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Original mixed methods research

Reducing the risks of extreme heat for seniors: communicating risks and building resilience

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Abstract

Introduction: As the global climate changes, heat waves are having a disproportionate impact on seniors and other socially vulnerable groups. In order to mitigate the threats of extreme heat, it is critical to develop and promote resources for coping during these events. A better understanding of the role of risk perceptions and the factors that influence them is needed in order to improve public responses to threatening events, particularly among seniors.

Methods: This mixed-methods study examined risk perceptions and coping practices in seniors using qualitative interviews (n = 15) and a survey (n = 244) of seniors across Waterloo Region, Ontario.

Results: Seniors showed relatively accurate risk tracking as indicated by the link between measures of actual risk and perception of personal risk. While vulnerability to heat is often believed to be associated with inaccurate perceptions of risk, within our sample, vulnerability appears more strongly related to social location and access to resources. Participants described social connections as important resources for resilience, but the stigma surrounding vulnerability, and other social norms, as barriers to seeking support.

Conclusion: The positive relationship between participants' risk perceptions and actual risk for negative consequences of extreme heat was an important finding, given that problems of emergency preparedness and risk reduction are often framed as issues of awareness of risk, rather than social location and inequality. Along with increased public resources for coping with extreme heat, communicating about resources, fostering social connections and reducing stigma may be important leverage points for increasing the resiliency of seniors to heat waves.

Keywords: *climate change, heat waves, seniors, health promotion*

Highlights

- Mitigating the risks of increasing extreme heat events for seniors requires the development and promotion of public resources for coping during these events.
- The lack of response to public efforts to mitigate these risks has previously been framed in terms of inaccurate risk perceptions.
- Vulnerability to heat has been associated with inaccurate perceptions of risk; however, seniors in our sample showed relatively accurate risk perceptions, and vulnerability appears more strongly related to social location and access to resources.
- Improving communication about available resources, building social connections and reducing social stigma and inequality can help promote better resilience among seniors during heat waves.

Introduction

Recent climate models predict that extreme weather events will increase in frequency and intensity over the next several decades,[1-4] leading to significant consequences for human health.[5] An increase in heat waves is particularly concerning, given the correlations among increasing global ambient temperature, increases in extreme heat events (also known as heat waves) and heat-related mortality risk. Studies have found a nonlinear association between hospitalization rates and episodic heat waves, with increased temperatures contributing to a seven-fold rise in hospital admission rates.[6] The severity of heat waves is greater in cities, because of the urban heat island effect,[7] and has become increasingly salient following the heat-related deaths of over 700 people in Chicago during a heat wave in 1995[8] and 70 000 Europeans in 2003.[9]

Studies have also begun to demonstrate that heat-related illnesses and deaths disproportionately affect individuals from lower socioeconomic backgrounds,[3,10] those who live alone[11] and those living in areas with higher crime rates or substandard housing,[2,12] suggesting that heat waves have impacts that are both socially and spatially differentiated.[2,13] Seniors (those aged 65 years and older) are at higher risk for the negative consequences of heat, including hospitalization for heat-related illnesses such as heat exhaustion, heat stroke and heat syncope.[6] They are also at greater risk for hospitalization for complications of pre-existing conditions and increased mortality rates during heat waves,[2,6,14] a risk that is further amplified by the presence of the additional

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heat-related illnesses listed above.[2,14] While seniors are at particular risk from the negative consequences of heat, there are only a few studies that have examined the effects of heat on this population.[14-16] Given demographic trends indicating an aging population in Canada and around the world,[15] a better understanding of heat mortality prevention strategies among this specific group is urgently needed.[2,6,10,17]

