. *American Journal of Epidemiology*. 1990 Jul 1;132(supp1):43-7.
20. National Collaborating Centre for Health Public Policy. *Structural Profile of Public Health in Canada*. [Internet]. 2018 [cited 2021 May 22]. Available from: <http://www.ncchpp.ca/en/structuralprofile.aspx>
21. Neimeyer RA. Constructivist approaches to the measurement of meaning. In: Neimeyer GJ, ed. *Counseling psychologist casebook series, Vol. 2. Constructivist assessment: A casebook*. Sage Publications, Inc; 1993. p. 58–103.
22. Terry G, Hayfield N, Clarke V et al. Chapter 2: Thematic Analysis. In: Willig C, Stainton-Rogers W, eds. *The SAGE Handbook of Qualitative Research in Psychology*. 2nd ed. London: SAGE; 2017. p. 17-37.
23. Thomas DR. *A general inductive approach for qualitative data analysis*. University of Auckland. [Internet]. 2003 [cited 2021 Jun 4]. Available from:

- <https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.462.5445&rep=rep1&type=pdf>
24. Aldrich T, Sinks T. Things to know and do about cancer clusters. *Cancer investigation*. 2002 Jan 1;20(5-6):810-6. <https://doi.org/10.1081/cnv-120003546>
 25. Lavoie JG. Policy silences: why Canada needs a National First Nations, Inuit and Métis health policy. *International Journal of Circumpolar Health*. 2013 Jan 31;72(1):22690.
 26. Beaumont H. 'Them plants are killing us': Inside a cross-border battle against cancer and pollution. *EHN [Internet]*. 2020 Apr 7 [cited 2021 Oct 7]; Available from: <https://www.ehn.org/air-pollution-cancer-michigan-ontario-2645647668.html>
 27. Anderson, H., Blackmore, C., Stanbury, M., et al. A Synopsis of the 2010 National Assessment of State Cancer Cluster Investigations and Protocols. Council of State and Territorial Epidemiologists. [Internet] 2012 [cited 2021 May 22]. Available from: <http://www.cste2.org/webpdfs/ASynopsisofthe2010NationalAssessmentofStateCancerClusterInvestigationsandProtocols.pdf>
 28. Lundgren RE, McMakin AH. *Risk communication: A handbook for communicating environmental, safety, and health risks*. Hoboken, NJ: John Wiley & Sons; 2018.
 29. Heath RL, O'Hair HD, eds. *Handbook of risk and crisis communication*. New York, NY: Routledge; 2020.
 30. Covello VT, McCallum DB, Pavlova MT, eds. *Effective risk communication: the role and responsibility of government and nongovernment organizations*. Springer Science & Business Media; 2012.
 31. Kingsley BS, Schmeichel KL, Rubin CH. An update on cancer cluster activities at the Centers for Disease Control and Prevention. *Environmental Health Perspectives*. 2007 Jan;115(1):165-71.
 32. Siegrist M, Cvetkovich GT, Gutscher H. Shared values, social trust, and the perception of geographic cancer clusters. *Risk Analysis*. 2001 Dec;21(6):1047-54. <https://doi.org/10.1111/0272-4332.216173>
 33. Simpson BW, Truant P, Resnick BA. Stop and listen to the people: an enhanced approach to cancer cluster investigations. *American journal of public health*. 2014 Jul;104(7):1204-8. <https://doi.org/10.2105/ajph.2013.301836>
 34. Thomas M, Narayan P. The role of participatory communication in tracking unreported reproductive tract issues in marginalized communities. *Information Technology for Development*. 2016 Jan 2;22(1):117-33. <https://doi.org/10.1080/02681102.2014.886549>

CHAPTER 4

Investigating the impacts of communication source and format on perceptions of information trustworthiness and cancer risk

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4.1. INTRODUCTION

Cancer is a disease that can invoke feelings of anxiety and concern among people irrespective of their personal susceptibility or likelihood of receiving a diagnosis. It is frequently cited as among the most dreaded diseases, which influences individual perceptions around its risk (Robb et al. 2014). This is because cancer risk perceptions depend largely on intuitive affective risk judgments, which are often based on negative feelings people have about cancer due to personal experiences, memories or soundbites from popular media (Peters et al. 2006). Nearly 20 million individuals a year are diagnosed with cancer globally (Sung et al. 2021), therefore, most people have a personal connection to it. In addition, information about cancer is ubiquitous, some of which sensationalizes risks (Hesse-Biber, Flynn, and Farrelly 2018) or presents information that is inaccurate (Gage-Bouchard et al. 2018). As a result, concerns over cancer risk may lead to overestimations of actual risk (Lipkus et al. 2005).

The social amplification of risk is a theory proposed by Kasperson et al. (1988) about how perceptions of risks depend on a complex interplay between risk events (i.e. unexpected occurrences in which societies can incur losses of life, finances, etc.) and psychological, social and cultural processes. In other words, even an event with a low absolute probability may be perceived as very risky because numerous processes influence the transfer of information about a risk that an individual receives and also shape an individual's response to that information. The

transfer of information about a risk event is largely dependent on the ways that risks are portrayed by the sources of information we consult (e.g. people we know, the media, etc.), which can intensify certain pieces of information and at times result in public overreactions due to amplified individual responses (Binder et al. 2014). Recently, Bearth and Siegrist (2021) found that trustworthy sources of information could attenuate individual responses to risk events and reduce these types of overreactions, underscoring trust as an important factor in the study of the social amplification of risk. Yet, dreaded risks like cancer appear to be especially susceptible to this process of amplification as the portrayal of cancer is mostly negative and risk information is amplified by multiple trusted and non-trusted sources, which shapes people's understanding of cancer risk (Jagiello and Hills 2018). Less is known about the influence of specific sources and types of information about cancer on shaping cancer risk perceptions and whether trust could modify levels of concern.

In this study, we tested whether the portrayal of a cancer risk event that differed by information source and format would influence perceptions of the information's trustworthiness and concerns about cancer. Prior research has found that trust in certain sources of information can impact risk perceptions as people anchor their risk judgments around trusted reference points (Weaver et al. 2017; Takebayashi et al. 2017; Jacobson and Adams 2017). However, little research has tested whether certain information formats are perceived as more trustworthy (McQueen et al. 2011) and whether this may influence risk perceptions (Kuhn 2000). Furthermore, being viewed as a trustworthy source of information is critical in today's post-truth world whereby risk judgments appear to be more influenced by personal beliefs and emotional reactions than objective facts (Spiegelhalter 2019). Identifying which information formats are

perceived as trustworthy could aid risk educators seeking to gain more public trust and improve the uptake of risk messaging.

Using an online experiment, we randomly assigned participants to different informational vignettes that were designed to either look like a news story or a government report, which either included contextual information about a risk event and/or personal stories from community members or neither. We then surveyed participants about their perceived trust in the information and their concerns about cancer with respect to the informational vignette and a separate hypothetical scenario. This work has significant implications for how we inform the public about cancer risks in order to garner public trust and avoid overreactions to hazards that pose little risk. Importantly, we show how some information sources and formats perceived as more or less trustworthy appear to play an important role in attenuating and amplifying perceptions of cancer risk at a societal and personal level.

4.2. PREVIOUS RESEARCH

4.2.1 Impact of information on trust

Believing that something or someone is trustworthy depends on our innate impressions of those objects or individuals, as well as our personal experiences that may update these beliefs over time (Chang et al. 2010). Numerous studies have examined which sources of cancer information people tend to find the most trustworthy. Among them, the media (e.g. radio, newspapers, television) tends to rank the lowest (Shea–Budgell et al. 2014; Somera et al. 2016), while physicians and government officials tend to rank the highest (Befort et al. 2013; Trivedi et al. 2020). This may be in large part due to the way that the media sometimes sensationalizes

cancer (Moorhead, Krakow, and Maggio 2021), which could impact the media's credibility as a source for health information. Yet, the media serves as a common source of information on cancer and attention to health news has been found to be linked to higher levels of knowledge about cancer risks (Stryker, Moriarty, and Jensen 2008). Notably, trust in cancer news coverage can vary by news type (e.g. TV versus newspapers) (Mayer et al. 2007), suggesting that there is significant nuance in the amount of credibility people ascribe to various communicators of risk. Based on the findings from these previous works, we hypothesize that:

(H1) The likelihood of perceiving the information in the vignette as trustworthy will be higher among participants viewing the information from a government source, relative to those viewing the news source.

Less research has explored whether the format of information and/or characteristics about its content can influence levels of trust in information. An experiment by Jensen (2008) found that when news coverage of cancer research contained information about study limitations and scientific uncertainty that both scientists and journalists were perceived as more trustworthy. It has also been found that the presentation of contextual information about health risks can result in a greater sense of safety (Murakami et al 2017). The use of narratives and story-telling in cancer messaging has also been associated with increased trust in information as it may be perceived as more sincere when coming from someone's personal experiences (McQueen et al. 2011). On the other hand, Shaffer, Tomek, and Hulsey (2014) found that the use of narratives could lower perceived trustworthiness among those with higher levels of numeracy, which would suggest that there is an interaction between competencies like numeracy or education and perceptions trust. The influence of information format and its perceived trustworthiness has not

been tested using communications about a cancer risk event, however, based on the above scholarly literature we hypothesize that:

(H2) The likelihood of perceiving the information in the vignette as trustworthy will be higher among participants viewing contextual information and/or personal stories, relative to participants not viewing these formats.

4.2.2 Information effects on cancer perceptions

Exposure to information about cancer can impact attitudes about cancer through different cognitive mechanisms that individuals use to process information. Dual process theory posits that people use both intuitive heuristic processing and systematic analytical processing modes to aid in their interpretation of risk information (Johnson 2005). When it comes to interpreting information on cancer risks, the affect heuristic, which helps people make decisions quickly based on current emotions, appears to be especially influential in formulating people's judgments of risk. This is because of the many affective cues people encounter about cancer (e.g. stories about a family member's diagnosis, sensational news reports, etc.) that can lead to individuals relying disproportionately on negative feelings about cancer (e.g. dread, fear) in order to interpret information about its risks (Peters and Meilleur 2016). Interestingly, affect may also enhance memory of risk information (Tompkins, Bjälkebring, and Peters 2018), which would suggest that people retain negative emotionally-stimulating information about cancer even after their initial feelings subside. Indeed, exposure to affective cues like graphic images on cigarette packaging have been found to induce negative affect to smoking and increase quit intentions several weeks later (Evans et al. 2015).

The framing of a risk as either societal or personal also appears to influence perceptions of risk. Previous research has found that people do not necessarily draw from their general societal-level risk perceptions in order to formulate their own personal perceptions of risk, leading to two fairly distinct risk attitudes (Park, Scherer, and Glynn 2001). Personal risk perceptions appear to be more difficult to influence with new information than societal-level risk perceptions (Wahlberg and Sjoberg 2000), potentially as a result of an optimistic bias that leads to an underestimation of risks involving ourselves versus others (Masiero et al. 2018). Due to the effects of affective recall and differences in risk perceptions generated by societal versus personal risk framing, we hypothesized that:

(H3): The frequency of participants reporting concern about cancer will be highest directly after exposure to the societal-level cancer risk presented in the vignettes. The frequency of reporting cancer concern will subsequently decrease when the risk is framed as a personal risk in a separate hypothetical scenario.

When information about cancer employs narrative messaging and storytelling, it also appears to result in stronger cognitive and affective responses, resulting in increased engagement with the message and higher perceptions of risk (McQueen et al. 2011). This style of narrative message format is often employed by journalists, sometimes with highly affective fear-arousing messages, and has been found to increase both personal and societal-level perceptions of risk (Paek, Oh, and Hove 2016; Dahlstrom, Dudo, and Brossard 2012). In contrast, viewing more fact-based instructional information formats seems to result in less cancer fear than when narrative formats are viewed (Kreuter et al. 2010).

Risk perceptions after exposure to information may also depend on the source communicating risk because people expect different message content from different sources of

information. For example, Longman et al. (2012) found that participants had higher perceptions of risk after viewing uncertain risk information from sources they perceived as credible. This was because participants expected those credible sources to provide information with a higher degree of certainty and the presence of uncertain information was considered to be evasive. Indeed, Trumbo and McComas (2003) found that people who considered governments to be credible sources of information generally reported reduced perceptions of cancer risk when presented with reassuring information that health departments had found no significant increase in cancer risk in their communities. Still, few studies have used experiments to test the effects of both the source of risk information and the information format, though it seems likely that both are important factors shaping perceptions of cancer risk. Building off these prior works, we hypothesized that:

(H4) The likelihood of reporting concern about cancer will be higher among participants viewing the information from a news source, relative to those viewing the government source.

(H5) The likelihood of reporting concern about cancer will be higher among participants viewing the information containing personal stories, relative to those not viewing personal stories.

4.2.3 Other factors influencing trust and concern

Other factors have also been found to impact perceptions of information trustworthiness such as gender, income and education, which are known to moderate trust in various sources of health information. For example, higher income individuals appear to find information from media sources including the radio, television and social media to be less trustworthy than lower income individuals (Brown-Johnson et al. 2018). Conversely, women and less educated individuals may be more likely to trust health information reported by the media compared to men and more

highly educated individuals (Smith 2011). In addition, an individual's history of disease was found to reduce the odds of reporting trust in government-related sources of health information (Kwon et al. 2015).

Attitudes about cancer are also known to vary by certain sociodemographic characteristics, which are likely to impact risk information interpretation. Although women generally report a higher perceived risk of cancer than men, men who seek out cancer information also tend to report frequent worry about cancer (McQueen et al. 2008). Lower education and lower income levels have also been found to be associated with higher levels of cancer dread (Lee et al. 2005). Health status is also an important factor influencing cancer risk perceptions (Trumbo, McComas, and Kannaovakun 2007), likely because some medical conditions serve as cancer risk factors and increase one's cancer anxiety. In addition, being someone who avoids taking risks with respect to environmental health hazards appears to be associated with higher levels of cancer dread (Lee et al. 2005). In fact, the potential for harmful environmental exposures seems to elicit large emotional reactions and overestimations of risk (Böhm and Tanner 2018). Since this study randomly assigned participants to informational vignettes that described a suspected cancer cluster, which are often hypothesized to have some environmental link, we also included a measure related to concern about environmental pollution in our analysis. We hypothesized that:

(H6) Effects of the information vignettes on the odds of reporting trust and/or concern will vary across levels of sociodemographic variables (i.e. education, income, gender) and individual characteristics (i.e. health satisfaction, being health conscious and concerned about pollution).

4.3 METHOD

4.3.1 Vignettes and survey procedure

To test the hypotheses of this study, eight online surveys each containing different informational vignettes were developed to conduct a randomized experiment. The experiment was used to examine the effects of two information sources and four different information formats on perceptions of trust and cancer concern. The risk event portrayed in all vignettes was described as a cancer cluster in a fictitious community where public health officials were still investigating potential causes. Consistent with the ‘Accidents as Signals’ model, wherein risk events that are unknown and dreaded appear to result in the highest perceptions of risk due to the potential for harm they signal (Slovic 1987), our focus on cancer clusters as a risk event was deliberate in order to capture levels of concern that were measurable.

The informational vignettes differed by information source: they either appeared as an online newspaper article about a cancer cluster investigation in a community, or they appeared as an online government report about the same topic. The vignettes also differed by information format: they either contained contextual information and personal stories, no contextual information and personal stories, contextual information and no personal stories, or no contextual information and no personal stories. Contextual information in the vignettes contained information about historical environmental exposures in the community, the demographic makeup of the community members, cancer latency, cancer incidence rates in the community and surrounding region, and a risk ladder visual to contextualize cancer risks compared to other commonly known risks (for an example, see Appendix 7-1). Personal stories in the vignettes contained quotes from fictional local community members, including those diagnosed with cancer, and a photograph of a cancer survivor (see Appendix 7-2). All vignettes contained basic

descriptive information about the cancer cluster such as the number of cases of cancer in the cluster, the total number of people living in the fictional community and the fact that the rate of cancer was approximately double the national average. Vignette designs were based on real-life government reports and news stories of cancer clusters from various jurisdictions.

The surveys developed contained numerous closed-ended questions related to demographic variables such as age, income, sex and education. Participants were also asked a series of scaled questions related to health such as whether they were currently satisfied with their health, how frequently they considered their health when making decisions and whether they usually avoided taking risks for matters related to their health. After viewing the vignettes, participants were asked scaled questions related to how trustworthy they found the information in the vignette to be using a single survey item, as well as their level of concern about cancer using three survey items detailed further in section 4.3.3 below. The whole experiment (vignette and survey) was designed to take approximately 20-30 minutes to complete.

4.3.2 Participants

We recruited 172 Canadian participants between Fall 2019 and Fall 2020. Recruitment advertisements were posted in numerous locations on a Canadian university campus and in public community settings (e.g. libraries, parks) in the Greater Toronto and Hamilton Area in Ontario, Canada. Recruitment advertisements were also distributed online on social media (e.g. public Facebook groups) and in newsletters of a listserv for public health professionals in Canada. We also recruited students from an undergraduate course that the study authors were teaching in the Fall of 2019, who were offered a 1% bonus mark towards their final grades in exchange for participation. All study participants could opt to be included in a prize draw to win 1 of 4 gift cards that were valued at \$50CAD. All participants included in this study had to

provide consent to participate. Once consent was collected anonymously, participants were randomly assigned to view one of eight online surveys through Google Forms, which contained one of eight embedded vignettes. Ethics approval for the study was obtained from McMaster University's Research Ethics Board (MREB# 1763).

Most participants identified as female (n=134, 77.9%) and 34.9% were highly educated having either obtained a university graduate degree or a certificate/diploma above a bachelor's degree level (n=60). A little over half of the participants were aged between 18 to 24 (n=89, 51.7%) and were currently enrolled as students at an academic institution (n=102, 59.3%). Approximately half of the study participants reported having an individual income below \$40,000 CAD (n=87, 50.6%); for reference, a single-individual Canadian whose after-tax income was \$25,153 CAD in 2019 would be classified as low-income (Statistics Canada 2021). A summary of participant characteristics related to sociodemographic and individual characteristics are found in Table 4-1.

Table 4-1. Characteristics of survey participants (N=172).

Participant characteristics	N	%
Sex		
Male	37	21.5
Female	134	77.9
Non-binary	1	0.6
Age		
18-24	89	51.7
25-49	64	37.2
50+	18	10.5
Did not report	1	0.6
Education above a university bachelor's degree		
Yes	60	34.9
No	112	65.1
Current student		
Yes	102	59.3
No	70	40.7
Income		
<\$40,000 CAD	87	50.6
\$40,000-80,000 CAD	44	25.6
>\$80,000 CAD	24	14.0
Did not report	17	9.9
Satisfied with health		
Yes	108	62.8
No or neutral	64	37.2
Avoids health risks		
Yes	122	70.9
No or neutral	50	29.1
Health conscious		
Always or frequently	89	51.7
Sometimes or rarely	83	48.3
Concerned about pollution		
Yes or sometimes	132	76.7
No or not sure	40	23.3

4.3.3 Outcome measures

4.3.3.1 Trust

Participants' trust in the information they viewed was measured using a single survey item: "When reading the information in the news story/government report, how trustworthy did you think the information presented on cancer clusters was?". The question specifically referenced trust in information, rather than trust in the source of information they were viewing, as most people hold prior-established beliefs about which information sources they find credible. Rather than having participants potentially reflect on these prior beliefs, we sought to anchor their judgments of trust around the information they were viewing.

The question originally appeared as a 5-category response question in the survey, however, responses skewed towards the positive end and no participant selected the very untrustworthy response category. As a result, we re-categorized trust as a binary variable by grouping neutral responses with the somewhat untrustworthy responses and coding these as 0 to represent an absence of trust, while coding the somewhat trustworthy and very trustworthy responses as 1 to denote the presence of trust. This pattern of mid-point responses is not uncommon in survey research and has been found to most likely represent attitudes of no opinion or a negative opinion masked as neutral among respondents who are refraining from expressing them (Gilljam and Granberg 1993; Sturgis, Roberts, and Smith 2014).

4.3.3.2 Cancer concern for three information treatments

The second outcome variable explored in this study was cancer concern, which was assessed using three survey items that measured self-reported levels of concern. Since other studies have found anxiety and concern about cancer to be strong predictors of cancer risk perceptions

particularly when environmental hazards are involved (Lee et al. 2005; Trumbo, McComas, and Kannaovakun 2007), we consider participants' feelings of concern to indicate perceived cancer risk either at a societal or personal level.

We first measured concern about cancer directly following exposure to the vignettes. Concern was measured with the question: "How concerned are you about the cancer cluster reported in the news story/government report?". The question originally appeared as a 5-category response question in the survey, however, responses to this item were categorized as binary indicating either the presence of concern (=1) or absence of concern (=0). As the vignettes presented information about a cancer cluster in a fictional community and referenced risks to a population, this measure of cancer concern was used to indicate societal-level perceptions of cancer risk.

Responses measuring personal-level perceptions of cancer risk were collected later in the survey following the presentation of a hypothetical scenario. These responses were collected to test our study's third hypothesis and examine whether the levels of concern reported after viewing the informational vignettes would change following exposure to a hypothetical scenario about a cancer cluster in the participant's own neighbourhood. First, we presented participants with the following scenario: "Let's say the historical rate of cancer diagnosis in your community was 1 in 5,000 per year, and you found out that 5 cases of cancer were diagnosed in the community last year (4 more than usual). Rate your level of concern about the excess cases of cancer in your neighbourhood." Responses to this item were categorized as binary indicating either the presence of concern (=1) or absence of concern (=0).