Consequently, public health departments are beginning to use more comprehensive approaches to reduce community-dwelling seniors' vulnerability to heat waves, such as revamping infrastructure, increasing knowledge of risks and improving protective measures and response systems.[4] However, many current heat-health campaigns throughout Canada and abroad report a disconnect between the communication strategies used and the behaviour performed.[3,14,18-21] Others have reported little consensus on which communication styles are best for communicating an effective and impactful heat wave plan.[22] Seniors' subjective experiences of heat waves are critical to enhancing adaptive capacity,[10,13,19,22,23] and changing self-perceptions of risk remains key to preventive action.[1,2,19] However, only a few studies have looked at risk perceptions in relation to extreme weather, and to heat waves more specifically, among older adults.[9,23,24] Enhancing our understanding of these perceptions may contribute to the development of more efficient, effective and better-tailored heat-health communication strategies,[2,3,9,18] bolstering the information processing and behavioural strategies of seniors living in community or in supportive housing, and those who support them.[23,25]

Our current understanding of risk perceptions stems mostly from scholarship examining other forms of extreme weather (such as hurricanes or flooding).[1,26] Lower risk perceptions have been linked to less effective coping strategies,[21,27] whereas increased risk perceptions have been positively associated with more favourable adaptation attitudes.[27,28] Those who are more aware of their own constraints are more likely to react appropriately to environmental warnings.[2] Factors influencing risk perception include personal experiences of extreme weather,[27-30] political dispositions,[30-32] gender,[1,3] attitudes and beliefs about climate change[33] and sense of self-efficacy to adapt as needed.[31] Proximity to structural resources and social networks, or the lack thereof, can also amplify or dampen perceptions of risk.[24,33-35]

According to the few studies on seniors' risk perceptions of heat waves, many seniors do not consider themselves to be at a "vulnerable" age,[11,22] and consequently see themselves as at a lower risk than others.[1,14,21,36] In the event of heat waves, many seniors exaggerate the effectiveness of preventive measures used or deny their actual level of risk.[14] Others may experience cognitive dissonance because of alternative belief systems (e.g. need to be self-reliant) or may underestimate the risks due to their limited understanding of the issues at hand.[35-37]

While existing research offers some initial insights, the social and contextual circumstances that inform seniors' inadequate perceptions of the risks of heat waves and their consequent shortfalls in adaptive capacity remain largely unknown. With several researchers and public health advocates calling for further examination of this issue,[2,10,14] we sought to add to the existent literature by exploring and predicting factors that contribute to the risk perceptions and coping practices and resources used by seniors in Waterloo Region, Ontario. The objectives of this study were to (1) understand seniors' current perceptions of the risks of extreme heat, (2) identify factors that contribute to risk and risk perception, (3) explore how to improve risk perceptions and resilience to extreme heat, and (4) contribute to public policy and planning to reduce seniors' vulnerability to heat waves.

Methods

For this project, we took a community-based, participatory approach, using mixed methods and a sequential exploratory design to gain a deeper understanding of how seniors perceive, experience and cope with heat waves. Our approach was influenced by dominant theories of risk perception and planned behaviour, including Edelstein's risk personality,[38] which generally suggest that an individual's evaluation of possible outcomes and their attitudes toward prescribed behaviours that affect these outcomes can predict their intentions and behaviour,[38,39] but also by more recent critiques of these theories' emphasis on internal factors and lack of attention to the broader social and environmental context.[40]

The project had a community focus, building on the results of a previous study exploring the impacts of a changing climate on homeless people in Waterloo Region that identified seniors as a group at particular risk, and on the partnerships created through that study. An advisory committee (consisting of representatives from local agencies serving seniors, providing housing and overseeing public planning and policy) was formed to provide input on the study design and to oversee the data collection, analysis and dissemination of results. Two local seniors who were active in their community were also hired as peer researchers and participated in the study design, data collection and analysis and dissemination of results.

The Regional Municipality of Waterloo is a mid-sized municipality that includes three cities and several rural townships in Canada, where climate models are predicting increased heat waves within the next several decades. With the support and interest of local organizations, we sought to develop research that could inform local planning and policy, with the potential to be generalized to other regions.

The study included two data collection phases: an exploratory phase consisting of 15 qualitative interviews with Waterloo Region residents aged 65 and older, and a broader quantitative survey informed by the exploratory phase. We used a combination of snowball sampling and convenience sampling, working with community partners to connect with a sample of participants likely to have important and informative experiences while also conducting broader public outreach at public events such as weekly farmers' markets and community dinners. Exceptions to the age requirement were made for participants recommended by our community partners who had experiences that were unique or difficult to capture (such as street-involved and low-income seniors and newcomers to Canada). This allowed one interview participant, aged 51, and three survey participants, aged between 52 and 64, with important lived experiences to participate.

Ethical considerations

The Research Ethics Board at Wilfrid Laurier University approved all study procedures (REB#4482) including recruitment, data collection, storage and dissemination processes. We obtained informed consent from all interview and survey participants. The research assistants and peer researchers also participated in team interview training, which included a discussion of research ethics and confidentiality.

Qualitative interviews

In the initial interview phase, seniors were invited to participate in a brief screening questionnaire to determine their eligibility to participate in the study, and to assess demographic factors to improve the representativeness of our sample. We invited eligible participants to participate in an interview covering topics such as experiences of extreme weather, perceptions of current weather and broader climate, perceived risks of heat waves for themselves and other seniors and strategies for coping with extreme heat. In order to increase the quality of content in terms of both academic interest and participant expertise and shared experiences, interviews were conducted in person by pairs of research team members, each including one research staff member and one peer researcher. This allowed conversations to be guided by not only the interview guide and research expertise, but also by the insight and experiences of our senior peer researchers. The interviews were digitally recorded, anonymized and transcribed word for word. Interviews lasted approximately 60 to 90 minutes, and were conducted at locations of the participants' choosing.

Quantitative survey

The questionnaire for the second phase of this sequential design study was developed by the research team and community advisory group based on factors identified in the literature on seniors and heat waves, a measure of risk perception developed for emergency responses to threats of terrorism[40] and key themes from the qualitative interviews. Topics covered by the survey included demographic information (using questions based on those in the Canadian census form), risk factors, access to resources, perceptions of risk, protective behaviours, use of resources and perceptions of gaps in resources for seniors. The initial questionnaire was drafted by the research team, then reviewed to enhance content validity by additional researchers with expertise in climate change and risk perception and community advisors with experience working with seniors. Our research team adapted the survey questions based on the feedback from these expert reviewers to develop the final questionnaire. The survey was distributed online via email, in person at community events and through community partner agencies, both in person and by mail.

Analyses

Qualitative interviews were digitally recorded and transcribed verbatim by a research assistant from the project team. A second research assistant reviewed a sample of transcripts in order to ensure accuracy. The team conducted an initial, inductive thematic analysis of the interviews, in which two research assistants reviewed each transcript and noted major relevant themes and categories (clusters of themes). These themes were then organized into a coding framework, which was further refined to develop a coding scheme through discussion with the project team (including the two peer researchers). Once a final coding scheme was agreed upon, all transcripts were coded by at least two research team members independently, applying the final coding scheme to all transcripts. The coded transcripts were entered into a database using NVivo qualitative analysis software, version 11 (QSR International Americas Inc., Burlington, MA, USA), which was used to generate summaries of the major themes from the interviews. The research team used these summaries to highlight key results, summarize responses to our central research questions and note other important trends in the interviews. We presented the final overarching categories and themes to the community advisory board to allow for their input and to collaboratively develop the presentation of the final results.

Quantitative survey responses were entered into a Microsoft Access form using forced responses to ensure accurate data entry. We then analyzed the quantitative data using R version 3.0 (R Core Team, Vienna, Austria). We computed means or frequencies for all study variables. We further analyzed survey responses for Pearson's r or Spearman's rho correlations between various individual-level variables such as demographic characteristics and risk awareness, and factors contributing to risk in seniors in our sample. We developed two risk indices to assess objective risk using the clusters of factors within the survey associated with specific types of risk. For example, health risk, representing the likelihood of negative health effects in extreme heat, included two factors: (a) the presence of health conditions that are negatively impacted by heat, and (b) having previously experienced heat exhaustion or other heat-related illness. Adaptability risk, representing the ability to cope during extreme heat, included knowledge and behaviour factors: (a) knowing the symptoms of heat exhaustion; (b) being aware of heat warnings; (c) using or accessing resources during heat waves; and (d) demographic factors such as income level, living alone, and housing—including ventilation and air conditioning.