Next, we provided participants with a more detailed reassuring explanation of cancer rates relevant to the hypothetical scenario they were presented surrounding a cancer cluster in

their own community. For this item, we sought to assess whether information in the vignettes as well as reassuring information provided about the hypothetical scenario would affect participants' personal-level cancer risk perceptions. The survey item read: "Let's say your local public health agency investigated a suspected cancer cluster in your neighbourhood but found that the excess in cancer cases could be explained by normal year-to-year variations in cancer rates. Rate your level of concern about the excess cases of cancer in your neighbourhood.". Responses to this item were also categorized as binary indicating either the presence of concern (=1) or absence of concern (=0).

4.3.4 Analyses

We explored whether there were associations between the vignettes (i.e. information source and/or format) and perceived trust in the informational vignettes and cancer concern. We calculated odds ratios for the binary outcome variables trust and three binary concern variables by comparing participants who had viewed or not viewed vignettes containing news stories, contextual information and personal stories. The R package *epitools* was used to calculate odds ratios by median-unbiased estimation (mid-p) method with confidence intervals at the 95% level (Aragon et al. 2020).

Chi-square tests for independence were carried out to include only variables that were independent in stratified analyses. It was found that the variable 'Avoids health risks' was not independent of the variable 'Satisfied with health' ($X^2 = 9.55, p < 0.01$) nor 'Health conscious' ($X^2 = 12.15, p < 0.001$). Therefore, 'Avoids health risks' was omitted from further analyses. Age was found not to be independent of income ($X^2 = 79.83, p < 0.001$) and was also omitted.

To examine whether the crude odds ratios calculated for the associations between the vignettes and trust and concern varied across sub-groups of participants, we conducted exploratory stratified analyses to calculate adjusted odds ratios for each sub-group strata. Investigating the heterogeneity of treatment effects on various sub-groups in a randomized experiment is useful for highlighting which sub-populations are most likely to be impacted by the experimental treatments (Christensen, Bours, and Nielsen 2021). Based on the prior literature, we selected six sub-groups (each containing two strata) to explore in our stratified analysis consisting of income (above \$40,000 CAD versus below \$40,000 CAD, with 17 participants not reporting income being omitted), education (above a university bachelor's degree versus a university bachelor's degree or below), gender (females versus non-females), satisfied with health (yes versus no), concerned about environmental pollution (yes versus no) and being health conscious (yes versus no).

In some instances, the stratification of sub-groups resulted in small numbers that required the Haldane-Anscombe correction to be applied, whereby if one of the four cells of a stratified 2x2 contingency table contained a zero (i.e. zero cases or controls were reported for a given treatment or no-treatment exposure), 0.5 was added to each of the four cell values. Wherever this correction was applied, we used the small odds ratio estimation method to calculate adjusted odds ratios for these sub-groups. This correction has been found to result in an approximately unbiased odds ratio estimation (Lawson 2004). To summarize the results of the stratified analyses, we used forest plots using the R package *metafor* (Viechtbauer 2010). It has been suggested that when the outcome measure associated to a treatment differs by more than 10% between sub-group strata, this can indicate effect heterogeneity (VanderWeele and Knol 2011).

4.4 RESULTS

4.4.1 Trust

We found that the odds of perceiving the information in the vignettes as trustworthy was significantly lower among participants who viewed the news story vignettes (OR 0.48, 95% CI 0.26-0.88, $p = 0.02$) (Table 4-2).

Table 4-2. Crude odds of perceiving information as trustworthy by informational vignette viewed.

Informational vignette	Informational vignette perceived as trustworthy N (%)		OR (95% C.I.)
	Yes	No	
Source			
News	37 (44.6%)	46 (55.4%)	0.48* (0.26-0.88)
Government	56 (62.9%)	33 (37.1%)	1.00 (reference)
Format			
Contextual information present	54 (62.8%)	32 (37.2%)	2.02* (1.10-3.75)
No contextual information	39 (45.3%)	47 (54.7%)	1.00 (reference)
Personal stories present	43 (50.6%)	42 (49.4%)	0.76 (0.41-1.39)
No personal stories	50 (57.5%)	37 (42.5%)	1.00 (reference)

Note: † $p < 0.1$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Of the 89 participants who had viewed the government source vignettes, most reported the information as being trustworthy (N=56, 62.9%), whereas of the 83 participants who had viewed the news source vignettes, most reported the information viewed as not trustworthy (N=46, 55.4%). Our results also showed that there was a significant increase in the odds of participants reporting the information as trustworthy when they viewed the vignettes containing contextual

information (OR 2.02, 95% CI 1.10-3.75, $p = 0.02$). The odds of reporting the information as trustworthy were not significantly different between participants who had viewed the vignettes containing personal stories compared to those who had not (OR 0.76, 95% CI 0.41-1.39, $p = 0.37$).

4.4.2 Concern

Figure 4-1 displays the percentage of participants reporting feeling concerned about cancer in response to the three information treatments (consisting of the vignette and two hypothetical scenarios).

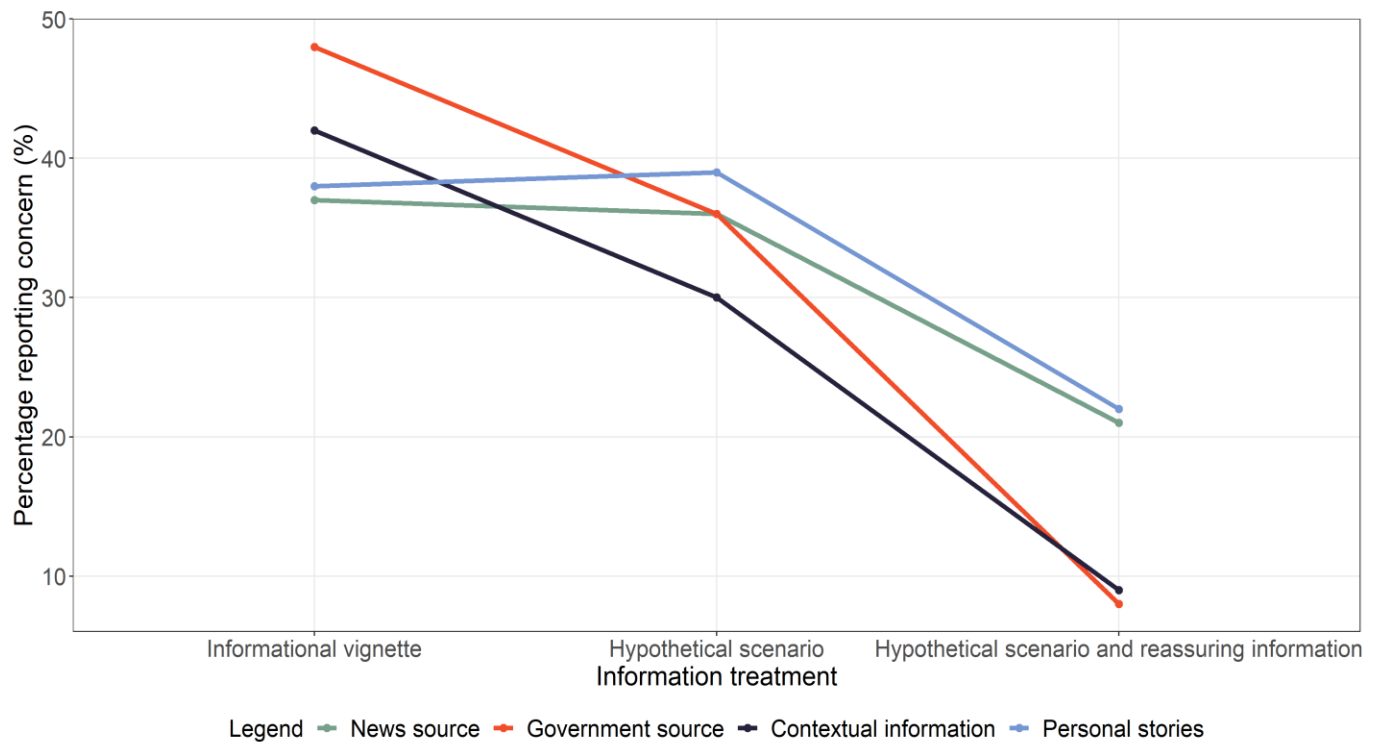


Figure 4-1. Percentage of participants reporting feeling concerned about cancer after exposure to information treatments consisting of informational vignette, hypothetical scenario, and hypothetical scenario plus reassuring information, by informational vignette viewed.

Note: vignette information source and format categories are not mutually exclusive.

After viewing a vignette, 48.3% of participants who had viewed the informational vignette authored by a government source reported feeling concerned about cancer. Of the participants who had viewed contextual information in their vignette, 41.9% reported feeling concerned about cancer, followed by 37.6% of participants who had viewed personal stories and 37.3% who had viewed the news source. After being presented the first hypothetical scenario and asked to report their cancer concern when considering the risk to their own community, there was a decline in the percentage of participants reporting concern among those who had viewed a government source vignette and/or contextual information (36.0% and 30.2%, respectively). The frequency of reporting concern about cancer appeared to remain steady or increase slightly among those who had viewed a vignette containing the news source or personal stories. After being presented with a hypothetical scenario and reassuring information, participants who had viewed a government source vignette and/or contextual information again saw large decreases in the frequency of reporting concern (7.9% and 9.3%, respectively). In comparison, the percentage of participants reporting cancer concern was higher among those who had viewed the news source vignettes and personal stories (20.5% and 22.4%, respectively).

Associations between the three concern variables and the vignettes viewed are summarized in Table 4-3. For the first concern variable, which reflected participants' concern about cancer after they viewed the informational vignette where risk was framed at a societal level, the odds of reporting concern were lower among those who had viewed news stories compared to those who had viewed the government source (OR 0.64, 95% CI 0.35-1.18). Participants who reported cancer concern were also less likely to have viewed the vignettes containing contextual information and personal stories (OR 0.91, 95% CI 0.50-1.67, $p = 0.76$ and OR 0.65, 95% CI 0.35-1.19, $p = 0.16$, respectively).

Table 4-3. Crude odds of reporting concern about cancer after viewing information treatments, consisting of informational vignette, hypothetical scenario, and hypothetical scenario plus reassuring information, by informational vignette viewed.

Informational vignette	Reported cancer concern after informational vignette N (%)		OR (95% C.I.)	Reported cancer concern after hypothetical scenario N (%)		OR (95% C.I.)	Reported cancer concern after hypothetical scenario with reassuring information N (%)		OR (95% C.I.)
	Yes	No		Yes	No		Yes	No	
Source									
News	31 (37.3)	52 (62.7%)	0.64 (0.35-1.18)	30 (36.1%)	53 (63.9%)	1.01 (0.54-1.89)	17 (20.5%)	66 (79.5%)	2.96* (1.19-8.17)
Government	43 (48.3%)	46 (51.7%)	1.00 (reference)	32 (36.0%)	57 (64.0%)	1.00 (reference)	7 (7.9%)	82 (92.1%)	1.00 (reference)
Characteristics									
Contextual information present	36 (41.9%)	50 (58.1%)	0.91 (0.50-1.67)	26 (30.2%)	60 (69.8%)	0.60 (0.32-1.13)	8 (9.3%)	78 (90.7%)	0.45† (0.17-1.11)
No contextual information	38 (44.2%)	48 (55.8%)	1.00 (reference)	36 (41.9%)	50 (58.1%)	1.00 (reference)	16 (18.6%)	70 (81.4%)	1.00 (reference)
Personal stories present	32 (37.6%)	53 (62.4%)	0.65 (0.35-1.19)	33 (38.8%)	52 (61.2%)	1.27 (0.68-2.38)	19 (22.4%)	66 (77.6%)	4.58** (1.72-14.72)
No personal stories	42 (48.3%)	45 (51.7%)	1.00 (reference)	29 (33.3%)	58 (66.7%)	1.00 (reference)	5 (5.7%)	82 (94.3%)	1.00 (reference)

Note: † $p < 0.1$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

The second concern variable measured reported cancer concern given a hypothetical scenario in which a suspected cancer cluster occurred in the participant's own community framed as a personal risk. Table 4-3 shows that there was no apparent difference in the odds of reporting concern between participants who had viewed the news vignettes and government vignettes (OR 1.01, 95%CI 0.54-1.89, $p = 0.98$). Participants appeared less likely to report concern about cancer after they had viewed the vignettes with contextual information and were more likely to report concern after they had viewed the vignettes containing personal stories (OR 0.60, 95%CI 0.32-1.13, $p = 0.12$ and OR 1.27, 95%CI 0.68-2.38, $p = 0.46$).

When participants were provided with a hypothetical scenario and reassuring information, where cancer risk was again framed as a personal risk, the odds of reporting concern about cancer differed relative to when they reported concern after viewing the hypothetical scenario alone. Table 4-3 shows that the odds of reporting cancer concern were significantly higher among participants who had viewed the news vignettes (OR 2.96, 95%CI 1.19-8.17, $p = 0.02$). Participants reporting concern were also less likely to have viewed vignettes with contextual information (OR 0.45, 95%CI 0.17-1.11, $p = 0.08$) and significantly more likely to have viewed vignettes with personal stories (OR 4.58, 95%CI 1.72-14.72, $p < 0.01$).

4.4.3 Results from stratified analyses

We observed some effect heterogeneity between the sub-groups when examining the odds of reporting the information as trustworthy by vignette type summarized in Figure 4-2. Among participants viewing the news source vignettes, the odds of reporting trust (relative to those viewing the government source vignettes) was lower among those who had obtained an education above a bachelor's degree (OR 0.35, 95%CI 0.12-1.00, $p = 0.05$).

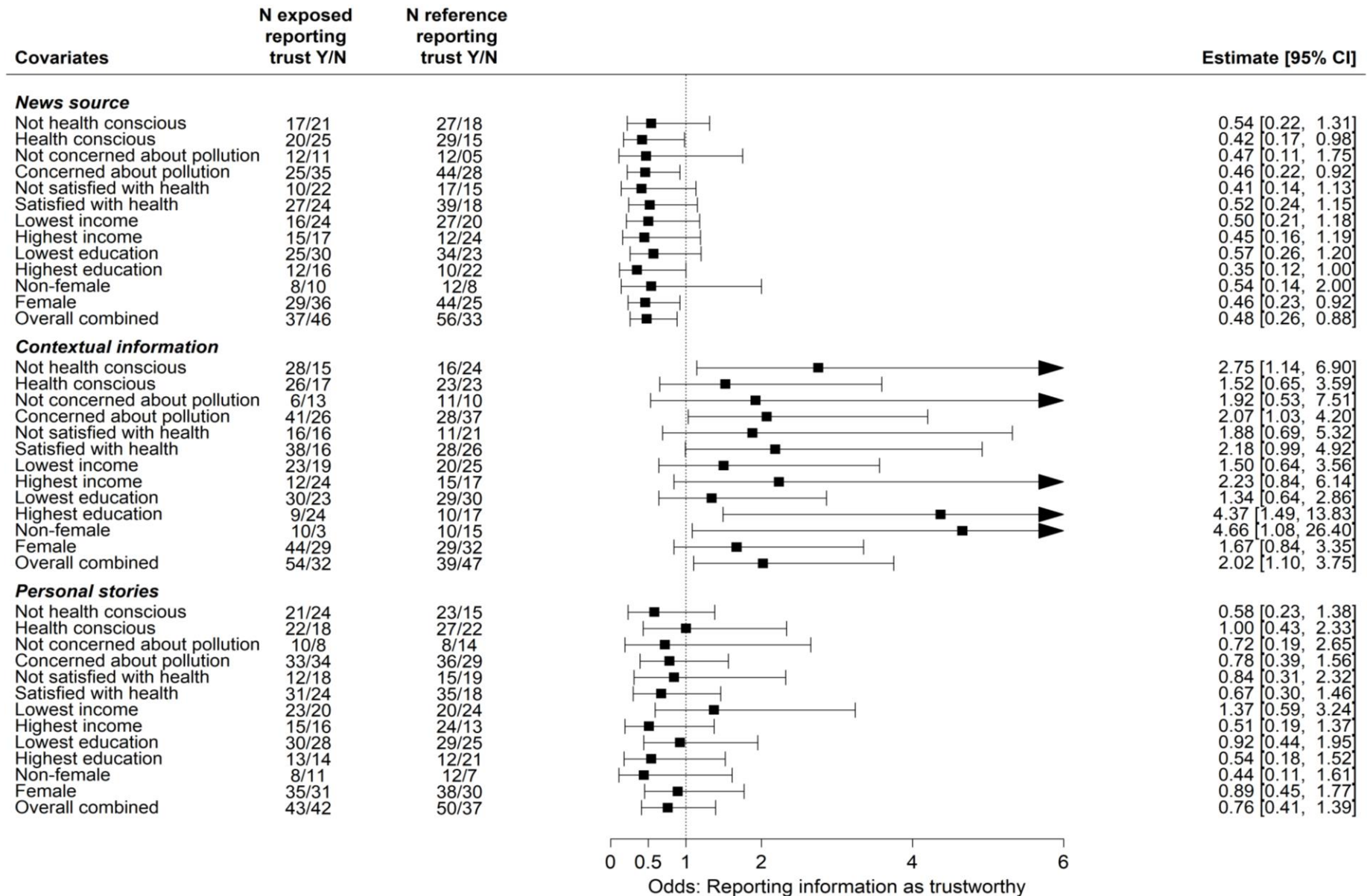


Figure 4-2. Forest plot displaying stratified analyses for the odds of reporting information viewed as trustworthy, by covariate strata and exposed informational vignette treatment group.

The overall combined crude odds of trust after viewing the news vignettes were 0.48 (95%CI 0.26-0.88, $p = 0.02$). There also appeared to be an association between some covariates and trust when viewing vignettes containing contextual information. We observed increased odds of reporting trust among non-female participants (OR 4.66, 95%CI 1.08-26.40, $p = 0.04$), participants with higher education (OR 4.37, 95%CI 1.49-13.83, $p < 0.01$) and those who reported not being health conscious (OR 2.75, 95% 1.14-6.90, $p = 0.02$). The overall combined crude odds ratio for contextual information and trust was 2.02 (95%CI 1.10-3.75, $p = 0.02$). There did not appear to be any noteworthy effect heterogeneity among participants viewing personal stories.

Figure 4-3 displays the results of the stratified analyses examining the odds of reporting concern about cancer after viewing the vignettes. Only one sub-group was found to have a significant association with the odds of reporting cancer concern, which was observed for the personal stories vignettes. We did not observe any significant effect heterogeneity between sub-groups when examining the associations between the vignette treatment groups and odds of reporting cancer concern after viewing the hypothetical scenario (Figure 4-4).

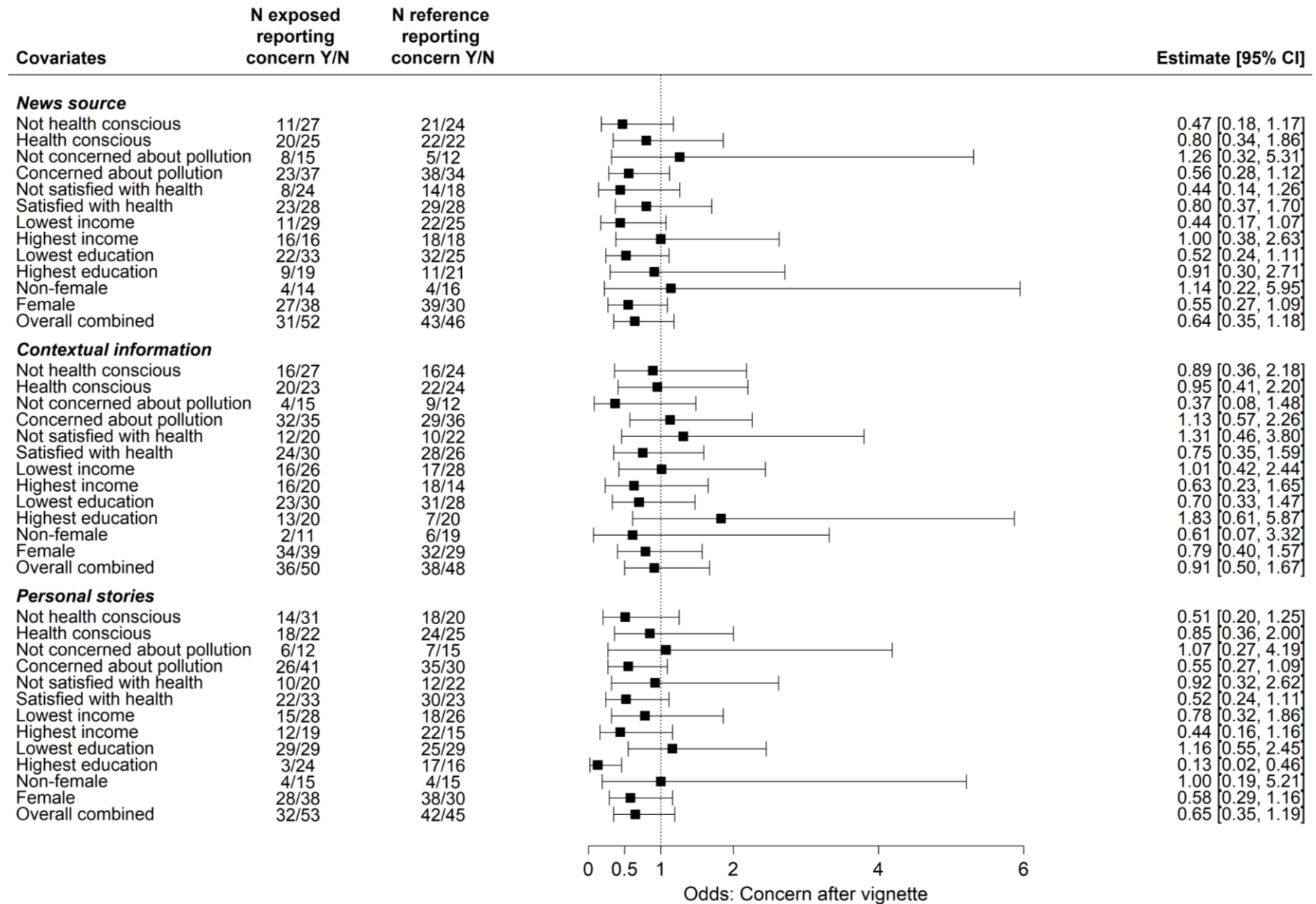


Figure 4-3. Forest plot displaying stratified analyses for the odds of reporting concern about cancer after viewing the informational vignettes, by covariate strata and exposed informational vignette treatment group.

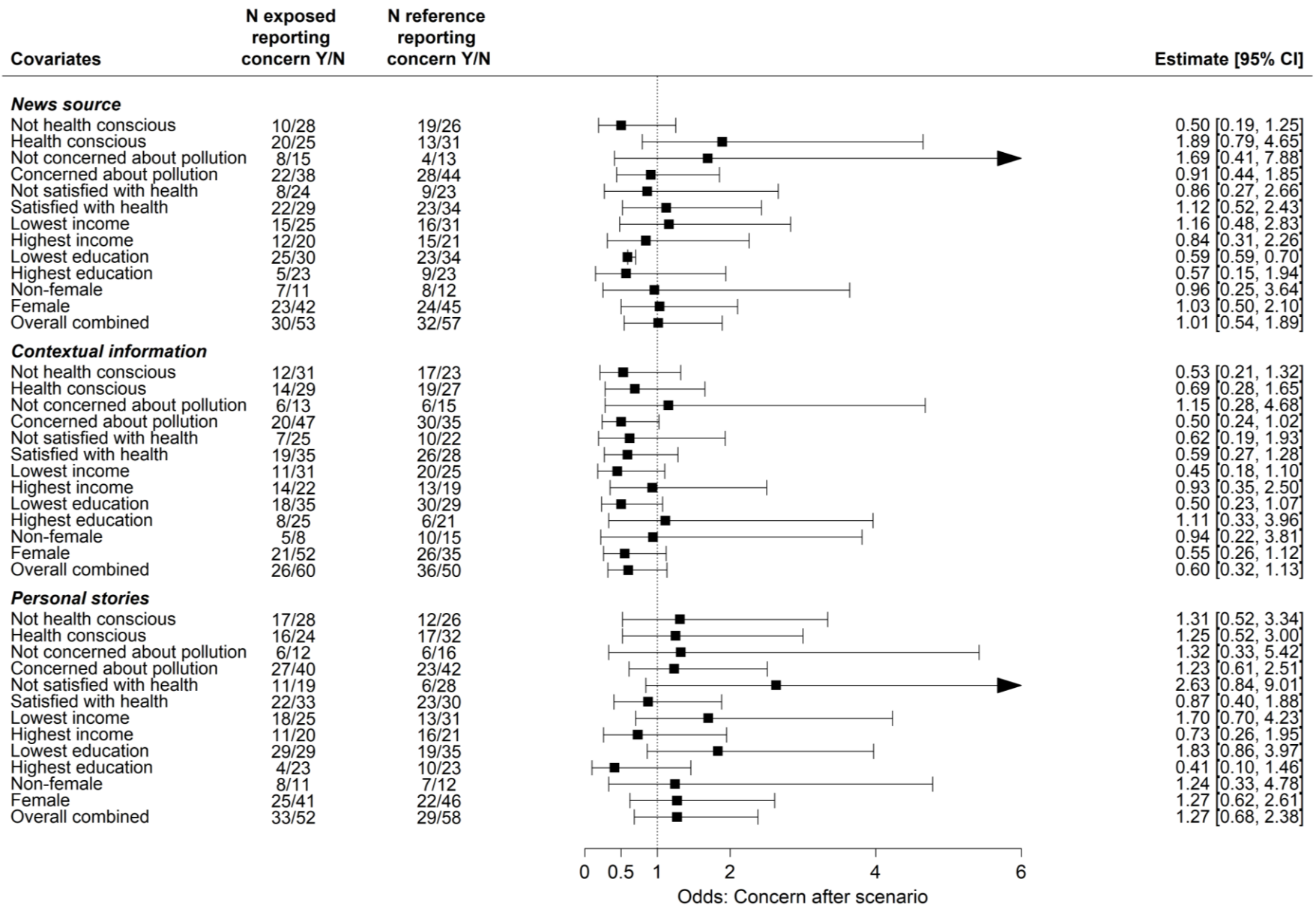


Figure 4-4. Forest plot displaying stratified analyses for the odds of reporting concern about cancer after presentation of a hypothetical scenario, by covariate strata and exposed informational vignette treatment group.

The stratified analyses for the odds of reporting concern about cancer after viewing the hypothetical scenario and reassuring information revealed significant effect heterogeneity among several sub-groups (Figure 4-5). For the news source vignette treatment group, we observed increased odds of reporting cancer concern among participants who reported being health conscious (OR 4.90, 95%CI 1.14-37.03, $p = 0.03$), being concerned about pollution (OR 3.31, 95%CI 1.29-9.36, $p = 0.01$) and being satisfied with their health (OR 4.20, 95%CI 1.17-20.67, $p = 0.03$). The overall combined crude odds ratio for news source and concern was 2.96 (95%CI 1.19-8.17, $p = 0.02$). Among participants viewing contextual information, the odds of reporting concern about cancer after viewing the hypothetical scenario and reassuring information were significantly lower among those who reported not being health conscious (OR 0.24, 95%CI 0.05-0.87, $p = 0.03$) relative to the overall combined crude odds of concern (OR 0.45, 95%CI 0.17-1.11, $p = 0.08$). For the personal stories vignette treatment group, we observed increased odds of reporting cancer concern among participants who reported not being health conscious (OR 11.70, 95%CI 2.10-297.35, $p < 0.01$), not being satisfied with their health (OR 6.34, 95%CI 1.42-49.11, $p = 0.01$) and those in the lower education stratum (OR 5.63, 95%CI 1.70-26.74, $p < 0.01$). The overall combined crude odds ratio for personal stories and concern was 4.58 (95%CI 1.72-14.72, $p < 0.01$).

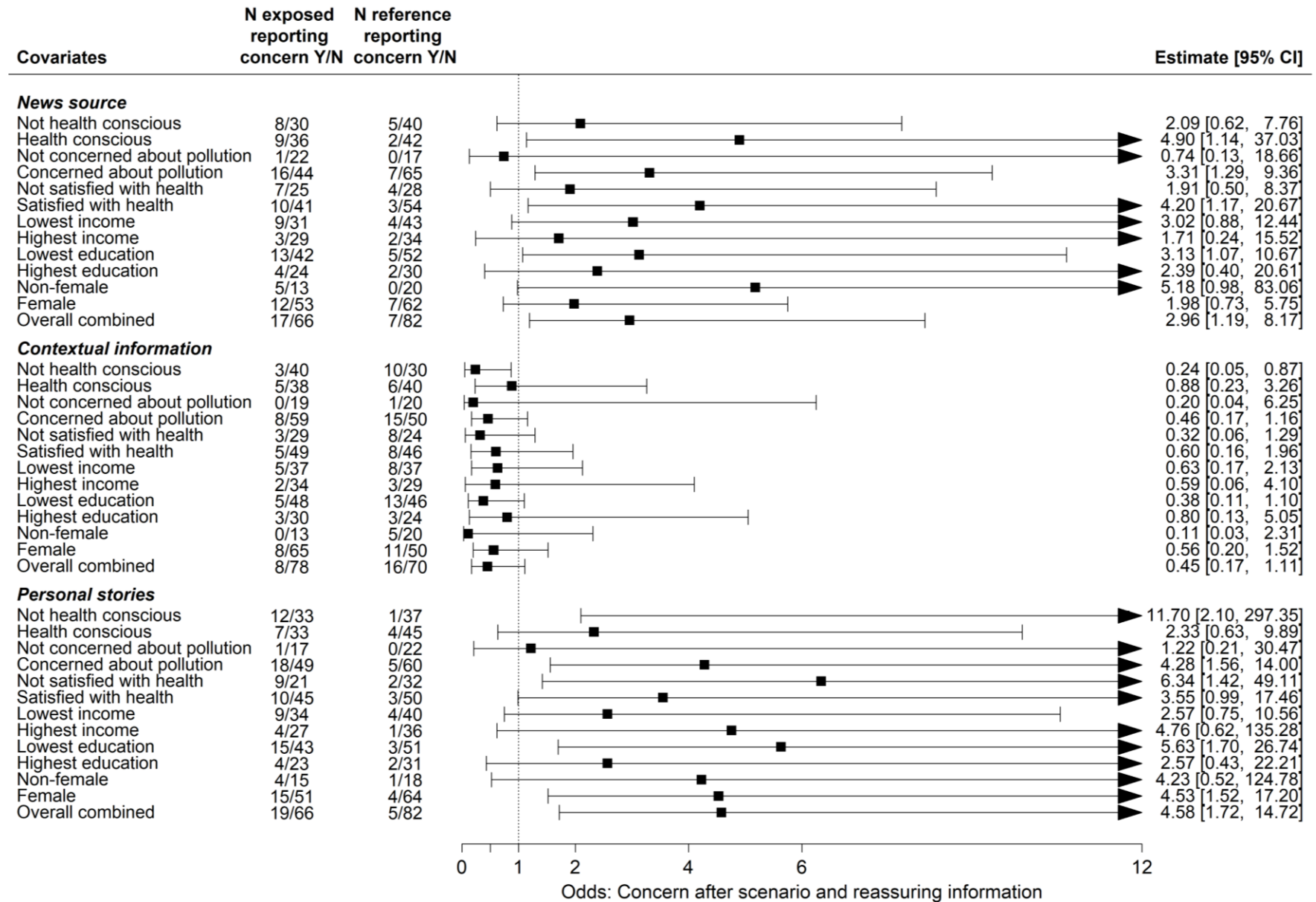


Figure 4-5. Forest plot displaying stratified analyses for the odds of reporting concern about cancer after presentation of a hypothetical scenario and reassuring information, by covariate strata and exposed informational vignette treatment group

4.5 DISCUSSION

The findings of this study show that information about cancer from some sources and formats is perceived as more trustworthy and may amplify concerns about cancer at a societal level in response to a risk event. Our findings also suggest that viewing information initially characterized as less trustworthy could lead to higher perceptions of cancer risk at a personal level when compared to viewing information considered more trustworthy. Effects of the treatments on trust and concern varied among some of the sub-groups we examined. This work has important implications for how we inform the public about cancer risks – particularly risks related to environmental hazards – in order to garner public trust and avoid overreactions to hazards that may pose little risk. Below we address these implications and discuss our findings in more detail.

This study found that information from a government source and information containing contextual information were associated with a doubling in the odds of perceiving the information to be trustworthy. This suggests that governments' cancer risk communications are likely to be trusted. It also suggests that any communicators of cancer risk information should consider crafting messages that contain contextual information about risk to increase perceptions of information trustworthiness. These findings were consistent with prior work that identified governments as generally trusted sources of cancer information (Trivedi et al. 2020) and the media as less trustworthy (Somera et al. 2016). The positive association we observed between contextual information and trust was also consistent with other experimental research that found that sources of cancer information were considered trustworthy when they included contextual information (Jensen 2008).

Unlike some previous research (McQueen et al. 2011), we did not find the use of personal stories in our informational vignettes to be associated with an increase in the likelihood of perceiving the information to be trustworthy. This may be due to the fact that the narratives used in our informational vignettes consisted mostly of first-hand accounts from fictional community members, who may not be perceived as the most credible sources of information. Indeed, Winterbottom et al. (2008) suggested that the expertise of the speaker is an important factor influencing the perceived credibility of narrative information. Therefore, it's possible that our vignettes containing personal stories may have been perceived as more trustworthy had they contained narratives from trusted experts rather than citizens. Future work exploring the trustworthiness of narrative information could build on this work by testing responses to various types of speakers.

Our results confirmed our third hypothesis that the frequency of participants reporting concern about cancer would differ in response to different information treatments framing the risk as either societal or personal. We found that concern about cancer was reported more frequently directly after viewing the informational vignettes, which framed the risk of cancer at a societal level. The frequency of concern subsequently decreased after participants were presented the hypothetical scenarios where risk was framed at a personal level. This finding is consistent with prior work that found perceptions of personal cancer risks tend to be lower than people's perceptions of risks to others (Masiero et al. 2018).

Still, the decline in concern observed across the three information treatments were not equal across vignette groups, suggesting differences in risk framing between the vignettes and hypothetical scenarios did not solely account for these differences in reported concern. The percentage of participants reporting cancer concern was initially higher among those who had

viewed the government source and contextual information vignettes. This result can be contextualized by our finding that participants viewing the government source and contextual information vignettes were more likely to perceive the information as trustworthy and perceptions of risk tend to be higher after viewing information from sources perceived as more credible (Longman et al. 2012).

In contrast, participants who had viewed the news source and/or personal stories vignettes reported cancer concern less frequently initially (directly after viewing the vignettes) compared to government and contextual information vignette groups; however, larger percentages of these participants reported feeling concerned after reading the hypothetical scenario and reassuring information. This result could suggest that affective recall may have played a role in amplifying concerns about cancer in the news source and personal stories vignette groups. Although our experiment did not measure affect, a more detailed study linking information characteristics to heuristic or systematic ways of information processing could offer insights into the role that information plays in shaping affective responses such as cancer dread. This result was also consistent with previous work that has found that narrative information and affective cues in news information may produce concerns even after people's initial reactions subside (Tompkins, Bjälkebring, and Peters 2018). Therefore, these findings suggest that personal stories could be leveraged as a way to elicit concerns about cancer that are modifiable based on personal risks. The implications of this finding on health behaviour change and cancer prevention warrant closer attention going forward.

The results from our stratified analyses suggest that the effects of the vignette treatments on trust varied among some sub-populations in our study. For example, we observed an association between higher education and lower odds of trust in information when viewing the

news source vignettes that was consistent with findings from other researchers (Smith 2011).

However, we did not observe any significant effect heterogeneity among sub-groups and concern after viewing the vignettes that have been found in other studies. Unlike some previous research, we did not find females, lower income individuals nor participants citing concerns over environmental pollution to be at a higher odds of reporting concern about cancer among any of the vignette treatment groups. However, it should be noted that due to the large proportion of students in our sample, it is difficult to evaluate the effects of income on the outcome variables given some students reporting low individual incomes may have belonged to higher household and/or family income categories.

Still, our stratified analyses revealed that the influence of the vignette treatments on cancer concern after the hypothetical scenario and reassuring information varied between some sub-groups. For example, the odds of concern were higher after viewing the news source vignettes among participants who reported feeling satisfied with their health and being health conscious. This may be because participants who felt satisfied with their health felt more threatened by the prospect of a negative health consequence like cancer and personal perceptions of risk became amplified after reading or recalling the information from the news source. On the other hand, individuals who reported not being satisfied with their health appeared to have a higher likelihood of reporting cancer concern after viewing the hypothetical scenario and reassuring information if they had previously viewed the personal stories vignettes. It's possible that participants experiencing ill-health experienced more affective responses to the personal stories about cancer because they were able to relate to the narratives. These observations warrant further study into the psychology of health and well-being and how feelings of health or ill-health could impact perceptions of personal risk of disease.

The findings of this work have demonstrated the importance of considering information source and format as key variables when studying the influence of cancer information on perceived trust and concern. The random assignment of participants to the experimental treatments was a major strength of this work and provided high internal validity for this study. Nonetheless, this study has important limitations to consider. First, our study relied on the recruitment of participants that mostly took place on a university campus in Canada, which led to an oversampling of university-educated younger-aged participants impacting external validity. A gender bias was also observed in our sample, which may simply reflect a difference in the willingness of female-identifying participants to volunteer for research about health risks particularly during a global pandemic. It is also worth noting that the stories presented to participants about a fictional community may not have elicited the same levels of concern that an actual cancer cluster in someone's community would, which may further impact this work's external validity.

Second, despite our exploratory stratified analyses identifying effect heterogeneity between some sub-groups, our study did not carry out interaction tests to confirm the presence of effect modifiers. Our stratified analyses were limited by small numbers. Therefore, due to issues related to inadequate power and multiple comparisons, results from these analyses serve as more of a starting point for generating hypotheses and exploring these potential interactions in future research. Still, our use of stratified analyses to explore how the odds of trust and concern may vary by sub-groups improves this study's external validity.

Third, our outcome variables trust and concern were assessed using single-item scales, which may have reduced the reliability and validity of these measures. Future work measuring these outcomes should consider the use of multiple-item scales to consistently and accurately

measure perceptions of trust and concern. Further, given that we did not ask participants about trusted sources of cancer information before the experiment, we can't say definitively whether participants' trust in the information that we measured was based more on prior judgments of trustworthy sources or the informational vignettes viewed. However, it has been suggested that people tend to base perceptions of trust on both initial judgments and update their perceptions over time after receiving new information (Chang et al. 2010).

4.6 CONCLUSION

In conclusion, our study provides insights into the complex relationship between information, trust and concerns about cancer. Building off the theory of the social amplification of risk (Kasperson et al. 1988), we have shown that trust in information source and/or format appear to be important in shaping the way that risks around cancer are amplified and perceived. While participants in our study considered government sources and contextual information as trustworthy when considering a societal-level risk, viewing these types of information also coincided with a higher frequency of feeling concerned about cancer. Information from news sources and personal stories were considered to be less trustworthy, yet they were associated with a much higher frequency of feeling concerned about personal cancer risks. Our findings also suggest that the news media and narrative message formats may play an important role in increasing the affective recall of cancer risk information and may amplify perceptions of personal cancer risk, which could encourage more health protective changes to behaviour.

4.7 REFERENCES

- Aragon, Tomas J., Michael P. Fay, Daniel Wollschlaeger, and Adam Omidpanah. 2020. *Epitools: Epidemiology Tools* (version 0.5-10.1). <https://CRAN.R-project.org/package=epitools>.
- Bearth, Angela, and Michael Siegrist. 2021. “The Social Amplification of Risk Framework: A Normative Perspective on Trust?” *Risk Analysis*. <https://doi.org/10.1111/risa.13757>.
- Befort, Christie A., Niaman Nazir, Kimberly Engelman, and Won Choi. 2013. “Fatalistic Cancer Beliefs and Information Sources Among Rural and Urban Adults in the USA.” *Journal of Cancer Education* 28 (3): 521–26. <https://doi.org/10.1007/s13187-013-0496-7>.
- Binder, Andrew R, Michael A Cacciatore, Dietram A Scheufele, and Dominique Brossard. 2014. “The Role of News Media in the Social Amplification of Risk.” *The SAGE Handbook of Risk Communication* 69.
- Böhm, Gisela, and Carmen Tanner. 2018. “Environmental Risk Perception.” In *Environmental Psychology*, 13–25. John Wiley & Sons, Ltd. <https://doi.org/10.1002/9781119241072.ch2>.
- Brown-Johnson, Cati G., Lindsay M. Boeckman, Ashley H. White, Andrea D. Burbank, Sjonna Paulson, and Laura A. Beebe. 2018. “Trust in Health Information Sources: Survey Analysis of Variation by Sociodemographic and Tobacco Use Status in Oklahoma.” *JMIR Public Health and Surveillance* 4 (1): e6260. <https://doi.org/10.2196/publichealth.6260>.
- Chang, Luke J., Bradley B. Doll, Mascha van ’t Wout, Michael J. Frank, and Alan G. Sanfey. 2010. “Seeing Is Believing: Trustworthiness as a Dynamic Belief.” *Cognitive Psychology* 61 (2): 87–105. <https://doi.org/10.1016/j.cogpsych.2010.03.001>.
- Christensen, Robin, Martijn J. L. Bours, and Sabrina M. Nielsen. 2021. “Effect Modifiers and Statistical Tests for Interaction in Randomized Trials.” *Journal of Clinical Epidemiology* 134 (June): 174–77. <https://doi.org/10.1016/j.jclinepi.2021.03.009>.
- Dahlstrom, Michael F., Anthony Dudo, and Dominique Brossard. 2012. “Precision of Information, Sensational Information, and Self-Efficacy Information as Message-Level Variables Affecting Risk Perceptions.” *Risk Analysis: An Official Publication of the Society for Risk Analysis* 32 (1): 155–66. <https://doi.org/10.1111/j.1539-6924.2011.01641.x>.
- Evans, Abigail T., Ellen Peters, Andrew A. Strasser, Lydia F. Emery, Kaitlin M. Sheerin, and Daniel Romer. 2015. “Graphic Warning Labels Elicit Affective and Thoughtful Responses from Smokers: Results of a Randomized Clinical Trial.” *PLOS ONE* 10 (12): e0142879. <https://doi.org/10.1371/journal.pone.0142879>.
- Gage-Bouchard, Elizabeth A., Susan LaValley, Molli Warunek, Lynda Kwon Beupin, and Michelle Mollica. 2018. “Is Cancer Information Exchanged on Social Media Scientifically Accurate?” *Journal of Cancer Education* 33 (6): 1328–32. <https://doi.org/10.1007/s13187-017-1254-z>.
- Gilljam, Mikael, and Donald Granberg. 1993. “Should We Take Don’t Know for an Answer?” *The Public Opinion Quarterly* 57 (3): 348–57.

Hesse-Biber, Sharlene, Bailey Flynn, and Keeva Farrelly. 2018. “The Pink Underside: The Commercialization of Medical Risk Assessment and Decision-Making Tools for Hereditary Breast Cancer Risk.” *Qualitative Health Research* 28 (10): 1523–38. <https://doi.org/10.1177/1049732318767395>.

Jacobson, Ginger, and Alison E. Adams. 2017. “Understanding Environmental Risk Perceptions: A Case of Contested Illness in South Florida.” *Sociological Inquiry* 87 (4): 659–84. <https://doi.org/10.1111/soin.12175>.