Results

While the qualitative and quantitative components and initial analyses in this study were conducted sequentially, in our final analyses we considered results across datasets to triangulate a more complete picture of seniors' risk and resilience. In this report, the results are discussed simultaneously by theme in order to triangulate them and for ease of understanding.

Sample

Recruitment for this study proved challenging, particularly for the qualitative component, as many seniors seemed to lack interest in talking about the subject of heat waves or climate change in general. Political orientation and beliefs about climate change also influenced people's willingness to participate in this study. In total, fifteen participants completed qualitative interviews between August 2014 and September 2015, and 244 participants completed the survey questionnaire between April 2016 and September 2016.

Of our fifteen interview participants, five (33.3%) identified as male and ten (66.7%) identified as female. They ranged in age from 51 to 84 years, with a mean age of 71.7 (SD 9.6). Nine participants lived alone (60%), while the other six lived with a partner or with other family members (30%). Four participants were born outside of Canada (26.7%). Four participants (26.7%) also identified as visible minorities, with two participants identifying as East Asian, one as First Nations and one as Latino, and the rest identifying as Caucasian and/or Canadian (73.3%). Two participants (13.3%) identified as people living with disabilities.

Survey participant demographics are summarized in Table 1, along with local comparison data from Canada's 2016 Census. Participant demographics are summarized in Table 2.

General awareness

Overall, participants reported being aware that weather was changing, and characterized the weather in Waterloo Region as unpredictable. Since we received mixed responses to climate change terminology in our introductory conversations and interviews, we chose to frame our conversations in the context of extreme weather and heat and to avoid broader climate questions unless participants raised the topic themselves. Many participants felt unqualified to make broader predictions about climate, choosing only to comment on immediate weather experiences and experiences from their past.

> I have tracked this in my mind for the last 20 years because I grew up on the farm and I know our seasons. You had spring … you had summer … you had fall. You had winter and spring. On the farm you are dependent on the weather for getting crops in and planting crops. I just know that the weather has changed a lot. (Ellen)

Among the survey participants, there was considerable variation in perceived negative influences of climate change. As participants' perception of negative impacts of climate change increased, so did their perceived risk for people in Waterloo Region ($r = .614$, $p < .001$).

Risk profile

To better understand the process by which environmental stressors such as extreme heat result in negative psychological consequences, Michael Edelstein proposed the formulation of a risk personality.[38] A risk personality describes the defining characteristics of the specific environmental stressor as it may be experienced by people living in a certain proximity to the stressor.[38] This is important because the psychological impacts are caused by an interaction of the characteristics of the environmental stressor and the way individuals appraise that risk and cope with its impacts. This framework focusses on three key factors that contribute to how a person evaluates risk: cause, consequence and controllability. In this section, key themes and results that emerged from our analyses are presented within this framework.

Causes

In assessing risk, people assess the causal attributes of the environmental stressor, such as its origins, its temporal and geographical boundaries and its nature.[36] In Waterloo Region, seniors considered not only heat waves in isolation, but also increased heat and other extreme weather as a component of global climate change more broadly.

When asked to reflect on their perceptions of how weather has or has not changed over time, many interview participants

TABLE 1
Demographic characteristics of respondents to survey on seniors' awareness of heat wave risks, Waterloo, Canada, 2016, compared to local census data

Demographic	N	%	2016 Canadian census comparison[a]	Range	Median	Mean
Age (years)	225	N/A	—	52–97	74	74.3
Gender	231	—	—	—	—	—
Female	157	63.6	—	—	—	—
Male	72	29.1	—	—	—	—
Other	2	0.8	—	—	—	—
Born outside Canada	15	6.4	—	—	—	—
Income	181		Median			
Less than $5000	15	8.2	$35 714.00	Less than $5000–$100 000 or more	$20 000–$49 999	—
$5000–$19 999	53	29.3				
$20 000–$49 999	68	37.6				
$50 000–$79 999	29	16.0				
$80 000–$99 999	8	4.4				
$100 000 or more	8	4.4				
Housing condition	230		% Regional population			
House	107	46.5	55.7	—	—	—
Apartment or condominium	112	48.7	44.2	—	—	—
Retirement residence	11	4.8	N/A	—	—	—
Living alone	119	48.8	24.4	—	—	—

Abbreviation: N/A, not applicable.