Jagiello, Robert D., and Thomas T. Hills. 2018. “Bad News Has Wings: Dread Risk Mediates Social Amplification in Risk Communication.” *Risk Analysis* 38 (10): 2193–2207. <https://doi.org/10.1111/risa.13117>.

Jensen, Jakob D. 2008. “Scientific Uncertainty in News Coverage of Cancer Research: Effects of Hedging on Scientists and Journalists Credibility.” *Human Communication Research* 34 (3): 347–69. <https://doi.org/10.1111/j.1468-2958.2008.00324.x>.

Johnson, Branden B. 2005. “Testing and Expanding a Model of Cognitive Processing of Risk Information.” *Risk Analysis* 25 (3): 631–50. <https://doi.org/10.1111/j.1539-6924.2005.00609.x>.

Kasperson, Roger E., Ortwin Renn, Paul Slovic, Halina S. Brown, Jacque Emel, Robert Goble, Jeanne X. Kasperson, and Samuel Ratick. 1988. “The Social Amplification of Risk: A Conceptual Framework.” *Risk Analysis* 8 (2): 177–87. <https://doi.org/10.1111/j.1539-6924.1988.tb01168.x>.

Kreuter, Matthew W., Kathleen Holmes, Kassandra Alcaraz, Bindu Kalesan, Suchitra Rath, Melissa Richert, Amy McQueen, Nikki Caito, Lou Robinson, and Eddie M. Clark. 2010. “Comparing Narrative and Informational Videos to Increase Mammography in Low-Income African American Women.” *Patient Education and Counseling* 81S (December): S6–14. <https://doi.org/10.1016/j.pec.2010.09.008>.

Kuhn, Kristine M. 2000. “Message Format and Audience Values: Interactive Effects of Uncertainty Information and Environmental Attitudes on Perceived Risk.” *Journal of Environmental Psychology* 20 (1): 41–51. <https://doi.org/10.1006/jevpe.1999.0145>.

Kwon, Jeong Hyun, Su-Yeon Kye, Eun Young Park, Kyung Hee Oh, and Keeho Park. 2015. “What Predicts the Trust of Online Health Information?” *Epidemiology and Health* 37 (June): e2015030. <https://doi.org/10.4178/epih/e2015030>.

Lawson, Raef. 2004. “Small Sample Confidence Intervals for the Odds Ratio.” *Communications in Statistics - Simulation and Computation* 33 (4): 1095–1113. <https://doi.org/10.1081/SAC-200040691>.

Lee, Jennifer E. C., Louise Lemyre, Pierre Mercier, Louise Bouchard, and Daniel Krewski. 2005. “Beyond the Hazard: The Role of Beliefs in Health Risk Perception.” *Human and Ecological Risk Assessment: An International Journal* 11 (6): 1111–26. <https://doi.org/10.1080/10807030500278636>.

- Lipkus, Isaac M., William M. P. Klein, Celette Sugg Skinner, and Barbara K. Rimer. 2005. “Breast Cancer Risk Perceptions and Breast Cancer Worry: What Predicts What?” *Journal of Risk Research* 8 (5): 439–52. <https://doi.org/10.1080/1366987042000311018>.
- Longman, Thea, Robin M. Turner, Madeleine King, and Kirsten J. McCaffery. 2012. “The Effects of Communicating Uncertainty in Quantitative Health Risk Estimates.” *Patient Education and Counseling* 89 (2): 252–59. <https://doi.org/10.1016/j.pec.2012.07.010>.
- Masiero, Marianna, Silvia Riva, Serena Oliveri, Chiara Fioretti, and Gabriella Pravettoni. 2018. “Optimistic Bias in Young Adults for Cancer, Cardiovascular and Respiratory Diseases: A Pilot Study on Smokers and Drinkers.” *Journal of Health Psychology* 23 (5): 645–56. <https://doi.org/10.1177/1359105316667796>.
- Mayer, Deborah K., Norma C. Terrin, Gary L. Kreps, Usha Menon, Kathy McCance, Susan K. Parsons, and Kathleen H. Mooney. 2007. “Cancer Survivors Information Seeking Behaviors: A Comparison of Survivors Who Do and Do Not Seek Information about Cancer.” *Patient Education and Counseling* 65 (3): 342–50. <https://doi.org/10.1016/j.pec.2006.08.015>.
- McQueen, Amy, Matthew W. Kreuter, Bindu Kalesan, and Kassandra I. Alcaraz. 2011. “Understanding Narrative Effects: The Impact of Breast Cancer Survivor Stories on Message Processing, Attitudes, and Beliefs among African American Women.” *Health Psychology* 30 (6): 674–82. <https://doi.org/10.1037/a0025395>.
- McQueen, Amy, Sally W. Vernon, Helen I. Meissner, and William Rakowski. 2008. “Risk Perceptions and Worry About Cancer: Does Gender Make a Difference?” *Journal of Health Communication* 13 (1): 56–79. <https://doi.org/10.1080/10810730701807076>.
- Moorhead, Laura, Melinda Krakow, and Lauren Maggio. 2021. “What Cancer Research Makes the News? A Quantitative Analysis of Online News Stories That Mention Cancer Studies.” *PLOS ONE* 16 (3): e0247553. <https://doi.org/10.1371/journal.pone.0247553>.
- Paek, Hye-Jin, Sang-Hwa Oh, and Thomas Hove. 2016. “How Fear-Arousing News Messages Affect Risk Perceptions and Intention to Talk About Risk.” *Health Communication* 31 (9): 1051–62. <https://doi.org/10.1080/10410236.2015.1037419>.
- Park, Eunkyung, Clifford W. Scherer, and Carroll J. Glynn. 2001. “Community Involvement and Risk Perception at Personal and Societal Levels.” *Health, Risk & Society* 3 (3): 281–92. <https://doi.org/10.1080/13698570120079886>.
- Peters, Ellen, Kevin D. McCaul, Michael Stefanek, and Wendy Nelson. 2006. “A Heuristics Approach to Understanding Cancer Risk Perception: Contributions from Judgment and Decision-Making Research.” *Annals of Behavioral Medicine* 31 (1): 45–52. https://doi.org/10.1207/s15324796abm3101_8.
- Peters, Ellen, and Louise Meilleur. 2016. “The Influence of Affect on Health Decisions.” In *Handbook of Health Decision Science*, edited by Michael A. Diefenbach, Suzanne Miller-Halegoua, and Deborah J. Bowen, 109–20. New York, NY: Springer New York. https://doi.org/10.1007/978-1-4939-3486-7_8.

Robb, Kathryn A., Alice E. Simon, Anne Miles, and Jane Wardle. 2014. “Public Perceptions of Cancer: A Qualitative Study of the Balance of Positive and Negative Beliefs.” *BMJ Open* 4 (7): e005434. <https://doi.org/10.1136/bmjopen-2014-005434>.

Shaffer, Victoria A., Sara Tomek, and Lukas Hulsey. 2014. “The Effect of Narrative Information in a Publicly Available Patient Decision Aid for Early-Stage Breast Cancer.” *Health Communication* 29 (1): 64–73. <https://doi.org/10.1080/10410236.2012.717341>.

Shea–Budgell, M. A., X. Kostaras, K. P. Myhill, and N. A. Hagen. 2014. “Information Needs and Sources of Information for Patients during Cancer Follow-Up.” *Current Oncology* 21 (4): 165–73. <https://doi.org/10.3747/co.21.1932>.

Slovic, Paul. 1987. “Perception of Risk.” *Science* 236 (4799): 280–85. <https://doi.org/10.1126/science.3563507>.

Smith, Diane. 2011. “Health Care Consumer’s Use and Trust of Health Information Sources.” *Journal of Communication in Healthcare* 4 (3): 200–210. <https://doi.org/10.1179/1753807611Y.0000000010>.

Somera, Lilnabeth P., Hye-Ryeon Lee, Grazyna Badowski, and Kevin Cassel. 2016. “Health Information Seeking, Source Trust, and Culture: A Comparative Analysis of Health Information Trends and Needs Between Guam and the United States.” *Journal of Health Communication* 21 (4): 469–78. <https://doi.org/10.1080/10810730.2015.1095822>.

Spiegelhalter, David J. 2019. “Trust in Numbers.” In *Risk and Uncertainty in a Post-Truth Society*, edited by Ragnar. E. Löfstedt and Sander van der Linden, 4–25. New York, NY: Routledge.

Statistics Canada. 2021. “Low Income Measure (LIM) Thresholds by Income Source and Household Size.” March 23, 2021. <https://www150.statcan.gc.ca/t1/tb11/en/cv.action?pid=1110023201>.

Stryker, Jo Ellen, Cortney M. Moriarty, and Jakob D. Jensen. 2008. “Effects of Newspaper Coverage on Public Knowledge about Modifiable Cancer Risks.” *Health Communication* 23 (4): 380–90. <https://doi.org/10.1080/10410230802229894>.

Sturgis, Patrick, Caroline Roberts, and Patten Smith. 2014. “Middle Alternatives Revisited: How the Neither/nor Response Acts as a Way of Saying ‘I Don’t Know?’” *Sociological Methods & Research* 43 (1): 15–38. <https://doi.org/10.1177/0049124112452527>.

Sung, Hyuna, Jacques Ferlay, Rebecca L. Siegel, Mathieu Laversanne, Isabelle Soerjomataram, Ahmedin Jemal, and Freddie Bray. 2021. “Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries.” *CA: A Cancer Journal for Clinicians* 71 (3): 209–49. <https://doi.org/10.3322/caac.21660>.

Takebayashi, Yoshitake, Yuliya Lyamzina, Yuriko Suzuki, and Michio Murakami. 2017. “Risk Perception and Anxiety Regarding Radiation after the 2011 Fukushima Nuclear Power Plant

Accident: A Systematic Qualitative Review.” *International Journal of Environmental Research and Public Health* 14 (11): 1306. <https://doi.org/10.3390/ijerph14111306>.

Tompkins, Mary Kate, Pär Bjälkebring, and Ellen Peters. 2018. “Emotional Aspects of Risk Perceptions.” In *Psychological Perspectives on Risk and Risk Analysis*, edited by Martina Raue, Eva Lermer, and Bernhard Streicher, 109–30. Cham: Springer International Publishing. https://doi.org/10.1007/978-3-319-92478-6_5.

Trivedi, Neha, Melinda Krakow, Katherine Hyatt Hawkins, Emily B. Peterson, and Wen-Ying Sylvia Chou. 2020. “‘Well, the Message Is From the Institute of Something’: Exploring Source Trust of Cancer-Related Messages on Simulated Facebook Posts.” *Frontiers in Communication* 5: 12. <https://doi.org/10.3389/fcomm.2020.00012>.

Trumbo, Craig W., and Katherine A. McComas. 2003. “The Function of Credibility in Information Processing for Risk Perception.” *Risk Analysis* 23 (2): 343–53. <https://doi.org/10.1111/1539-6924.00313>.

Trumbo, Craig W., Katherine A. McComas, and Prathana Kannaovakun. 2007. “Cancer Anxiety and the Perception of Risk in Alarmed Communities.” *Risk Analysis* 27 (2): 337–50. <https://doi.org/10.1111/j.1539-6924.2007.00886.x>.

VanderWeele, Tyler J., and Mirjam J. Knol. 2011. “Interpretation of Subgroup Analyses in Randomized Trials: Heterogeneity Versus Secondary Interventions.” *Annals of Internal Medicine* 154 (10): 680. <https://doi.org/10.7326/0003-4819-154-10-201105170-00008>.

Viechtbauer, Wolfgang. 2010. “Conducting Meta-Analyses in R with the Metafor Package.” *Journal of Statistical Software* 36 (August): 1–48. <https://doi.org/10.18637/jss.v036.i03>.

Wahlberg, Anders A F, and Lennart Sjoberg. 2000. “Risk Perception and the Media.” *Journal of Risk Research* 3 (1): 31–50. <https://doi.org/10.1080/136698700376699>.

Weaver, Scott R., Amelia Jazwa, Lucy Popova, Paul Slovic, Richard B. Rothenberg, and Michael P. Eriksen. 2017. “Worldviews and Trust of Sources for Health Information on Electronic Nicotine Delivery Systems: Effects on Risk Perceptions and Use.” *SSM - Population Health* 3 (December): 787–94. <https://doi.org/10.1016/j.ssmph.2017.09.003>.

Winterbottom, Anna, Hilary L. Bekker, Mark Conner, and Andrew Mooney. 2008. “Does Narrative Information Bias Individual’s Decision Making? A Systematic Review.” *Social Science & Medicine* 67 (12): 2079–88. <https://doi.org/10.1016/j.socscimed.2008.09.037>.

CHAPTER 5

Impacts of numeracy, health literacy and health information-seeking on cancer risk management beliefs: A cross-sectional study

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5.1 INTRODUCTION

Many cancers have been linked to potentially modifiable risk factors representing opportunities to reduce cancer morbidity and mortality through changes of behavior. Nearly half of cancer deaths in the United States were recently attributed to modifiable risk factors such as smoking, excess body weight and the consumption of alcohol (Islami et al., 2018). Thus, understanding how and why healthy decisions are made and whether they can be motivated by educational interventions has become a key goal of health promotion.

Numerous theories have been developed and applied to understand how information may influence taking health protective actions. Among these theories, protection motivation theory is thought to be particularly useful for predicting cancer-preventive behaviors such as the uptake of cancer screening (Seyde et al., 1990). The theory originally stemmed from research around fear appeals – communications using fear-based messaging to stimulate individuals' concerns about the negative consequences of their behaviors – and how they could stimulate health protective actions by generating a desire to avoid negative consequences (Milne et al., 2000). As cancer is a highly feared and dreaded disease (Lee et al., 2005), fear is thought to be an important motivator influencing the adoption of behaviors related to cancer. Protection motivation theory describes two cognitive processes that individuals carry out to reduce or eliminate negative health

consequences and protect themselves. The first process, threat appraisal, occurs when assessing the severity of a threat like cancer and one's vulnerability to its consequences.

The second process, coping appraisal, includes an assessment of one's own capabilities to cope with the threat by taking some recommended action like scheduling a colonoscopy (i.e. self-efficacy belief) as well as an assessment of whether the recommended action taken would be effective at reducing the threat (i.e. response efficacy belief) (Prentice-Dunn & Rogers, 1986). The two coping appraisals differ primarily on the basis of perceptions of control over the threat. Self-efficacy beliefs are subject to individual attitudes about internal (self) regulation and control in managing risks (e.g. I can quit smoking to avoid developing lung cancer) (Bandura, 1982). In comparison, response efficacy beliefs depend more on individual attitudes around external control such as policy or institutional effectiveness (e.g. this smoking cessation program can help me avoid developing lung cancer) (Rogers, 1983). Understanding these differences is important as they may require different cognitive interventions and/or message framing to motivate actions (Keller, 2006).

The threat appraisal process is often the target of cancer education campaigns that aim to inform the public about the risk of cancer. However, measures of coping appraisal like self-efficacy appear to serve as better predictors of adopting cancer-preventive behavior changes (Bashirian et al., 2019; Wong, 2009). This could be because when people believe they have some level of control over their cancer risk, they apply that confidence to carry out actions to cope with the risk. Indeed, when people believe that cancer poses a large threat and there isn't much they can do to manage the risk, they seem to take less action (Kobayashi & Smith, 2016). However, the mechanisms behind developing self-efficacy and response efficacy beliefs that

precede action are not well understood, which makes it difficult to design interventions that target coping appraisals to increase the uptake of cancer-preventive behaviors.

Prior research has identified individual knowledge, information seeking behaviors and some sociodemographic characteristics as key factors impacting efficacy beliefs. For example, individual competencies such as high numeracy skills have been associated with higher self-efficacy beliefs related to managing health (Chen & Feeley, 2014; Osborn et al., 2010). This may be due to highly numerate individuals possessing the skills to understand and interpret numeric health risk information, resulting in self-confidence to apply statistical information to assess one's own personal risk circumstances. In addition, low levels of health literacy have been linked to decreased self-efficacy, particularly with respect to participating in cancer screening (von Wagner et al., 2009). This is likely because having limited health literacy is indicative of having less awareness about cancer and therefore less knowledge of cancer prevention services (Waters et al., 2018). Associations have also been found between health literacy scores and self-efficacy for diabetes care (Ishikawa et al., 2008).

When it comes to response efficacy beliefs, lower cognitive abilities have been found to influence perceptions of expert competence and views of science (Dieckmann et al., 2017), which are known to impact risk management responses such as people's perceived effectiveness of proposed solutions. For example, perceptions of expert competence appear to decline in the presence of uncertain information, which is often presented using numerical range estimates that require numeric skills to interpret (Dieckmann et al., 2015; Johnson & Slovic, 1995). Therefore, it may be that higher numeracy results in a greater ability to interpret statistical findings, recognize gaps in scientific research and acknowledge the limits of expert knowledge. Whether or not high levels of health literacy can also shape perceptions of expert efficacy has not been

studied. Still, the relationship between literacy and numeracy appears to be complex. Although one might expect these variables to be somewhat correlated and produce similar outcomes, there is evidence to suggest that they may interact and influence judgments and health behaviors differently (Nouri et al., 2019; Portnoy et al., 2010).

Health information seeking (i.e. the volume of health information accessed or the time spent interacting with health information) has also been found to be an important factor predicting self-efficacy due to its mediating relationship with health literacy. Information seeking can impact people's knowledge of cancer risk factors in a way that shapes their perceptions of personal susceptibility to cancer (von Wagner et al., 2009). Different sources of health information also appear to influence people's beliefs towards response efficacy. For example, Nisbet et al. (2002) found that the consumption of news media was associated with the acquisition of scientific knowledge and developing positive perceptions of science and scientific institutions. Access to information from expert and authoritative sources is also seen as an important factor influencing perceptions of how disease risks are managed (Garforth et al., 2013). In fact, access to experts who are perceived as competent and/or trusted has been linked to the uptake of some healthier behavior changes such as exercise and diet (Bleich et al., 2007; Hellem et al., 2012).

Cancer risk perceptions are also important to consider in the context of cancer efficacy due to the ways that people's anxieties over cancer and their perceived risk of a diagnosis can shape the extent to whether they feel in control of their risk of cancer. For example, cancer worry can empower people to seek out medical help and available screening programs to cope with uncertainty (Whitaker et al., 2016). Conversely, very high perceptions of individual cancer risk can fuel fatalistic attitudes leading to less uptake of cancer preventive actions (Werk et al., 2017).

Gender also appears to be a key predictor of efficacy beliefs, with men generally reporting higher self-efficacy and women reporting higher response efficacy (Gecas, 1989; Seyde et al., 1990).

This may be explained by gender differences in perceived disease fatalism as well as differences in internal and external control beliefs that can facilitate or hinder self-confidence and confidence in others to manage disease risks (Finucane et al., 2000; Welch & Ellis, 2018). Self-efficacy has also been found to increase with increasing educational status due to the higher levels of knowledge and health literacy present among higher educated individuals (Tiraki & Yilmaz, 2018). Still, very little research has taken a broader approach to investigate the role these various factors play in shaping efficacy beliefs and whether they impact self-efficacy and response efficacy differently.

The first goal of this study was to investigate associations between participant skills/expertise, health information seeking, health risk perceptions and three beliefs related to cancer risk management: self-efficacy, expert efficacy and science efficacy. Second, we sought to build on the literature exploring interactions between numeracy and literacy by examining whether numeracy could moderate associations between health literacy and the efficacy beliefs, while adjusting for sociodemographic factors. We focused on numeracy and health literacy as two modifiable factors that could be the target of future educational interventions informed by this research. We hypothesized that skills/expertise, information seeking, and health risk perceptions would influence the likelihood of reporting each efficacy outcome and that numeracy would moderate the relationship between health literacy and each efficacy belief.

5.2 METHODS

5.2.1 Data source

The data analyzed in this study were collected using Google Forms in an anonymous survey that was administered separately to participants who had been recruited to participate in an online randomized experiment. The experiment tested responses to different sources of cancer information. Between Fall 2019 and Fall 2020, 172 Canadian adults were recruited using advertisements posted on message boards at a Canadian university campus and in public community settings in the Greater Toronto and Hamilton areas in Ontario, Canada, as well as online on social media. Additionally, as this study sought to compare responses from participants with both higher and lower health literacy, targeted recruitment of participants likely to have high health expertise was carried out using study advertisements shared with attendees of a Canadian public health conference in the Fall of 2019 as well as using a listserv for public health professionals in Canada. Lastly, the study authors recruited students from an undergraduate course they were teaching in exchange for a 1% bonus participation mark. All recruited participants were eligible to win 1 of 4 gift cards (valued at \$50CAD) if they opted into a prize draw. Ethics approval was obtained from McMaster University's Research Ethics Board (MREB# 1763).

5.2.2 Participants

The majority of this study's participants identified as female ($n = 134$), with smaller subsets identifying as male ($n = 37$) and non-binary ($n = 1$). Most participants were students currently enrolled at an academic institution ($n = 102$); therefore, our sample consisted of mostly younger-aged adults with lower incomes. Slightly over half were aged 18-24 ($n = 89$), 37% were aged 25-

49 ($n = 64$), 10% were aged 50 and over ($n = 18$) and 1 participant did not report their age. About half of participants reported (CAD) an individual income below \$40,000 ($n = 87$), about a quarter had an income between \$40,000 to \$80,000 ($n = 44$), 24 participants reported an income above \$80,000 and 17 participants did not report any income. Twelve percent had obtained a high school diploma ($n = 20$), 53% had obtained a college-level diploma/certificate or university Bachelor's degree ($n = 92$) and 35% had obtained a graduate degree or certificate above a Bachelor's level ($n = 60$). Approximately 14% of participants had a graduate degree in a health-related field ($n = 24$).