Note: — signifies no data.

[a] Data from Statistics Canada. Census Profile, 2016 Census—Waterloo, CY [census subdivision], Ontario and Waterloo, RM, Ontario [Internet]. Ottawa (ON): Statistics Canada; 2017. [Catalogue No.: 98-316-X2016001]. Released November 29, 2017 [cited 2019 Apr 11]. Available from: https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/index.cfm?Lang=E

TABLE 2
Summary of results of survey on seniors' awareness of heat wave risks, Waterloo, Canada, 2016

Variable		N	%	Range	Median	Mean
Risk factors						
Health risk		244	—	0–3	1.00	1.44
Adaptability risk		241	—	0–8	2.00	1.85
Experience of heat-related health problems		241	44	—	—	—
Number of heat-related health conditions		238	—	0–6	1.00	1.26
Knowledge of heat-related health symptoms		238	8	—	—	—
Perceptions of risk						
Negative impact of CC	Self	221	—	1–4	3.00	2.86
	Community	216	—	1–4	3.00	3.02
Negative impact of heat waves	Self	227	—	1–4	3.00	2.88
	Community	208	—	1–4	4.00	3.41
Protective behaviours						
Preparedness for heat waves		229	—	1–3	3.00	2.52
Check up on others		241	—	1–3	2.00	2.20
Resources						
Knowledge		208	63.5	—	—	—
Access	Cooling	232	98.3	—	—	—
	Information	205	97.6	—	—	—
	Friend/family	181	86.7	—	—	—
	Water	208	98.6	—	—	—
Likelihood of use	Cooling	178	—	1–3	2.33	2.34
	Information	157	—	1–3	2.50	2.44
	Friend/family	133	—	1–3	2.00	2.21
	Water	145	—	1–3	3.00	2.81
Perception of gap		222	—	0–3	3.00	2.56

Abbreviation: CC, climate change.
Note: — signifies no data.

believed that weather patterns had changed, but were reluctant to draw conclusions about overall trends. They frequently described the weather as unpredictable, and often felt unqualified to make predictions for future weather.

> We are definitely not getting the weather that we did get 10 even 15 years ago. The whole change of weather, the whole atmosphere has changed. I think it has. Like you are not getting the same good weather. It's either good or it has completely gone the opposite direction. It is completely measurable. The smogginess. The sun, you don't get as much sun anymore. It is dull and dreary. Maybe it is because I am getting older, I don't know … (Sanaa)

Participants had a mixed response to climate change terminology, with some supporting and having knowledge of global climate change and its causes, and others not believing there was a broader global pattern, or that changes to climate were natural long-term patterns.

> It's been more changeable than before I think … yeah. I am very aware of climate change … I even went on a march to Toronto a few weeks ago … (Leslie)

Experiences with extreme heat were mediated by personal factors such as age, health and resources. Some participants were very aware of heat waves and their effects on their own well-being, while others did not notice any effects or found increased heat easy to deal with.

Consequences

The second factor contributing to risk perceptions is the potential consequences of the environmental stressor.[38] This includes the known impacts on the environment and the physical and psychological well-being of the people experiencing the stressor. Participants in this study had varied experiences with extreme heat and its consequences, as well as varied perceptions of the potential consequences of extreme heat and sense of personal preparedness to cope with extreme heat.