5.2.3 Measures

5.2.3.1 Skills and health expertise

Three survey questions measured participants' skills and health expertise. First, we assessed participants' objective numeracy (i.e. their ability to understand probabilistic concepts) with the following survey item: "If you flipped a fair coin 4 times and you got heads each time, what is the probability you'll get heads the 5th time you flip the coin?". Correct responses were categorized as having higher numeracy. We measured objective numeracy rather than subjective numeracy (i.e. one's self-reported ability to perform math tasks) as it has been found to be a more accurate measure of numeric competencies (Peters, 2012).

Second, we assessed participants' subjective health literacy (i.e. self-reported ability to read and understand health information) with the following survey item: "After reading a news article about a health issue, how confident do you usually feel that you understood all of the written information in the article?". The question originally appeared as a 5-category response question in the survey; however, it was re-categorized as a binary variable during analysis by grouping "Not at all confident", "A little bit confident", "Somewhat confident" responses

together (coded as 0) to indicate lower health literacy, while grouping “Extremely confident” and “Quite a bit confident” responses (coded as 1) to indicate higher health literacy. Although subjective measures have been considered more optimistic than objective measures, a review by Kiechle et al. (2015) comparing performance-based versus self-reported measures of health literacy reported that most studies found little to no difference between results of the two.

Lastly, participants indicating they had obtained a graduate degree were asked to provide the name and subject of their degree in an open-ended response to assess health expertise. If the subject of their graduate degree was related to public health or health care (e.g. epidemiology, nursing, global health) then they were categorized as having obtained a graduate degree in a health-related field.

5.2.3.2 Health information seeking

We assessed participants’ health information seeking habits using self-reported responses about the amount of health information they obtained from four sources: news media, government, friends and relatives, and researchers and scientists. The following survey item was used: “Rate the amount of information you receive about health issues from each source in an average year. (1=no information and 5=a lot of information)”. We grouped responses numbered 1 to 3 together to indicate less information seeking from each source and grouped 4 to 5 to indicate more information seeking.

5.2.3.3 Health risk perceptions

Health risk perceptions were measured using three survey questions to assess various aspects of risk control. The first question asked: “Do you agree with the following statement: If it concerns my health, I am someone who avoids taking risks.” This survey item measured risk avoidance,

which is a key risk judgment related to people's perception of their ability to control their risk of cancer (Leventhal et al., 1999). The next item measured perception of adequate regulation of health risks to assess their perception of external risk control: "Do you believe that most health risks are adequately regulated by governmental agencies?". Lastly, participants self-reported their concern about cancer with the following survey item: "Are you concerned about your risk of getting cancer?". Responses to all three questions were re-categorized such that "Yes" and "Sometimes" responses (coded as 1) indicated the presence of the risk perception item and "No" and "Not sure" (coded as 0) indicated the absence of the risk perception item.

5.2.3.4 Attitudes about cancer risk management

We measured participants' self-efficacy, which we define here as the belief that someone can do something to reduce their risk of cancer, using the following survey item: "Do you believe that you can take individual actions to control your risk of cancer?". As Bandura (2006) suggested, any self-efficacy scale should be phrased using *can do* language to capture people's perceived capability to personally execute some performance. The question originally appeared as a 4-category response question in the survey and was re-categorized as a binary variable during analysis by coding all "Yes" responses as 1 and grouping all other responses ("No", "Not sure", "Sometimes") together (coded as 0) to indicate an absence of self-efficacy. As it has been found that people tend to overestimate their capabilities in their appraisal of self-efficacy measures (Bandura, 1994), we only considered "Yes" responses to this question to minimize optimistic bias.

We used two variables, expert efficacy and science efficacy, to explore participants' beliefs of response efficacy (i.e. their beliefs related to the effectiveness of current methods to estimate cancer risks). We measured expert efficacy, which we define as the belief that health

experts are capable of managing cancer risks, with the following survey item: “Do you believe that health experts (e.g. medical researchers, health scientists) have all of the facts and knowledge they need to correctly estimate people’s cancer risk?”. We measured science efficacy, which we define as the belief that science and research institutions are capable of managing cancer risks, with the following survey item: “Do you believe that the science on estimating people’s cancer risk is correct most of the time?”. Responses to both questions were re-categorized such that “Yes” and “Sometimes” responses (coded as 1) indicated the presence of the efficacy belief and “No” and “Not sure” (coded as 0) indicated the absence of the efficacy belief.

5.2.3.5 Sociodemographic variables

Measures of gender, age, education (re-categorized as a binary variable during analysis as either having achieved a Bachelor’s degree or lower versus having achieved above a Bachelor’s degree) and income were also obtained.

5.2.4 Analysis

We calculated odds ratios to investigate associations between participant skills/expertise, health information seeking, health risk perceptions and the binary outcome variables self-efficacy, expert efficacy and science efficacy. We used the R package *epitools* to calculate odds ratios by small sample-adjusted method and confidence intervals at the 95% level using a normal approximation (Wald) (Aragon et al., 2020).

We conducted chi-square tests for independence to examine associations between the various sociodemographic variables used in this study. We found that age was not independent of income ($X^2 = 79.83, p < 0.001$) nor education ($X^2 = 78.66, p < 0.001$), therefore it was omitted

from further analyses. Income was also not independent of education ($X^2 = 18.90, p < 0.001$). However, as educational attainment has been found to be an important mediating variable for self-efficacy, numeracy and health literacy (Apter et al., 2006; Curtin et al., 2008; McCleary-Jones, 2011; Tiraki & Yılmaz, 2018) it was retained in our analyses and income was omitted. Additionally, given the focus of this study on skills and learned knowledge, education was retained as variable of interest that could be the target of public health interventions.

To explore interactions between numeracy and health literacy, while adjusting for gender and education, binary logistic regression analyses were conducted for the outcomes self-efficacy, expert efficacy and science efficacy. The log odds were then converted into odds ratios to obtain the odds of the efficacy variables occurring based on the combination of values taken by the independent variables included in the models. In the appendices, we provide summaries of model parameter estimates and regression results. Mathematically, the binary logistic regression model followed:

$$\log(\text{odds}) = \text{logit}(p_i) = \log\left(\frac{p_i}{1-p_i}\right) = \beta_o + \beta_1 x_{i1} + \dots + \beta_n x_{in}$$

where p_i represents the probability of the efficacy outcome for the i -th person, β_o represents the intercept, β_n represents the model coefficients for a given explanatory variable x_{in} for the i -th person. The independent variables used in all three efficacy models were *health literacy (H)*, *numeracy (N)*, as well as their interaction term *health literacy*numeracy (HN)*, *education above a Bachelor's degree (E)* and *female gender (F)*. The model for each of the three models can each be summarized by:

$$\text{logit}(p) = \beta_o + \beta_1 x_H + \beta_2 x_N + \beta_3 x_{HN} + \beta_4 x_E + \beta_5 x_F$$

To visualize interactions between health literacy and numeracy, probabilities of each efficacy outcome were obtained by dividing the odds obtained from each model by one plus the odds. The R package *ggplot2* (Wickham et al., 2021) was used to create graphs summarizing the probabilities of each efficacy outcome by health literacy, moderated by numeracy, gender and education.

5.3 RESULTS

5.3.1 Participant skills and health expertise

The results summarized in Table 5-1 show that just over half of the participants in this study reported self-efficacy and believed they can take actions to individually manage their risk of cancer ($n = 90$, 52.3%). Among participants who had obtained a graduate degree in a health-related field, 70.8% reported self-efficacy ($n = 17$) corresponding to odds of 2.15 that were marginally significant (0.96-5.98; $p = 0.05$) relative to participants without a graduate degree in a health-related field. Odds of reporting self-efficacy appeared higher among participants with higher objective numeracy and health literacy (OR = 1.11; 0.52-2.90 and OR = 1.78; 0.97-3.63, respectively), however only odds for health literacy were marginally significant ($p = 0.06$). Both health literacy and having a graduate degree in a health-related field also appeared to increase the odds of reporting expert efficacy (OR = 1.14; 0.63-2.32 and OR = 1.29; 0.61-3.32, respectively) and increase the odds of reporting science efficacy (OR = 1.44; 0.78-2.99 and OR = 1.80; 0.75-5.58, respectively). Participants with higher objective numeracy appeared less likely to report expert efficacy (OR = 0.58; 0.27-1.52) and science efficacy (OR = 0.45; 0.19-1.43).

Table 5-1. Associations between participant expertise and skills and cancer risk management beliefs, $n = 172$.

Skills	Self efficacy <i>n</i> (%)		OR (95% CI)	Expert efficacy <i>n</i> (%)		OR (95% CI)	Science efficacy <i>n</i> (%)		OR (95% CI)
	Yes	No		Yes	No		Yes	No	
Graduate degree in health-related field									
Yes	17 (70.8%)	7 (29.2%)	2.15[†] (0.96-5.98)	13 (54.2%)	11 (45.8%)	1.29 (0.61-3.32)	19 (79.2%)	5 (20.8%)	1.80 (0.75-5.58)
No	73 (49.3%)	75 (50.7%)	1.00	67 (45.3%)	81 (54.7%)	1.00	94 (63.5%)	54 (36.5%)	1.00
Objective numeracy									
Higher	79 (53.0%)	70 (47.0%)	1.11 (0.52-2.90)	67 (45.0%)	82 (55.0%)	0.58 (0.27-1.52)	95 (63.8%)	54 (36.2%)	0.45 (0.19-1.43)
Lower	11 (47.8%)	12 (52.8%)	1.00	13 (56.5%)	10 (43.5%)	1.00	18 (78.3%)	5 (21.7%)	1.00
Health literacy									
Higher	69 (57.0%)	52 (43.0%)	1.78[†] (0.97-3.63)	58 (47.9%)	63 (52.1%)	1.14 (0.63-2.32)	83 (68.6%)	38 (31.4%)	1.44 (0.78-2.99)
Lower	21 (41.2%)	30 (58.8%)	1.00	22 (43.1%)	29 (56.9%)	1.00	30 (58.8%)	21 (41.2%)	1.00

Note: CI = confidence interval; OR = odds ratio; [†] denotes marginally significant p -value between 0.05-0.09.

5.3.2 Health information-seeking

Of the four information sources we studied, the odds of reporting self-efficacy were highest among participants who reported receiving a lot of health information from government sources (OR = 1.22; 0.61-2.85) (Table 5-2).

Table 5-2. Associations between participant health information-seeking habits and cancer risk management beliefs, n = 172.

Amount of health information from each source	Self efficacy n (%)		OR (95% CI)	Expert efficacy n (%)		OR (95% CI)	Science efficacy n (%)		OR (95% CI)
	Yes	No		Yes	No		Yes	No	
News									
More	46 (51.1%)	44 (48.9%)	0.86 (0.50- 1.64)	49 (54.4%)	41 (45.6%)	1.86* (1.06- 3.57)	57 (63.3%)	33 (36.7%)	0.76 (0.43- 1.51)
Less	44 (53.7%)	38 (46.3%)	1.00	31 (37.8%)	51 (62.2%)	1.00	56 (68.3%)	26 (31.7%)	1.00
Government									
More	18 (58.1%)	13 (41.9%)	1.22 (0.61- 2.85)	18 (58.1%)	13 (41.9%)	1.16 (0.80- 3.79)	24 (77.4%)	7 (22.6%)	1.73 (0.79- 4.65)
Less	72 (51.1%)	69 (48.9%)	1.00	62 (44.0%)	79 (56.0%)	1.00	89 (63.1%)	52 (36.9%)	1.00
Friends and relatives									
More	25 (43.1%)	33 (56.9%)	0.55‡ (0.31- 1.08)	27 (46.6%)	31 (53.4%)	0.95 (0.53- 1.88)	39 (67.2%)	19 (32.8%)	1.04 (0.57- 2.14)
Less	65 (57.0%)	49 (43.0%)	1.00	53 (46.5%)	61 (53.5%)	1.00	74 (64.9%)	40 (35.1%)	1.00
Researchers and scientists									
More	43 (53.1%)	38 (46.9%)	1.01 (0.58- 1.92)	40 (49.4%)	41 (50.6%)	1.18 (0.68- 2.26)	58 (71.6%)	23 (28.4%)	1.55 (0.87- 3.09)
Less	47 (51.6%)	44 (48.4%)	1.00	40 (44.0%)	51 (56.0%)	1.00	55 (60.4%)	36 (39.6%)	1.00

Note: CI = confidence interval; OR = odds ratio; * denotes significant *p*-value < .05; ‡ denotes marginally significant *p*-value between 0.05-0.09.

The odds of reporting self-efficacy were lower among those who reported receiving a lot of health information from friends and relatives (OR = 0.55; 0.31-1.08; $p = 0.08$). A significant increase in the odds of reporting the expert efficacy belief was observed among news health information-seekers (OR = 1.86; 1.06-3.57; $p < .05$). For the science efficacy belief, those receiving a lot of health information from governments sources and researchers and scientists appeared to have higher odds of reporting this belief (OR = 1.73; 0.79-4.65 and OR = 1.55; 0.87-3.09, respectively).

5.3.3 Health risk perceptions

Among the health risk perception variables studied, belief that there was adequate regulation of health risks was associated with an increase in the odds of reporting the expert efficacy belief (OR = 3.11; 1.76-6.10; $p < .001$) (Table 5-3). Participants who reported being concerned about cancer appeared to have a decreased odds of reporting the expert efficacy belief (OR = 0.50; 0.26-1.08; $p = 0.08$). Participants who reported generally avoiding taking risks with their health appeared to have increased odds of reporting all three efficacy beliefs.

Table 5-3. Associations between participant health risk perceptions and cancer risk management beliefs, $n = 172$.

Health risk perceptions	Self efficacy <i>n</i> (%)		OR (95% CI)	Expert efficacy <i>n</i> (%)		OR (95% CI)	Science efficacy <i>n</i> (%)		OR (95% CI)
	Yes	No		Yes	No		Yes	No	
Avoids risks to health									
Yes	67 (54.9%)	55 (45.1%)	1.35 (0.74- 2.74)	59 (48.4%)	63 (51.6%)	1.22 (0.67- 2.48)	84 (68.9%)	38 (31.1%)	1.51 (0.82- 3.14)
No	23 (46.0%)	27 (54.0%)	1.00	21 (42.0%)	29 (58.0%)	1.00	29 (58.0%)	21 (42.0%)	1.00
Adequate regulation of health risks									
Yes	44 (51.8%)	41 (48.2%)	0.91 (0.53- 1.74)	52 (61.2%)	33 (38.8%)	3.11*** (1.76- 6.10)	61 (71.8%)	24 (28.2%)	1.61 (0.90- 3.20)
No	46 (52.9%)	41 (47.1%)	1.00	28 (32.2%)	59 (67.8%)	1.00	52 (59.8%)	35 (40.2%)	1.00
Concerned about cancer									
Yes	68 (51.9%)	63 (48.1%)	0.88 (0.47- 1.88)	56 (42.7%)	75 (57.3%)	0.50† (0.26- 1.08)	84 (64.1%)	47 (35.9%)	0.70 (0.36- 1.60)
No	22 (53.7%)	19 (46.3%)	1.00	24 (58.5%)	17 (41.5%)	1.00	29 (70.7%)	12 (29.3%)	1.00

Note: CI = confidence interval; OR = odds ratio; *** denotes significant p -value < .001; † denotes marginally significant p -value between 0.05-0.09.

5.3.4 Regression analysis

Figures 5-1 to 5-3 show the results of the logistic regression analyses used to investigate whether numeracy would moderate associations between health literacy on the three efficacy beliefs, while adjusting for gender and education. We did not observe any significant individual effects

between numeracy, health literacy, gender, education and the odds of reporting self-efficacy (Appendix 7-3), suggesting that these variables did not independently predict variation in cancer risk management belief. Still, numeracy was found to have a possible mediating effect between health literacy and self-efficacy in the sub-groups we explored (Figure 5-1).

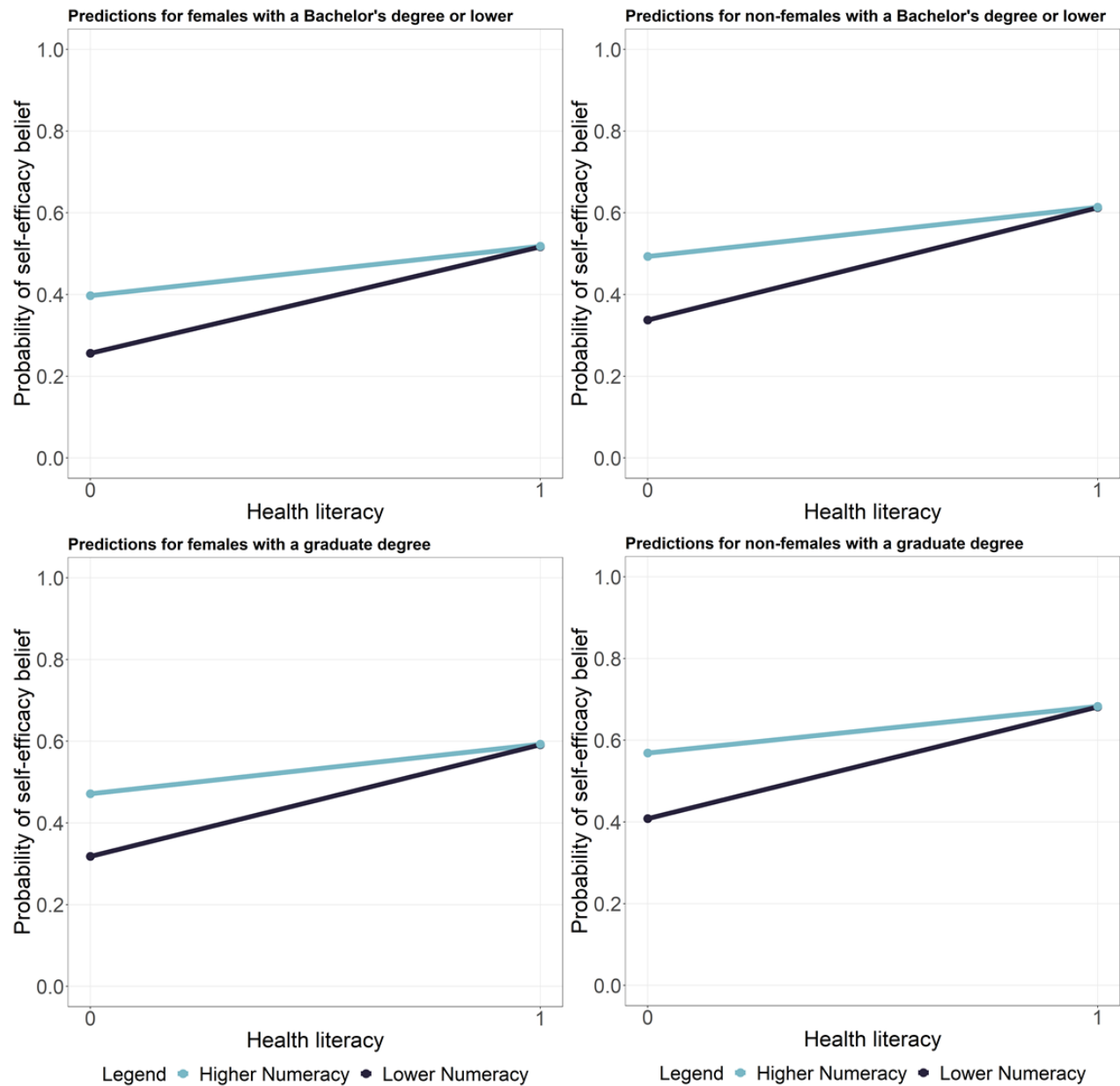


Figure 5-1. Results from logistic regression analysis summarizing probabilities of reporting self-efficacy belief by health literacy, moderated by numeracy, gender and education.

For each dichotomous gender and education category, the probability of reporting self-efficacy increased in the presence of health literacy for both higher and lower numeracy groups.

However, the increase in predicted self-efficacy in the presence of higher health literacy was largest among individuals with lower numeracy. Non-females with an education above a Bachelor's degree and with higher health literacy had the largest probability of reporting self-efficacy of any sub-group (0.68) for both higher and lower numeracy groups. Females holding a Bachelor's degree or lower with lower health literacy and lower numeracy had the smallest probability of reporting self-efficacy (0.26).

We also did not observe any significant individual effects between numeracy, health literacy, gender, education and the odds of reporting expert efficacy (Appendix 7-4), suggesting that these variables did not independently predict variation in this efficacy belief. However, the results from our regression analysis summarized in Figure 5-2 suggest that numeracy may modify the relationship between health literacy and the expert efficacy belief. We found that the probability of reporting expert efficacy decreased among lower numerate individuals in the presence of higher health literacy in each sub-group. Among individuals with higher numeracy, the presence of higher health literacy only marginally increased the probability of reporting the expert efficacy belief. We observed very little difference between the sub-groups in our predictions of expert efficacy.

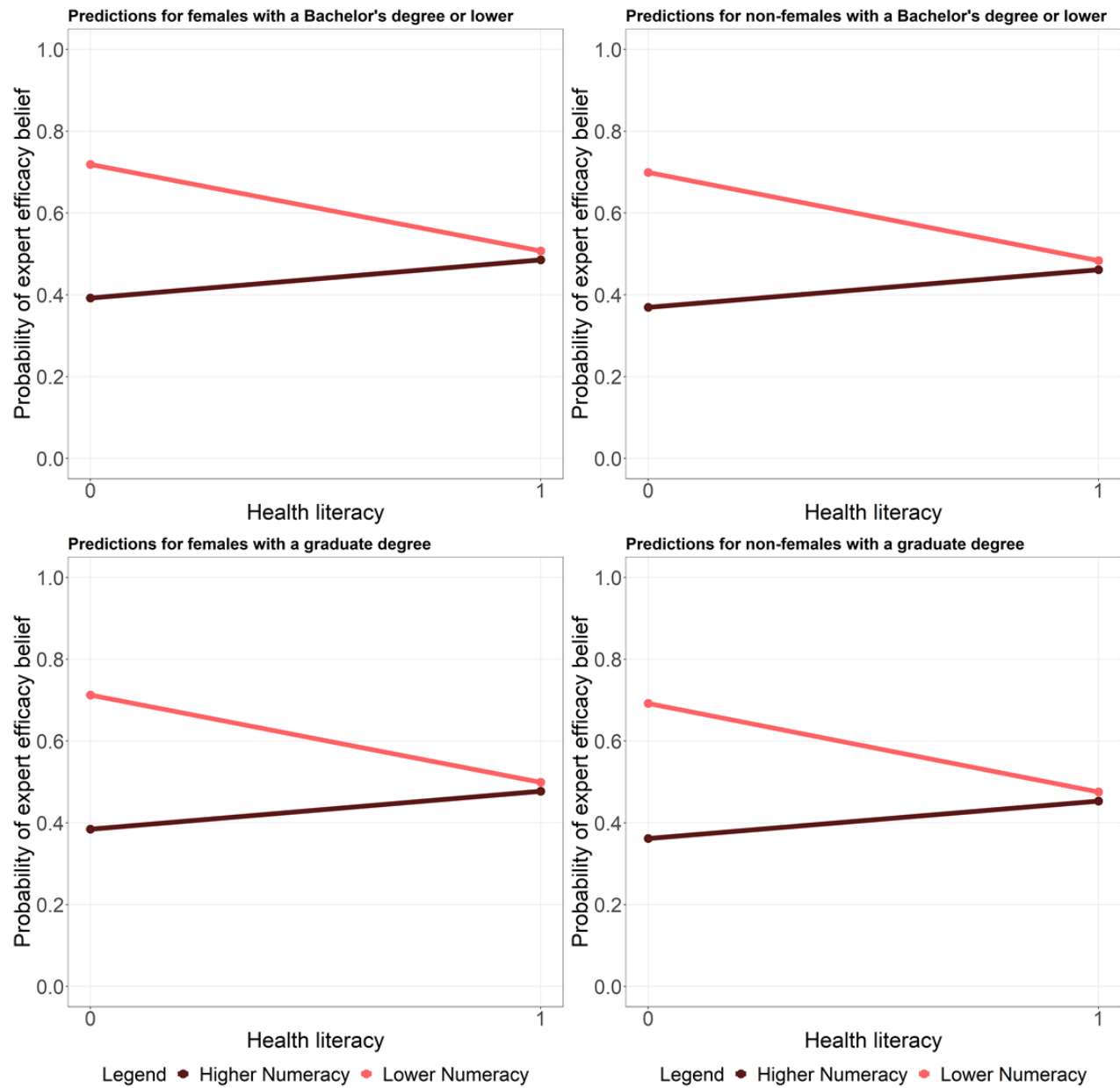


Figure 5-2. Results from logistic regression analysis summarizing probabilities of reporting expert efficacy belief by health literacy, moderated by numeracy, gender and education.

Our regression results for the science efficacy belief model (Appendix 7-5) showed that obtaining an education above a Bachelor's degree was significantly associated with an increased likelihood of reporting science efficacy (OR = 2.13; 1.04-4.36; $p < .05$). Figure 5-3 displays predictions of the science efficacy belief and shows that the effect of health literacy on the

probability of reporting this belief were not moderated by numeracy. For each gender and education combination, the likelihood of reporting the science efficacy belief increased marginally with higher health literacy for both numerate and less numerate individuals.

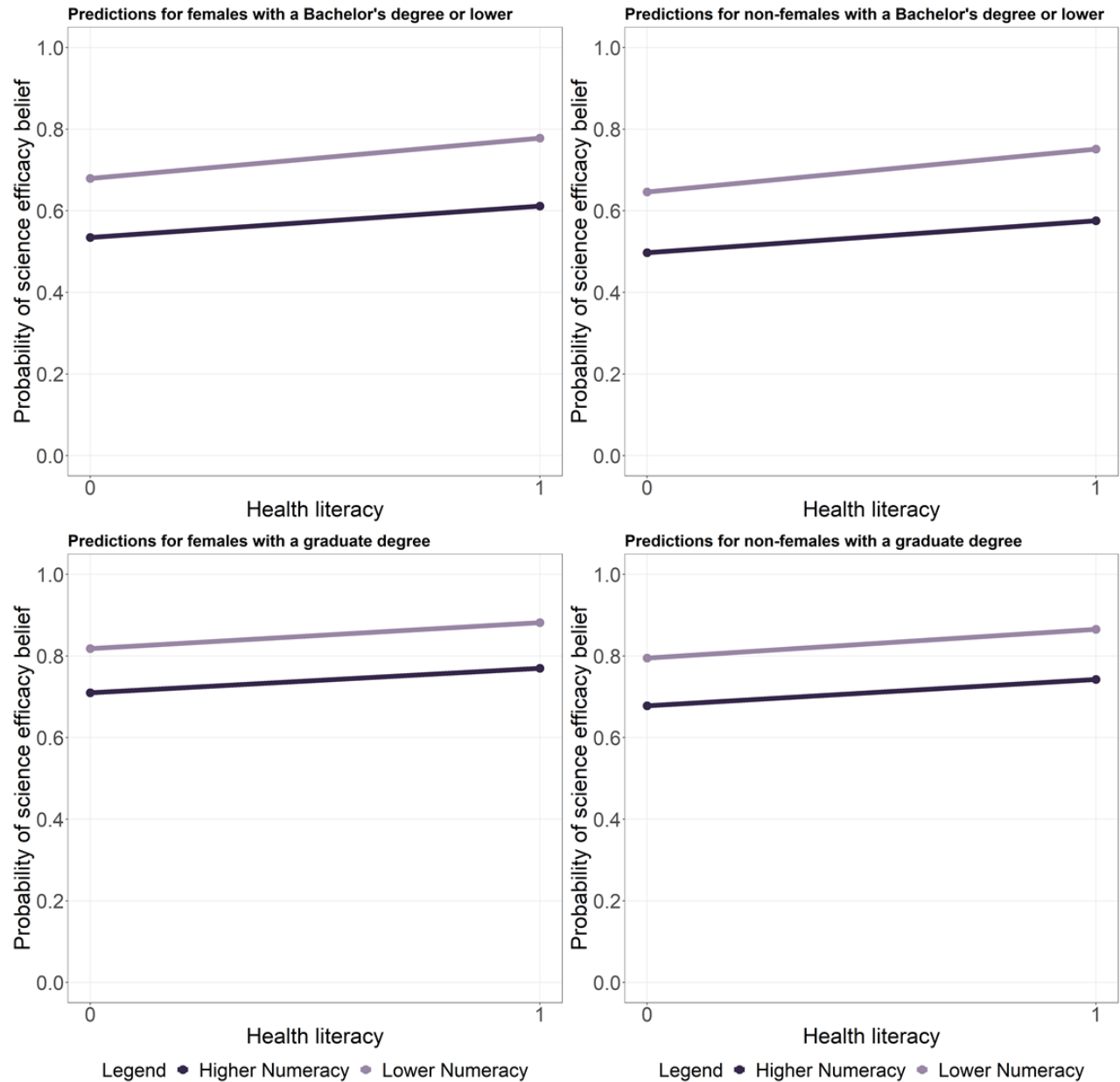


Figure 5-3. Results from logistic regression analysis summarizing probabilities of reporting science efficacy belief by health literacy, moderated by numeracy, gender and education.

5.4 DISCUSSION

This work aimed to investigate the impact of expertise and skills, information seeking and health risk perceptions on beliefs related to how cancer risks are managed. The associations between these variables and the three efficacy beliefs we studied have practical implications on the ways in which health educators choose to approach designing future interventions. Whether the goal is to influence people's self-appraised capabilities of reducing their own risk of cancer, or whether the primary aim is to influence people's perceptions of the capabilities of experts and institutions in charge of cancer management, different approaches may be required.

Our results suggest that health expertise, as indicated by a graduate degree in a health-related field, and higher levels of health literacy could be two factors influencing people's self-appraisal of their capability at managing cancer risks. This would mean that knowledge about health acquired from formal educational settings or elsewhere may give people the confidence to cope with the threat that cancer poses, which could lead to the adoption of more cancer-preventive behavior changes (Wong, 2009). On the other hand, health information acquired from friends and relatives appears to reduce people's self-efficacy related to cancer risk. This may point to the type of health information that is being received from family and friends and the extent to which modifiable factors are emphasized or not. For example, if family members tend to discuss genetic risk factors of cancer in one's family, then this may lead to a reduction in self-efficacy. Therefore, acquiring knowledge specifically about cancer risk factors that one can self-manage may be a key factor influencing self-efficacy.

Our finding that higher levels of health information seeking from news sources was associated with the belief that health experts had the capabilities to manage cancer risks was consistent with prior work that has linked the consumption of news media with positive

perceptions of scientists (Nisbet et al., 2002). This would suggest that continued promotion of scientific studies and experts' research by news outlets could be part of a strategy to promote beliefs around response efficacy, which can shape people's perceptions around whether or not healthy actions (often based on the advice of experts) are effective methods of managing disease risks. Future research could build on these findings by exploring the effects of scientific news reporting, through op-eds for example, on measures of response efficacy and individual intentions of health behavior change.

The results from our regression analyses also have implications for future research in health education and behavior change and echo findings from previous studies that suggest numeracy and literacy could be key factors influencing individual abilities and efficacy (Brown et al., 2011; Nouri et al., 2019; Portnoy et al., 2010). First, our study highlights the need to consider interactions between health literacy and numeracy since mastering both competencies may only benefit some efficacy beliefs and not others. Second, our results have shown the importance of considering the influence of sociodemographic factors like gender and education particularly on the self-efficacy belief, as developing future educational interventions that improve individual numeracy or health literacy (or both) may be especially beneficial for certain segments of the population.

For example, our study found that increasing the health literacy of individuals with lower numeracy may be associated with an increased likelihood of reporting self-efficacy to a greater extent than among those with higher numeracy. This finding would suggest that people's confidence in their ability to cope with cancer appears to depend more on their perceived capabilities of understanding health information rather than their numeric abilities. Other studies have also identified health literacy as one of the biggest barriers to self-efficacy related to

chronic disease management (Farley, 2019). Our results also point to females with low educational attainment and lower numeracy skills as a sub-population that may benefit the most from educational interventions to improve health literacy, as this group appeared to have the lowest likelihood of reporting of self-efficacy. This result was consistent with prior research that has linked women to lower self-efficacy outcomes related to managing cancer risks (Foster et al., 2015). Fortunately, improvements to health literacy can be achieved by designing simple patient education tools and by making minor adjustments to the way that health information is communicated to individuals (Kountz, 2009). In contrast, fewer educational interventions have been tested to measure improvements to numeracy (Garcia-Retamero et al., 2019).

Contrary to the self-efficacy outcome, our regression results indicated that increasing the health literacy of individuals with lower numeracy may reduce the likelihood of reporting expert efficacy. This would suggest that while educational interventions aiming to improve the health literacy of individuals with lower numeracy may be effective at increasing self-efficacy, they may reduce levels of expert efficacy beliefs. One explanation for this finding is that increased knowledge and understanding about health risks could increase awareness around scientific uncertainty, which has been found to increase perceptions of expert incompetence (Johnson & Slovic, 1995). As a result, if a health educator's goal is to increase the frequency of beliefs around expert efficacy, our study's findings would indicate that any interventions designed to improve the health literacy of a population may also require strategies to simultaneously improve skills in numeracy. Future work should further explore potential interactions between health literacy and numeracy and their differential impact on different types of efficacy beliefs.

This study has numerous limitations. First, due to the cross-sectional nature of this study, causality cannot be established between any independent and dependent variables investigated.

Second, we used single-item survey measures to measure each independent and dependent variable, which can impact the reliability and validity of results obtained. Future research should include validated scales of many of the constructs explored in this work (e.g. health literacy, numeracy, self-efficacy) wherever possible. Our findings are also limited by a small number of study participants, which skewed towards younger-aged females and are not representative of the general population. Although our regression analyses were adjusted for gender and education, other unmeasured confounders may have affected the associations identified in this work. Overall, the effect sizes reported in this study were weak and associations observed may have been a result of Type I error as a result of testing multiple hypotheses. The use of statistical procedures adjusting for multiple comparisons (e.g. Bonferroni correction) should be considered in future studies to reduce the likelihood of this error. Still, in a given study with small sample sizes such as this one, the costs and benefits associated with more conservative adjustments must be carefully weighed as these corrections can exacerbate the issues of low power and increase the likelihood of Type II error (Moran, 2003).

Despite the limitations, this exploratory study has generated numerous starting points for further research into the ways that skills, expertise and information acquisition may influence individuals' coping appraisals of cancer and could motivate cancer-preventive actions. First and foremost, our research indicates that the complex interplay between health literacy and numeracy on beliefs related to cancer coping appraisals warrants further study. In addition, our work has important implications on research into the design and implementation of cancer education materials targeting self-efficacy and response efficacy beliefs, which appear to be associated with different skills and individual characteristics based on our findings. Self-efficacy and response efficacy beliefs are known to influence the adoption of different types of health-related

behaviors, for example behaviors that are health-promoting versus those that are preventive against negative health outcomes (Keller, 2006); therefore, more empirical evidence linking different individual factors to either self-efficacy or response efficacy beliefs is needed to inform the approaches that health educators should use to achieve a particular set of desired behaviors.

5.5 CONCLUSION

Motivating the adoption of actions that reduce an individual's risk of cancer can significantly reduce the burden of cancer on society. Fortunately, the uptake of cancer-preventive behavior changes can be influenced by health education interventions that target individuals' beliefs in their ability to execute actions that reduce the risk of cancer, as well as their beliefs around the effectiveness of those actions. This study explored the role of expertise, skills, information seeking and health risk perceptions on these efficacy beliefs. Our findings advance the current literature related to cancer efficacy by identifying factors influencing perceptions of self-management of cancer risk and the management of cancer risk by experts and institutions. We also highlight a number of opportunities for researchers and health educators to build off this work and further explore how factors such as health literacy and numeracy can shape individuals' beliefs around cancer risk management.

5.6 REFERENCES

- Apter, A. J., Cheng, J., Small, D., Bennett, I. M., Albert, C., Fein, D. G., George, M., & Van Horne, S. (2006). Asthma Numeracy Skill and Health Literacy. *Journal of Asthma*, 43(9), 705–710. <https://doi.org/10.1080/02770900600925585>
- Aragon, T. J., Fay, M. P., Wollschlaeger, D., & Omidpanah, A. (2020). *epitools: Epidemiology Tools* (0.5-10.1) [Computer software]. <https://CRAN.R-project.org/package=epitools>

- Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, 37(2), 122–147. <https://doi.org/10.1037/0003-066X.37.2.122>
- Bandura, A. (1994). Self-efficacy. In V. S. Ramachaudran (Ed.), *Encyclopedia of human behavior* (Vol. 4, pp. 71–81). Academic Press.
- Bandura, A. (2006). Guide for constructing self-efficacy scales. *Self-Efficacy Beliefs of Adolescents*, 5(1), 307–337.
- Bashirian, S., Barati, M., Shoar, L. M., Mohammadi, Y., & Dogonchi, M. (2019). Factors Affecting Breast Self-examination Behavior Among Female Healthcare Workers in Iran: The Role of Social Support Theory. *Journal of Preventive Medicine and Public Health*, 52(4), 224–233. <https://doi.org/10.3961/jpmp.18.277>
- Bleich, S., Blendon, R., & Adams, A. (2007). Trust in Scientific Experts on Obesity: Implications for Awareness and Behavior Change. *Obesity*, 15(8), 2145–2156. <https://doi.org/10.1038/oby.2007.255>
- Brown, S. M., Culver, J. O., Osann, K. E., MacDonald, D. J., Sand, S., Thornton, A. A., Grant, M., Bowen, D. J., Metcalfe, K. A., Burke, H. B., Robson, M. E., Friedman, S., & Weitzel, J. N. (2011). Health literacy, numeracy, and interpretation of graphical breast cancer risk estimates. *Patient Education and Counseling*, 83(1), 92–98. <https://doi.org/10.1016/j.pec.2010.04.027>
- Chen, Y., & Feeley, T. H. (2014). Numeracy, Information Seeking, and Self-Efficacy in Managing Health: An Analysis Using the 2007 Health Information National Trends Survey (HINTS). *Health Communication*, 29(9), 843–853. <https://doi.org/10.1080/10410236.2013.807904>
- Curtin, R. B., Walters, B. A. J., Schatell, D., Pennell, P., Wise, M., & Klicko, K. (2008). Self-Efficacy and Self-Management Behaviors in Patients With Chronic Kidney Disease. *Advances in Chronic Kidney Disease*, 15(2), 191–205. <https://doi.org/10.1053/j.ackd.2008.01.006>
- Dieckmann, N. F., Johnson, B. B., Gregory, R., Mayorga, M., Han, P. K. J., & Slovic, P. (2017). Public perceptions of expert disagreement: Bias and incompetence or a complex and random world? *Public Understanding of Science*, 26(3), 325–338. <https://doi.org/10.1177/0963662515603271>
- Dieckmann, N. F., Peters, E., & Gregory, R. (2015). At Home on the Range? Lay Interpretations of Numerical Uncertainty Ranges. *Risk Analysis*, 35(7), 1281–1295. <https://doi.org/10.1111/risa.12358>
- Farley, H. (2019). Promoting self-efficacy in patients with chronic disease beyond traditional education: A literature review. *Nursing Open*, 7(1), 30–41. <https://doi.org/10.1002/nop.2.382>
- Finucane, M. L., Slovic, P., Mertz, C. K., Flynn, J., & Satterfield, T. A. (2000). Gender, race, and perceived risk: The “white male” effect. *Health, Risk & Society*, 2(2), 159–172. <https://doi.org/10.1080/713670162>

- Foster, C., Breckons, M., Cotterell, P., Barbosa, D., Calman, L., Corner, J., Fenlon, D., Foster, R., Grimmett, C., Richardson, A., & Smith, P. W. (2015). Cancer survivors' self-efficacy to self-manage in the year following primary treatment. *Journal of Cancer Survivorship*, *9*(1), 11–19. <https://doi.org/10.1007/s11764-014-0384-0>
- Garcia-Retamero, R., Sobkow, A., Petrova, D., Garrido, D., & Traczyk, J. (2019). Numeracy and Risk Literacy: What Have We Learned so Far? *The Spanish Journal of Psychology*, *22*. <https://doi.org/10.1017/sjp.2019.16>
- Garforth, C. J., Bailey, A. P., & Tranter, R. B. (2013). Farmers' attitudes to disease risk management in England: A comparative analysis of sheep and pig farmers. *Preventive Veterinary Medicine*, *110*(3–4), 456–466. <https://doi.org/10.1016/j.prevetmed.2013.02.018>
- Gecas, V. (1989). The Social Psychology of Self-Efficacy. *Annual Review of Sociology*, *15*(1), 291–316. <https://doi.org/10.1146/annurev.so.15.080189.001451>
- Hellem, Elisabet, Bruusgaard, Kari Anette, & Bergland, Astrid. (2012). Exercise maintenance: COPD patients' perception and perspectives on elements of success in sustaining long-term exercise. *Physiotherapy Theory and Practice*, *28*(3), 206–220. <https://doi.org/10.3109/09593985.2011.587502>
- Ishikawa, H., Takeuchi, T., & Yano, E. (2008). Measuring functional, communicative, and critical health literacy among diabetic patients. *Diabetes Care*, *31*(5), 874–879. <https://doi.org/10.2337/dc07-1932>
- Islami, F., Goding Sauer, A., Miller, K. D., Siegel, R. L., Fedewa, S. A., Jacobs, E. J., McCullough, M. L., Patel, A. V., Ma, J., Soerjomataram, I., Flanders, W. D., Brawley, O. W., Gapstur, S. M., & Jemal, A. (2018). Proportion and number of cancer cases and deaths attributable to potentially modifiable risk factors in the United States. *CA: A Cancer Journal for Clinicians*, *68*(1), 31–54. <https://doi.org/10.3322/caac.21440>
- Johnson, B. B., & Slovic, P. (1995). Presenting uncertainty in health risk assessment: Initial studies of its effects on risk perception and trust. *Risk Analysis: An Official Publication of the Society for Risk Analysis*, *15*(4), 485–494. <https://doi.org/10.1111/j.1539-6924.1995.tb00341.x>
- Keller, P. A. (2006). Regulatory Focus and Efficacy of Health Messages. *Journal of Consumer Research*, *33*(1), 109–114. <https://doi.org/10.1086/504141>
- Kiechle, E. S., Bailey, S. C., Hedlund, L. A., Viera, A. J., & Sheridan, S. L. (2015). Different Measures, Different Outcomes? A Systematic Review of Performance-Based versus Self-Reported Measures of Health Literacy and Numeracy. *Journal of General Internal Medicine*, *30*(10), 1538–1546. <https://doi.org/10.1007/s11606-015-3288-4>
- Kobayashi, L. C., & Smith, S. G. (2016). Cancer Fatalism, Literacy, and Cancer Information Seeking in the American Public. *Health Education & Behavior*, *43*(4), 461–470. <https://doi.org/10.1177/1090198115604616>

Kountz, D. S. (2009). Strategies for Improving Low Health Literacy. *Postgraduate Medicine*, 121(5), 171–177. <https://doi.org/10.3810/pgm.2009.09.2065>

Lee, J. E. C., Lemyre, L., Mercier, P., Bouchard, L., & Krewski, D. (2005). Beyond the Hazard: The Role of Beliefs in Health Risk Perception. *Human and Ecological Risk Assessment: An International Journal*, 11(6), 1111–1126. <https://doi.org/10.1080/10807030500278636>

Leventhal, H., Kelly, K., & Leventhal, E. A. (1999). Population Risk, Actual Risk, Perceived Risk, and Cancer Control: A Discussion. *JNCI Monographs*, 1999(25), 81–85. <https://doi.org/10.1093/oxfordjournals.jncimonographs.a024214>

McCleary-Jones, V. (2011). Health literacy and its association with diabetes knowledge, self-efficacy and disease self-management among African Americans with diabetes mellitus. *ABNF Journal*, 22(2).