Interview participants who lived with health conditions such as heart disease or respiratory conditions often reported being aware of the effects of increased heat on their well-being, and took measures to cope and protect themselves during heat waves. Participants mentioned impacts on both their physical and mental well-being:

> I am slower, I move slower. Sometimes just moving horribly slow. My knees hurt sometimes, you know? I do not, like, my body doesn't like it, and I don't like it. I don't think well. There's a distract … It's a distraction for me because my body doesn't want it. It's a huge distraction for me. (Philip)

> … I don't like heat waves, I can't stand them. I am cranky and I can't tolerate BS from people when it's, it's overheated. So I stay where I can get angry with 'em. I stay home … (Sanaa)

Several interview participants reported specific instances when they became aware of previously unknown risks, often due to a personal experience of overheating, whether their own or that of a loved one:

> And I said I could sleep in the family room, it's no big deal. Well, my son came over to check up on me around 7 p.m., and I thought that I was warm—I felt warm, but I guess I looked worse than I felt. He said "That's it, you're coming to my house—pack your bag. This is ridiculous! I mean, look at you, your face is as red as that cup." So anyway he packed me up and we went over to his place. It wasn't until we got to his place did we realize how hot I really was. (Eleanor)

While some participants who had experiences with heat-related health consequences were aware of the impact of heat on their health, in general, participants' awareness of the health consequences of heat and the symptoms of heat-related illness was relatively low. When asked to select the symptoms of heat exhaustion or heat stroke from a checklist, only 8.4% of our survey participants correctly identified all eight symptoms, and fewer than half of the participants (46.2%) correctly identified six out of eight symptoms.

Waterloo Region is typically cold and snowy in the winter, which often lasts almost six months. Thus, for residents of this area, heat is connected with summer and generally perceived as something positive. This was also true for the participants of this study. Some participants distinguished summer heat (which they liked) from the high humidity during heat waves that bothered them more:

> No, again, I don't do a whole lot of complaining about the weather, 'cause the only time I do a lot of complaining, like I said, is in the summer when it is humid like this and that really irritates me. (Maria)

Risk assessment

In this study, participants were asked about both their perceptions of their own vulnerability to extreme heat, and the objective factors that influenced their risk. In order to better understand the relationship between perceived and actual risk, we created two indices representing actual assessments of risk: health risk and adaptability risk. Health risk represented the influence of health conditions affected by heat and previous heat-related illness. Adaptability risk represented factors and resources that affect the likelihood of coping well with extreme heat, including knowledge of heat-related illness, awareness of heat alerts, access to emergency resources and support, having air conditioning or good ventilation at home, living alone, likelihood of using available resources, and income.

Overall, seniors showed some degree of accurate risk tracking as indicated by the link between our assessment of actual risk and their perception of their own risk. Those with higher actual *health risk* did perceive higher personal risk of negative impacts of extreme heat ($r = .443$, $p < .001$). Those with higher *adaptability risk* (i.e. less awareness and access to resources) also perceived a higher degree of personal risk of negative impacts of extreme heat ($r = .184$, $p = .006$).

While vulnerability to heat is often thought to be related to inaccurate perceptions of risk, within our sample, vulnerability to extreme heat appears more strongly related to social location and access to resources. Income was one key factor, as perceptions of higher risk of negative consequences of heat were correlated with lower income ($r = -.198$, $p = .004$), with the level of perceived risk decreasing as income increased. Type of housing was a contributor to perceived risk, with 61.9% of those at high risk living in apartments as opposed to houses (38.1%). In general, the fewer the resources participants felt were available to them, the higher their perceived risk of negative impacts of extreme heat ($r = .288$, $p < .001$).

Controllability

The perceived controllability of a stressor is a final important assessment that affects people's risk perceptions and response. One way to control negative outcomes is to prepare for them in advance in order to mitigate or avoid negative impacts. We asked our survey participants to rate their general sense of preparedness for extreme heat, as well as their access to specific coping resources. Overall, 50% of participants felt they were well prepared to cope with extreme heat. In terms of specific resources to help cope with heat, 98.7% of participants expected to see some sort of warning in the news if there were an extreme heat event, 97.6% reported having access to information about the weather and coping strategies, 98.3% had access to at least one way of cooling themselves (e.g. air conditioning, fans), 98% had access to extra bottled water at home and 86.7% had friends or family members nearby whom they could ask for help.