Milne, S., Sheeran, P., & Orbell, S. (2000). Prediction and Intervention in Health-Related Behavior: A Meta-Analytic Review of Protection Motivation Theory. *Journal of Applied Social Psychology*, 30(1), 106–143. <https://doi.org/10.1111/j.1559-1816.2000.tb02308.x>

Moran, M. D. (2003). Arguments for Rejecting the Sequential Bonferroni in Ecological Studies. *Oikos*, 100(2), 403–405.

Nisbet, M. C., Scheufele, D. A., Shanahan, J., Moy, P., Brossard, D., & Lewenstein, B. V. (2002). Knowledge, Reservations, or Promise?: A Media Effects Model for Public Perceptions of Science and Technology. *Communication Research*, 29(5), 584–608. <https://doi.org/10.1177/009365002236196>

Nouri, S. S., Damschroder, L. J., Olsen, M. K., Gierisch, J. M., Fagerlin, A., Sanders, L. L., McCant, F., & Oddone, E. Z. (2019). Health Coaching Has Differential Effects on Veterans with Limited Health Literacy and Numeracy: A Secondary Analysis of ACTIVATE. *Journal of General Internal Medicine*, 34(4), 552–558. <https://doi.org/10.1007/s11606-019-04861-7>

Osborn, C. Y., Cavanaugh, K., Wallston, K. A., & Rothman, R. L. (2010). Self-Efficacy Links Health Literacy and Numeracy to Glycemic Control. *Journal of Health Communication*, 15(sup2), 146–158. <https://doi.org/10.1080/10810730.2010.499980>

Peters, E. (2012). Beyond Comprehension: The Role of Numeracy in Judgments and Decisions. *Current Directions in Psychological Science*, 21(1), 31–35. <https://doi.org/10.1177/0963721411429960>

Portnoy, D. B., Roter, D., & Erby, L. H. (2010). The role of numeracy on client knowledge in BRCA genetic counseling. *Patient Education and Counseling*, 81(1), 131–136. <https://doi.org/10.1016/j.pec.2009.09.036>

Prentice-Dunn, S., & Rogers, R. W. (1986). Protection Motivation Theory and preventive health: Beyond the Health Belief Model. *Health Education Research*, 1(3), 153–161. <https://doi.org/10.1093/her/1.3.153>

Rogers, R. (1983). *Cognitive and physiological processes in fear appeals and attitude change: A revised theory of protection motivation* (J. Cacioppo & R. Petty, Eds.; pp. 153–177).

Seyde, E., Taal, E., & Wiegman, O. (1990). Risk-appraisal, outcome and self-efficacy expectancies: Cognitive factors in preventive behaviour related to cancer. *Psychology & Health*, 4(2), 99–109. <https://doi.org/10.1080/08870449008408144>

Tiraki, Z., & Yilmaz, M. (2018). Cervical Cancer Knowledge, Self-Efficacy, and Health Literacy Levels of Married Women. *Journal of Cancer Education*, 33(6), 1270–1278. <https://doi.org/10.1007/s13187-017-1242-3>

von Wagner, C., Semmler, C., Good, A., & Wardle, J. (2009). Health literacy and self-efficacy for participating in colorectal cancer screening: The role of information processing. *Patient Education and Counseling*, 75(3), 352–357. <https://doi.org/10.1016/j.pec.2009.03.015>

Waters, E. A., Biddle, C., Kaphingst, K. A., Schofield, E., Kiviniemi, M. T., Orom, H., Li, Y., & Hay, J. L. (2018). Examining the Interrelations Among Objective and Subjective Health Literacy and Numeracy and Their Associations with Health Knowledge. *Journal of General Internal Medicine*, 33(11), 1945–1953. <https://doi.org/10.1007/s11606-018-4624-2>

Welch, J. D., & Ellis, E. M. (2018). Sex Differences in the Association of Perceived Ambiguity, Cancer Fatalism, and Health-Related Self-Efficacy with Fruit and Vegetable Consumption. *Journal of Health Communication*, 23(12), 984–992. <https://doi.org/10.1080/10810730.2018.1534905>

Werk, R. S., Hill, J. C., & Graber, J. A. (2017). Impact of Knowledge, Self-Efficacy, and Perceived Importance on Steps Taken Toward Cancer Prevention Among College Men and Women. *Journal of Cancer Education*, 32(1), 148–154. <https://doi.org/10.1007/s13187-016-0996-3>

Whitaker, K. L., Cromme, S., Winstanley, K., Renzi, C., & Wardle, J. (2016). Emotional responses to the experience of cancer ‘alarm’ symptoms. *Psycho-Oncology*, 25(5), 567–573. <https://doi.org/10.1002/pon.3964>

Wickham, H., Chang, W., Henry, L., Pedersen, T. L., Takahashi, K., Wilke, C., Woo, K., Yutani, H., Dunnington, D., & RStudio. (2021). *ggplot2: Create Elegant Data Visualisations Using the Grammar of Graphics* (3.3.5) [Computer software]. <https://CRAN.R-project.org/package=ggplot2>

Wong, N. C. H. (2009). Investigating the Effects of Cancer Risk and Efficacy Perceptions on Cancer Prevention Adherence and Intentions. *Health Communication*, 24(2), 95–105. <https://doi.org/10.1080/10410230802676474>

6 CONCLUSIONS

Many of the issues with the current methodologies of cancer risk communication discussed in this dissertation will be familiar to readers having experienced two years of the global COVID-19 pandemic. During this time, the field of health risk communication has gained both admirers and critics among health experts and non-expert citizens alike, with challenges present for those both on the giving and the receiving end of risk communication. Problems with inconsistent public health messaging, communicating uncertainties associated with disease modelling, interpreting risk probabilities and maintaining public trust are common during any health-related crisis. Thus, this final chapter will also touch on the implications of this work and future research directions beyond the scope of cancer clusters and cancer risk perceptions.

Over the course of the four substantive chapters of this dissertation, the objectives were first to summarize current issues with cancer risk communication that the major players face during cluster investigations, then, to investigate whether changes to communication formats could change perceptions of cancer risk using experiments, and finally, to explore potential interventions that influence people's attitudes around managing the risk of cancer. The first substantive chapter (Chapter 2) began with a study of the media's risk communication practices during cluster investigations and presented findings pertaining to the news coverage of cancer clusters in Ontario. Building off this work, Chapter 3 explored the risk communication practices and cancer cluster investigation procedures undertaken by health officials from jurisdictions across Canada. Following this, Chapter 4 aimed to investigate and test the impacts of media and government communications related to cancer clusters on cancer risk perceptions. Finally, in Chapter 5, associations between different skills and competencies and cancer risk attitudes were

studied to explore whether educational interventions could be used to impact beliefs about cancer risk management and motivate healthier changes to behaviour.

In the following section of this chapter, the contributions of these works to diverse research fields are discussed in more detail. Subsequently, the implications of these works on policies and procedures related to risk communication are presented and future research directions are examined.

6.1 RESEARCH CONTRIBUTIONS

The primary goals of this dissertation were to explore how various expert and non-expert stakeholders interpret and engage with cancer information and perceive risk as it pertains to cancer clusters, and to identify improved methods of conducting cancer risk communication and risk education. Thus, the work carried out as a part of this dissertation draws on and significantly contributes to three research fields that will be discussed further: cancer risk communication, cancer risk perceptions and cancer risk education.

6.1.1 Cancer risk communication

The research discussed in this dissertation substantially contributes to our understanding of how to improve the cancer communication approaches and practices of diverse risk communicators, and particularly those of the media and government agencies and/or health officials. In 1987, Peter Sandman, a leading risk communication expert, famously coined the formula “risk = hazard + outrage” to describe how the perception of a risk is a result of the hazard it poses as well as the outrage it causes. According to the formula, the type of risk communication required to respond to the public’s perceptions of a risk is based on whether the risk constitutes a high or

low hazard and produces a high or low amount of outrage. Cancer clusters, which constitute a low hazard-high outrage scenario according to most public health experts would therefore require an outrage management risk communication response that works to reassure outraged citizens about a mostly low risk to their health.

However, it is estimated that about 2 in 5 Canadians will develop cancer at some point during their lifetime (Canadian Cancer Society, 2021). Therefore, a cancer diagnosis poses a very real threat to many people. As a result, Sandman's original outrage management approach to risk communication may require a bit of tweaking to deliver effective risk communication for cancer – we still want to reassure citizens about the cancer risk factors that pose a generally lower risk to their health, but we also want citizens to care more about the risk factors they can control and to take actions that would meaningfully reduce the burden of cancer (e.g. quitting smoking).

A growing body of literature on cancer risk communication has recognized the importance of providing contextual information when communicating about cancer to help people compare their risks to other risks and to gain a richer understanding of the disease (Schwartz et al., 1999; Trevena et al., 2013; Hamilton et al., 2020). The research findings from Chapter 4 appear to confirm that providing contextual information about the risk of cancer can go a long way in reassuring people and reducing their concerns about cancer. It may also address low levels of health literacy, which was found to be an important factor promoting beliefs related to people's abilities to cope with the risk of cancer in Chapter 5. However, in Chapter 2, it was found that the media's reporting about cancer risk often lacks key contextual information about cancer risk factors. These results from Chapter 2 highlight the fact that any improvements to cancer risk communication approaches adopted by official government communicators or health experts

may require more knowledge translation in order to become a dominant practice adopted by other non-expert communicators of health information such as news agencies.

The results of this dissertation would also indicate that where current best practices for cancer risk communication fall particularly short is the lack of attention given to participatory communication approaches and face-to-face opportunities for cancer risk education. For example, after contrasting the experiences of cancer cluster investigators across Canada in Chapter 3, it is clear that health officials often recognize the benefits of participatory collaborative communication approaches. These approaches strive to include citizens as active participants in a dialogue about cancer clusters versus vertical top-down approaches to sharing information. Still, these participatory community-centered approaches were not regularly adopted by health officials based on our findings.

Such strategies aim to improve public engagement by using face-to-face connections wherever possible, addressing concerns and by building trust, and mirror the efforts of public health researchers seeking to engage in more community-based participatory research. Beyond these benefits, face-to-face communications about cancer risk also appear to generate improvements to risk information comprehension especially among individuals with lower numeracy (Gaglio et al., 2012). This would be consistent with the results summarized in Chapter 5, which identified less numerate individuals as potentially benefiting the most from risk education interventions that target beliefs around people's ability to cope with cancer. Thus, this dissertation adds another voice to the growing calls from researchers to incorporate more horizontal modes of communication into public health practices that emphasize citizen empowerment (Jones & Wells, 2007; Dasgupta, 2019).

6.1.2 Cancer risk perceptions

This research has also made important contributions to the research field around cancer risk perception. Although the study of the affective heuristic (i.e. making judgments based on intuitive emotions) as it pertains to cancer risk judgments is not a new field of research (Klein & Stefanek, 2007); Peters et al., 2006; Slovic et al., 2005), this dissertation contributes some key knowledge to recent developments in risk perception research – particularly research examining the role that affect plays in the recall of risk information that informs people’s perceptions of cancer risk. It is already known that people tend to disproportionately rely on negative feelings about cancer (e.g. dread, fear) when interpreting cancer risk information thanks to the frequent negative cues they encounter about cancer (e.g. family members’ death, sensational news stories) (Peters and Meilleur 2016). Indeed, the research in this dissertation confirmed a large presence of such cues based on the prevalence of Canadian news reports using qualitative descriptors of risk in their coverage of cancer clusters (Chapter 2), which are more likely to induce affective cognitive responses than probabilistic numeric risk information. It was also found that risk information containing affective cues (i.e. information authored by news agencies and/or employing personal stories about cancer) seemed to elicit higher levels of concern about cancer even after other reassuring information was presented (Chapter 4). What this last finding suggests is that people may retain affective risk information in their memory more easily, which is consistent with the direction of recent literature exploring the use of graphic imagery and affective illustrations to enhance the recall of cancer information (Ma 2021; Shoots-Reinhard et al., 2020).

This dissertation’s focus on information trustworthiness as a key factor shaping people’s perceptions of risk from various sources of information about cancer has also yielded important

contribution to this field of research. When Kasperson et al. (1988) first proposed the social amplification of risk framework to describe how risk perceptions and public concern are transmitted – beginning with social and institutional actors who communicate a piece of information, which is received by another set of actors who re-transmit the message based on their own interpretations of that piece of information, until it is received by an individual who filters this information according to their own interpretations of the risk – it helped to explain why some improbable events are still perceived as very risky and how these risks become amplified. According to the framework, some characteristics of the information itself may contribute to the amplification of citizen risk perceptions, for example, large volumes of information about the risk or negative facts about the risk that dramatize it (Kasperson and Kasperson, 1996). However, the findings from this dissertation would suggest that the information's trustworthiness is also an important factor to consider in this process of risk interpretation and the amplification of cancer risks in particular.

In Chapter 4, it was found that when a source of cancer risk information (i.e. authored by government) or the format of information (i.e. containing contextual information) was perceived as trustworthy, then the percentage of individuals reporting that they were concerned about cancer was higher than when other less trustworthy information sources/formats were viewed. This may be because cancer is known to trigger a lot of dread through cognitive mechanisms such as affective heuristic processing, therefore, any trusted piece of information found to be discussing cancer risks could reaffirm individual beliefs that cancer is something to be concerned about unless otherwise instructed (Jagielle & Hills, 2018). Indeed, providing reassuring information after viewing the risk information from trusted sources/formats resulted in a large decline in reported levels of cancer concern, pointing to trustworthiness as a key factor capable

of amplifying or attenuating individual perceptions of risk depending on how the risk is framed in the piece of trusted information. In Chapter 3, trust was also a theme that emerged from the interviews conducted with Canadian cancer cluster investigators and one interviewee indicated that demonstrating trustworthiness by being transparent about the progress of the investigation appeared to diminish perceptions of cancer risk. Therefore, these findings would suggest that trust is a key dimension to add to the social amplification of risk framework.

6.1.3 Cancer risk education

This dissertation has also contributed key findings to the growing body of literature around cancer risk education. Much of the available research into which educational interventions can lead to the increased comprehension of cancer risk information has centered around studying the effectiveness of tools used for cancer treatment decision-making (McAlpine et al. 2018; Stacey et al., 2008) or for the adoption of cancer-preventive actions (Hernandez et al., 2014; Hinyard et al., 2007). However, few studies have focused on exploring the potential mechanisms behind people's beliefs and characteristics that inform individual decision-making and/or the willingness to take certain cancer-preventive actions. In Chapter 5, numeracy and health literacy were identified as important competencies that may impact individual beliefs around one's ability to take actions to reduce their risk of cancer. Importantly, it was revealed that numeracy appeared to have a mediating effect between health literacy and two cancer coping beliefs, underscoring the need to consider interactions between health literacy and numeracy when investigating the influence of competencies on cancer-related beliefs in future works.

6.2 IMPLICATIONS FOR POLICIES AND PROCEDURES

The implications of this work extend beyond cancer cluster investigations and improved risk communication practices. Following the discussion above, in which this dissertation's most significant contributions to several research fields were discussed, some practical implications on policies and procedures will be outlined to consider how the knowledge generated from this dissertation can be mobilized for changes to practice.

6.2.1 Media risk reporting

The findings from this dissertation as well as other works (Paek et al., 2016; Stryker et al., 2008; Wahlberg & Sjoberg, 2000) point to the news media as an important source of health information with significant potential influence over individual and societal perceptions of risk.

Unfortunately, the media is sometimes known for sensationalizing risks and reporting risks inaccurately (Dahlstrom et al. 2012; Tang and Rundblad 2015) and as discussed in Chapter 2, news coverage of cancer may not be reporting risk using language that can help people to form accurate perceptions of risk. Still, in Chapter 3, interviews with Canadian public health officials revealed that having a positive relationship with local members of the news media can be highly beneficial for health officials who leverage reporters as key players involved in the dissemination of information to citizens. As a result, some health officials considered the media to be partners in the knowledge translation process capable of transferring scientific expertise to non-expert audiences and even discussed working together on press releases and other communications.

In addition, it may be beneficial for news agencies to make use of the higher levels of trust people appear to afford government health communications compared to media communications (Chapter 4). Therefore, this dissertation provides a case for public health officials and news agencies to consider fostering a more collaborative relationship to carry out

public education about cancer risks and other health topics. For example, health departments could use communications toolkits that supply sample written materials as well as tip sheets on reporting health risks to media partners in order to conduct risk education campaigns. Such collaborations would capitalize on the media's audience reach and health officials' ability to produce high-quality trustworthy health information.

This dissertation has also drawn attention to the discrepancies in risk reporting by news agencies that may exist across different geographies. In particular, the absence of information on key contextual information such as cancer risk factors in the media's reporting of cancer clusters in rural areas (Chapter 2) should give pause to public health educators working to address health disparities across geographic regions. As populations concentrated in rural areas already face issues of lower access to high quality health information from mainstream news sources, primary care providers and less reliable Internet connections, differences in media risk reporting can exacerbate existing disparities in health literacy between rural and urban populations (Chen et al. 2019).

Given that lower levels of health literacy appear to be associated with a lower likelihood of developing successful cancer coping beliefs – which are believed to be important in motivating the adoption of cancer-preventive behaviors (Chapter 5) – implementing policies and practices that would address discrepancies in health literacy should be a public health priority. Here again, public health educators should consider harnessing the reach of local media and other community forums to disseminate health information in an effort to improve health literacy alongside enhancing knowledge around cancer risks. In addition, this dissertation has shown that news stories may be particularly useful at drawing public attention to health information using affective cues that could aid in the recall of cancer risk information especially with respect to

personal cancer risks (Chapter 4). Still, any use of affective information (e.g. personal stories) in cancer news reporting may require some adaptations in journalistic practices to simultaneously increase the amount of contextual information used. As contextual information appeared to reduce the likelihood of reporting the highest levels of concern about cancer (Chapter 4) and a shortage of this type of information appears to exist in the news coverage of cancer (Chapter 2), this may represent a key opportunity to improve the media's reporting of health risks.

6.2.2 Participatory cancer communication

The benefits of promoting collaborations among different disseminators of risk information (e.g. between health officials and the media) have already been discussed above. However, incorporating community-centered participatory approaches to cancer risk communication activities between these stakeholders and the target audience (i.e. individual citizens) also represents a key opportunity for improving current cancer risk communication practices based on the findings of this dissertation.

Communication infrastructure theory is a particularly useful framework to consider here, which encompasses an ecological approach to carrying out multi-level health communications involving three key players: community organizations, local media and citizens (Wilkin et al., 2010). The theory provides a practical roadmap to fostering collaborations between these players using settings such as workshops and storytelling networks, which can lead to increased social connections, civic engagement and opportunities for knowledge exchange between various stakeholders. The framework's focus around storytelling is particularly relevant to this dissertation's findings, which found that cancer risk information using personal stories may influence perceptions of personal cancer risk as these stories appeared to be better retained by individuals due to affective recall (Chapter 4). Therefore, this dissertation expands our current

understanding of communication infrastructure theory through the discovery of memory as a potential mechanism behind why storytelling appears to be an effective method of participatory risk communication.

From a health promotion standpoint, these collaborations between communicators and citizens are also desirable because they can allow hard to reach individuals to interact directly with community leaders and health experts in a space where open dialogues and communicating face-to-face are encouraged. In fact, this dissertation revealed that public health officials appear to desire more training and opportunities to conduct participatory cancer risk communication because they view these interactions as particularly effective at building trust with community members (Chapter 3) and supplying trustworthy information is a key factor influencing perceptions of cancer risk (Chapter 4).

Furthermore, these strengthened connections between experts and non-experts can help address issues such as low health literacy in a community where citizens feel they can share what health information needs they have and health officials can readily identify community knowledge gaps (Wilkin et al., 2010). The implementation of participatory communication processes in public health practice would fundamentally change the way that many governments currently approach health risk education, for example by adopting more of a co-designer role when planning health education materials. Thus, this dissertation's research findings add weight to the theory of communication infrastructure as a potential framework for carrying out some cancer risk communication activities in a way that emphasizes more active citizen participation.

6.3 FUTURE RESEARCH DIRECTIONS

This dissertation has explored how the interpretation of cancer risk information by diverse stakeholders can impact perceptions of risk and has contributed some key insights into potential ways to improve methods of risk communication and risk education. Following a discussion of this work's contributions to various research fields and its advancements to communications theories and practices, some directions for future research will be discussed in the subsequent section.

6.3.1. Future methodological needs

One of the biggest limitations of research studying risk perceptions and human behaviours is the reliance on survey tools to indirectly measure human thoughts and judgments, which require participants to understand questions and provide accurate and honest responses. This dissertation faced many of the common methodological challenges that tend to complicate survey-based research, including response bias and the oversimplification of social reality. However, some methodological advancements in the psychology and communications research fields could provide exciting new opportunities for carrying out similar research with more rigour going forward.

One of these advancements includes the use of eye tracking technology in experimental studies to record participants' eye motions and gaze locations as they carry out certain visual-based tasks. Until fairly recently, there were barriers to adopting eye tracking tools among researchers such as high cost and complex programming; however, the development of improved methods of eye tracking have greatly increased access to this technology (Carter & Luke, 2020). Although their use in the communications research field is not yet widespread, eye tracking holds enormous potential for researchers seeking to examine participants' visual attention to

certain cues and cognitive processing. For example, researchers have started to explore the application of eye tracking for studying affective processing by measuring pupil dilation and gaze measurements (Rahal & Fiedler, 2019), which could provide exciting new avenues for risk communication research that currently still relies largely on self-reported measures of affect. Since eye tracking can be carried out simultaneously during a decision task without interrupting a study participant's thought process, it can provide researchers an opportunity to measure people's interpretations of visual information in the same moment that the information is being viewed.

Recent advancements in immersive virtual reality technology have also provided researchers incredible opportunities to measure participant responses to risk events in scenarios that closely resemble the real world. Compared to prior two-dimensional virtual reality set-ups that utilized desktop or mobile displays, currently available three-dimensional immersive simulations that utilize head-mounted displays may trigger more realistic affective responses to risk stimuli (Simpson et al., 2022). For obvious ethical reasons, a common issue in research investigating perceptions of risk related to environmental phenomena is the inability to actually expose participants to hazards that may be harmful to health and measure their real-life responses. Therefore, these virtual environments could have major implications on the way risk research is carried out in the future.

Finally, another methodological development that has the potential to significantly improve the validity of research in this field is the development of recent survey scales, which have been tested to accurately measure some of the variables studied in this dissertation. Survey scales are assessment instruments used to measure a variable using multiple survey questions that have been validated by researchers. The use of well-established survey scales to improve the

validity of survey-based research is not new, however, recent updates to some common instruments used in health decision-making research have provided opportunities to generate more accurate research findings. For example, although a variety of scales exist to measure the numeric skills of research participants (Lipkus et al., 2001; Weller et al., 2012), Hill et al.'s recently developed numeracy scale appears to offer numerous benefits that may aid future research studies investigating numeracy (2019). Chou et al.'s development of a health literacy scale focusing on cancer literacy is another new survey scale that is likely to advance future research examining people's knowledge about cancer risks (2020).

6.3.2 Social media risk communication landscape

As societies increasingly rely on online communication platforms (e.g. WhatsApp) and social media (e.g. Facebook, TikTok) to connect, risk educators aiming to communicate to the masses will also inevitably need to shift their focus towards disseminating information using these networks. Although this dissertation did not examine cancer risk communications on these platforms, future work in risk communication design and development will increasingly need to consider this new media landscape. Some recent works have begun to characterize current communications about cancer that exist on these platforms (Cho et al., 2018; Parker et al. 2021). Still, many public health departments have been slow to adopt and implement cancer risk education campaigns on social media platforms (Han et al., 2019), leaving mostly user-generated content to fill the void of information. The development and evaluation of online health risk communication tools and programs will likely become an increasingly important part of carrying out public health research and practice going forward.

6.4 REFERENCES

- Canadian Cancer Society. (2021). Cancer statistics at a glance. Retrieved from: <https://cancer.ca/en/research/cancer-statistics/cancer-statistics-at-a-glance>
- Carter, B. T., & Luke, S. G. (2020). Best practices in eye tracking research. *International Journal of Psychophysiology*, 155, 49–62. <https://doi.org/10.1016/j.ijpsycho.2020.05.010>
- Chen, X., Orom, H., Hay, J. L., Waters, E. A., Schofield, E., Li, Y., & Kiviniemi, M. T. (2019). Differences in Rural and Urban Health Information Access and Use. *The Journal of Rural Health*, 35(3), 405–417. <https://doi.org/10.1111/jrh.12335>
- Cho, H., Silver, N., Na, K., Adams, D., Luong, K. T., & Song, C. (2018). Visual Cancer Communication on Social Media: An Examination of Content and Effects of #Melanomasucks. *Journal of Medical Internet Research*, 20(9), e10501. <https://doi.org/10.2196/10501>
- Chou, H.-L., Lo, Y.-L., Liu, C.-Y., Lin, S.-C., & Chen, Y.-C. (2020). Development and Psychometric Evaluation of the Cancer Health Literacy Scale in Newly Diagnosed Cancer Patients. *Cancer Nursing*, 43(5), E291–E303. <https://doi.org/10.1097/NCC.0000000000000711>
- Dahlstrom, M. F., Dudo, A., & Brossard, D. (2012). Precision of information, sensational information, and self-efficacy information as message-level variables affecting risk perceptions. *Risk Analysis: An Official Publication of the Society for Risk Analysis*, 32(1), 155–166. <https://doi.org/10.1111/j.1539-6924.2011.01641.x>
- Dasgupta, S. (2019). Participation as a Health Communication Strategy in HIV/AIDS Intervention Projects: An Examination of a Project Targeting Commercial Sex Workers in India. *Atlantic Journal of Communication*, 27(2), 139–151. <https://doi.org/10.1080/15456870.2019.1574535>
- Gaglio, B., Glasgow, R. E., & Bull, S. S. (2012). Do Patient Preferences for Health Information Vary by Health Literacy or Numeracy? A Qualitative Assessment. *Journal of Health Communication*, 17(sup3), 109–121. <https://doi.org/10.1080/10810730.2012.712616>
- Hamilton, J. G., Genoff Garzon, M., Shah, I. H., Cadet, K., Shuk, E., Westerman, J. S., Hay, J. L., Offit, K., & Robson, M. E. (2020). Illustrating Cancer Risk: Patient Risk Communication Preferences and Interest regarding a Novel BRCA1/2 Genetic Risk Modifier Test. *Public Health Genomics*, 23(1–2), 6–19. <https://doi.org/10.1159/000505854>
- Han, C. J., Lee, Y. J., & Demiris, G. (2018). Interventions Using Social Media for Cancer Prevention and Management: A Systematic Review. *Cancer Nursing*, 41(6), E19–E31. <https://doi.org/10.1097/NCC.0000000000000534>
- Hernandez, C., Wang, S., Abraham, I., Angulo, M. I., Kim, H., Meza, J. R., Munoz, A., Rodriguez, L., & Uddin, S. (2014). Evaluation of Educational Videos to Increase Skin Cancer Risk Awareness and Sun-Safe Behaviors Among Adult Hispanics. *Journal of Cancer Education*, 29(3), 563–569. <https://doi.org/10.1007/s13187-014-0624-z>

Hill, W. T., Brase, G. L., & Kenney, K. L. (2019). Developing a Better and More User-Friendly Numeracy Scale for Patients. *HLRP: Health Literacy Research and Practice*, 3(3), e174–e180. <https://doi.org/10.3928/24748307-20190624-01>

Hinyard, L. J., & Kreuter, M. W. (2007). Using Narrative Communication as a Tool for Health Behavior Change: A Conceptual, Theoretical, and Empirical Overview. *Health Education & Behavior*, 34(5), 777–792. <https://doi.org/10.1177/1090198106291963>

Jagiello, R. D., & Hills, T. T. (2018). Bad News Has Wings: Dread Risk Mediates Social Amplification in Risk Communication. *Risk Analysis*, 38(10), 2193–2207. <https://doi.org/10.1111/risa.13117>

Jones, L., & Wells, K. (2007). Strategies for Academic and Clinician Engagement in Community-Participatory Partnered Research. *JAMA*, 297(4), 407–410. <https://doi.org/10.1001/jama.297.4.407>

Kasperson, R. E., & Kasperson, J. X. (1996). The Social Amplification and Attenuation of Risk. *The Annals of the American Academy of Political and Social Science*, 545(1), 95–105. <https://doi.org/10.1177/0002716296545001010>

Kasperson, R. E., Renn, O., Slovic, P., Brown, H. S., Emel, J., Goble, R., Kasperson, J. X., & Ratick, S. (1988). The Social Amplification of Risk: A Conceptual Framework. *Risk Analysis*, 8(2), 177–187. <https://doi.org/10.1111/j.1539-6924.1988.tb01168.x>

Klein, W. M. P., & Stefanek, M. E. (2007). Cancer Risk Elicitation and Communication: Lessons from the Psychology of Risk Perception. *CA: A Cancer Journal for Clinicians*, 57(3), 147–167. <https://doi.org/10.3322/canjclin.57.3.147>

Lipkus, I. M., Samsa, G., & Rimer, B. K. (2001). General performance on a numeracy scale among highly educated samples. *Medical Decision Making*, 21(1), 37–44.

Ma, Z. (2021). The Role of Narrative Pictorial Warning Labels in Communicating Alcohol-Related Cancer Risks. *Health Communication*, 0(0), 1–9. <https://doi.org/10.1080/10410236.2021.1888456>

McAlpine, K., Lewis, K. B., Trevena, L. J., & Stacey, D. (2018). What Is the Effectiveness of Patient Decision Aids for Cancer-Related Decisions? A Systematic Review Subanalysis. *JCO Clinical Cancer Informatics*, 2, 1–13. <https://doi.org/10.1200/CCI.17.00148>

Paek, H.-J., Oh, S.-H., & Hove, T. (2016). How Fear-Arousing News Messages Affect Risk Perceptions and Intention to Talk About Risk. *Health Communication*, 31(9), 1051–1062. <https://doi.org/10.1080/10410236.2015.1037419>

Parker, C., Zomer, E., Liew, D., & Ayton, D. (2021). Characterising experiences with acute myeloid leukaemia using an Instagram content analysis. *PLOS ONE*, 16(5), e0250641. <https://doi.org/10.1371/journal.pone.0250641>

- Peters, E., Lipkus, I., & Diefenbach, M. A. (2006). The Functions of Affect in Health Communications and in the Construction of Health Preferences. *Journal of Communication*, 56(s1), S140–S162. <https://doi.org/10.1111/j.1460-2466.2006.00287.x>
- Peters, E., & Meilleur, L. (2016). The Influence of Affect on Health Decisions. In M. A. Diefenbach, S. Miller-Halegoua, & D. J. Bowen (Eds.), *Handbook of Health Decision Science* (pp. 109–120). Springer New York. https://doi.org/10.1007/978-1-4939-3486-7_8
- Rahal, R.-M., & Fiedler, S. (2019). Understanding cognitive and affective mechanisms in social psychology through eye-tracking. *Journal of Experimental Social Psychology*, 85, 103842. <https://doi.org/10.1016/j.jesp.2019.103842>
- Sandman, P. M. (1987). Risk communication: facing public outrage. *EPA J.*, 13, 21.
- Schwartz, L. M., Woloshin, S., & Welch, H. G. (1999). Risk Communication in Clinical Practice: Putting Cancer in Context. *JNCI Monographs*, 1999(25), 124–133. <https://doi.org/10.1093/oxfordjournals.jncimonographs.a024187>
- Shoots-Reinhard, B., Erford, B., Romer, D., Evans, A. T., Shoben, A., Klein, E. G., & Peters, E. (2020). Numeracy and memory for risk probabilities and risk outcomes depicted on cigarette warning labels. *Health Psychology*, 39(8), 721–730. <https://doi.org/10.1037/hea0000879>
- Simpson, M., Padilla, L., Keller, K., & Klippel, A. (2022). Immersive storm surge flooding: Scale and risk perception in virtual reality. *Journal of Environmental Psychology*, 101764. <https://doi.org/10.1016/j.jenvp.2022.101764>
- Slovic, P., Finucane, V., Peters, E., & Macgregor, D. (2002). The Affect Heuristics In: Gilovitch T, Griffin D, Kahneman D, editors. *Heuristics and Biases: The psychology of intuitive judgement*.
- Stacey, D., Samant, R., & Bennett, C. (2008). Decision Making in Oncology: A Review of Patient Decision Aids to Support Patient Participation. *CA: A Cancer Journal for Clinicians*, 58(5), 293–304. <https://doi.org/10.3322/CA.2008.0006>
- Stryker, J. E., Moriarty, C. M., & Jensen, J. D. (2008). Effects of newspaper coverage on public knowledge about modifiable cancer risks. *Health Communication*, 23(4), 380–390. <https://doi.org/10.1080/10410230802229894>
- Tang, C., & Rundblad, G. (2017). When “Safe” Means “Dangerous”: A Corpus Investigation of Risk Communication in the Media. *Applied Linguistics*, 38(5), 666–687. <https://doi.org/10.1093/applin/amv058>
- Trevena, L. J., Zikmund-Fisher, B. J., Edwards, A., Gaissmaier, W., Galesic, M., Han, P. K., King, J., Lawson, M. L., Linder, S. K., Lipkus, I., Ozanne, E., Peters, E., Timmermans, D., & Woloshin, S. (2013). Presenting quantitative information about decision outcomes: A risk communication primer for patient decision aid developers. *BMC Medical Informatics and Decision Making*, 13(2), S7. <https://doi.org/10.1186/1472-6947-13-S2-S7>

Wahlberg, A. A. F., & Sjoberg, L. (2000). Risk perception and the media. *Journal of Risk Research*, 3(1), 31–50. <https://doi.org/10.1080/136698700376699>

Weller, J. A., Dieckmann, N. F., Tusler, M., Mertz, C. K., Burns, W. J., & Peters, E. (2013). Development and Testing of an Abbreviated Numeracy Scale: A Rasch Analysis Approach. *Journal of Behavioral Decision Making*, 26(2), 198–212. <https://doi.org/10.1002/bdm.1751>

Wilkin, H. A., Moran, M. B., Ball-Rokeach, S. J., Gonzalez, C., & Kim, Y.-C. (2010). Applications of Communication Infrastructure Theory. *Health Communication*, 25(6–7), 611–612. <https://doi.org/10.1080/10410236.2010.496839>

7 APPENDICES

APPENDIX 7-1. Example vignette authored by government agency containing contextual information

Home
About Us
Careers
Reports
Health Line: 1-800-278-3055 ext 200



Your Health
Programs and Services
Health Topics

Home > Health Topics > Cancer > Bell Park Cancer Cluster Investigation

Press Release - Bell Park Cancer Cluster Investigation

Page Last Updated: September 28, 2018

Overview

In early 2018, the Greenville Health Unit started investigating a suspected cancer cluster located in the Bell Park neighbourhood of Greenville after a concerned citizen from the community reported 11 cases of cancer in the neighbourhood. Bell Park, located in Greenville's west end, is home to approximately 900 residents. Between 2013 and 2016, the rate of cancer in the neighbourhood was 1,222 per 100,000 residents, or about 2.1 times higher than the national rate.

Ongoing Investigation

The Greenville Health Unit is continuing to look for individuals diagnosed with cancer between 2013 and 2016, that lived in Bell Park for at least five years prior to 2013, or their next of kin, to find common exposures that could explain the cluster of cancer cases. Many industries and factories have been located in Bell Park historically, including Willamit Industries, a manufacturing plant specializing in soft plastics that operates in the North end of Bell Park and employs many of the neighbourhood's residents. Based on air quality testing conducted in Bell Park last month, officials from the Greenville Health Unit have concluded that the cancer cases are unlikely to be attributed to air pollution and are still examining other potential causes.

Cancer Facts

- One in two individuals are expected to develop cancer during their lifetime.
- Most cancers take at least 5 years to develop after first exposure. Some take longer.
- Family history is a risk factor for many types of cancer.
- Exposure to first-hand or second-hand tobacco smoke can greatly increase an individual's risk of cancer.

Information for Current and Former Residents of Bell Park

The Greenville Health Unit continues to meet with people who were diagnosed with cancer between 2013 and 2016 while living in the neighbourhood. The Health Unit will continue to monitor cancer rates in Bell Park and inform the community on how to lessen their risk of developing cancer in the future. Residents are encouraged to attend the next community meeting for updates on the investigation scheduled on Wednesday, October 17th, 2018 at the Lawrence Bradley Community Centre in Bell Park.

Any current or former residents of Bell Park diagnosed with cancer are encouraged to contact the Greenville Health Unit at: [1-800-278-3055](tel:1-800-278-3055) or health.unit@greenville.com



Hazard	Risk
Getting in a car accident	1 in 50
Smokers getting cancer	1 in 100
Getting diagnosed with heart disease after the age of 20	1 in 200
Death from influenza	1 in 10,000
Being struck by lightning	1 in 100,000

Risk ladder depicting the risks of common hazards a person could encounter in an average year.

Related Information:

[Screening for Cancer](#)

[Cancer Prevention](#)


[2017 Annual Greenville Public Health Report](#)

APPENDIX 7-2. Example vignette authored by news agency containing personal stories

GREENVILLE DAILY FEATURED: Annual Greenville festival SUBSCRIBE
13°C view full forecast>>

LOCAL OPINION WORLD POLITICS SPORTS HEALTH BUSINESS


Cluster of cancer cases discovered in Bell Park

JERRY WALSH  Updated: September 28, 2018

When John Houtten was diagnosed with stage two lung cancer nearly two years ago his focus was squarely on getting healthy and working out a treatment plan with his doctor that would give him the best chances of survival. But a few weeks after his diagnosis, his wife, Cheryl, happened to strike up a conversation with another neighbour at the local dog park and found out John was the third resident diagnosed with lung cancer in their neighbourhood that year.

‘There’s got to be something here.’

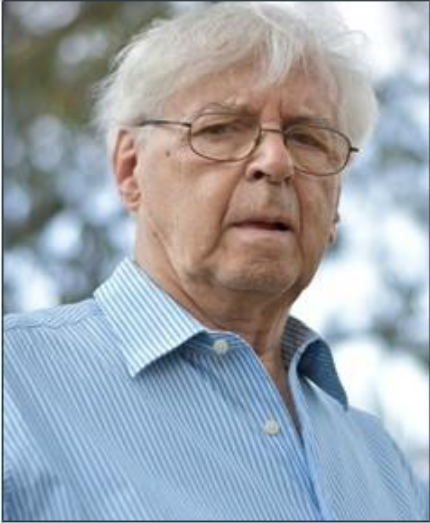
“It was a terrible coincidence. Soon we started to hear about neighbours with other cancers like breast and colon that had been diagnosed in the last few years until we had a list of 11 of us. I thought, wow, there’s got to be something here.” said Houtten, seated at his home’s back porch in Bell Park, a quiet residential neighbourhood of about 900 people in Greenville’s west end. Houtten contacted the Greenville Public Health Unit, which sparked an investigation into the cases of cancer earlier this year. “People are scared there’s something in this neighbourhood that’s making us sick” said Houtten.



The Greenville Public Health Unit provided updates on the investigation to residents of Bell Park last night. (Greenville Daily)

‘Coincidence, not cluster, residents told.’

The health unit is still investigating whether the cluster of cases in Bell Park constitutes a cancer cluster. “It could just be coincidence and bad luck that these cases clustered together. We are still investigating,” said Dr. Farrah Kent, Greenville’s Medical Officer of Health, at last night’s community meeting in Bell Park. The Greenville Public Health Unit hosted its first community meeting about the cancer cluster investigation with Bell Park residents on Thursday, where residents learned that the cancer rate in Bell Park may be more than double the national rate based on their preliminary analysis. Residents of Bell Park who have lived there for at least five years and have had a cancer diagnosis are being asked to contact Greenville’s Public Health Unit as they continue to gather information for their investigation. John Houtten remains hopeful he will get answers from the Health Unit soon. “It’s been tough not knowing why this happened. How many more people are going to get sick?”



John Houtten first reported the cancer cluster in Bell Park. He was diagnosed with lung cancer in 2016. (Greenville Daily)

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APPENDIX 7-3. Findings from logistic regression analyses for health literacy, numeracy, gender and education on self-efficacy belief outcome.

Parameter estimates	β	SE	Wald	<i>p</i>	Exp(β)	95% CI -	95% CI +
Intercept	-0.67	0.90	-0.75	0.46	0.51	0.09	2.98
Health literacy	1.13	0.98	1.16	0.25	3.10	0.45	21.19
Numeracy	0.65	0.89	0.73	0.47	1.91	0.33	11.02
Health literacy*Numeracy	-0.64	1.05	-0.61	0.54	0.53	0.07	4.09
Female gender	-0.39	0.38	-1.03	0.30	0.68	0.32	1.42
Education above Bachelor's degree	0.30	0.33	0.92	0.36	1.35	0.71	2.59

Note: β = regression coefficient; SE = standard error of the regression coefficient; Exp(β) = exponential coefficient or odds ratio; CI = confidence interval of Exp(β).

APPENDIX 7-4. Findings from logistic regression analyses for health literacy, numeracy, gender and education on expert efficacy belief outcome.

Parameter estimates	β	SE	Wald	<i>p</i>	Exp(β)	95% CI -	95% CI +
Intercept	0.84	0.90	0.94	0.35	2.32	0.40	13.55
Health literacy	-0.91	0.98	-0.93	0.35	0.40	0.06	2.72
Numeracy	-1.38	0.89	-1.54	0.12	0.25	0.04	1.45
Health literacy*Numeracy	1.29	1.04	1.24	0.22	3.63	0.47	27.96
Female gender	0.10	0.37	0.26	0.80	1.10	0.53	2.29
Education above Bachelor's degree	-0.03	0.33	-0.10	0.92	0.97	0.51	1.84

Note: β = regression coefficient; SE = standard error of the regression coefficient; Exp(β) = exponential coefficient or odds ratio; CI = confidence interval of Exp(β).

APPENDIX 7-5. Findings from logistic regression analyses for health literacy, numeracy, gender and education on science efficacy belief outcome.

Parameter estimates	β	SE	Wald	<i>p</i>	Exp(β)	95% CI -	95% CI +
Intercept	0.60	0.91	0.66	0.51	1.82	0.31	10.87
Health literacy	0.50	1.06	0.47	0.64	1.65	0.21	13.34
Numeracy	-0.61	0.90	-0.68	0.50	0.54	0.09	3.17
Health literacy*Numeracy	-0.19	1.13	-0.17	0.87	0.83	0.09	7.56
Female gender	0.15	0.39	0.38	0.70	1.16	0.54	2.51
Education above Bachelor's degree	0.75	0.37	2.06*	0.04	2.13	1.04	4.36

Note: β = regression coefficient; SE = standard error of the regression coefficient; Exp(β) = exponential coefficient or odds ratio; CI = confidence interval of Exp(β); * denotes significant *p*-value < .05.