Based on the broad availability of resources, seniors in our sample did not appear to be a group at particularly high overall risk. However, many of the same demographic factors that affected their actual risk and perceived personal risk of the negative impacts of extreme heat also predicted their perceptions of controllability and preparedness. Fifty percent of participants who felt they were not very well prepared (either completely unprepared or somewhat prepared) for extreme heat lived alone, with 62.5% of those who felt completely unprepared living alone, and 65.2% of those who felt "only somewhat prepared" living alone.

A total of 56.3% of those who lived alone felt unprepared or only somewhat prepared to cope with extreme heat, compared to 32.5% of those living with a partner, 38.9% of those living with family or 25% living with other older adults. This suggests that social connectedness may play an important role in preparedness and risk mitigation. Furthermore, while 86.7% of participants reported that they had friends or family members they could ask for assistance, only 50% of those who had support reported that they would be very likely to use it.

Some participants suggested that social stigma, perception of personal control and beliefs about individual responsibility may be factors influencing seniors' willingness to ask for help. Many spoke of the need to take personal responsibility for their well-being:

> … taking some responsibility … I can stay in if it is not urgent for me to stay out. I can just stay in with AC and do some other things like reading or some hobbies and stuff rather than complain because that is just going to make you hotter and affect your disposition so I am trying that way myself not to. (Florence)

> … take responsibility. If it's hot, don't stand there in the sun and say "Oh my goodness, it is hot." (Mark)

A common theme in the interviews was the need to simply accept and put up with difficult or uncomfortable conditions:

> I mean in the wintertime if it's misty and smoggy and crappy, well ok you don't want to go outside, I understand that, but have some nice weather so you can go out and enjoy the cold here. Suck it up buttercup, you know? (Sophie)

Finally, another element that may make seniors reluctant to ask for help may be a fear of being perceived as vulnerable, which could lead to a loss of independence.

Resilience

Another survey finding was that many seniors took time to check in on friends, family and neighbours during extreme heat, with 43.2% being somewhat likely to check on others, 38.2% very likely, and only 18.7% not at all likely to do so (data not shown). This is noteworthy, given the low likelihood that participants in this sample would ask friends or family for help, as well as the finding that individual knowledge of the symptoms of heatstroke was low and that those who were less likely to ask a friend or family member for help were likely to be at higher adaptability risk ($r = -.282$, $p = .001$).

Building resilience

Participants in this study had many helpful suggestions for ways to increase awareness of the risks of extreme heat and for resources that could support or build resilience. Seniors reported that heat warnings did not always reach them, and that there was a lack of information about local resources, such as cooling centres. They identified doctors, pharmacists, community centres and local news as trusted sources of information that could be used to disseminate this information further. Participants also noted that the majority of seniors learned to rate temperatures using the Fahrenheit scale, and that weather reports using Celsius were not as accessible to them.

Discussion

Risk awareness is an important component of building resilience to extreme heat, particularly in vulnerable populations. In this study, we set out to assess risk awareness, risk perceptions and preparedness for extreme heat among seniors in Waterloo Region. Researchers around the world have called for investigations of seniors' risk perceptions and coping practices during extreme heat; however, risk perceptions may not actually be the key to understanding seniors' risk and resilience.[2,10,14] We found that the seniors in our sample had a realistic overall assessment of their personal risks during heat waves. However, not all seniors in our sample were at equal risk, and not all seniors had equal or sufficient access to resources to protect themselves during extreme heat events. Seniors who perceived themselves to be at lower risk of negative consequences of extreme heat tended to have better health and access to more resources, while those who had concrete risk factors, such as pre-existing health conditions, lack of social support and lower income, tended to be aware of their elevated risks. Furthermore, stigma and social norms may have prevented some seniors who do have access to protective resources from making use of them.

The positive relationship between participants' risk perceptions and actual risk for negative consequences of extreme heat was an important finding, given that problems of emergency preparedness and risk reduction are often framed as issues of awareness of risk.[1,3,5,14,21,34,35] Our participants appeared to have accurate assessments of their own risks. However, there were significant differences in the demographic factors associated with the risks of extreme heat. Participants who were lower income, lived alone or had existing health conditions were at increased risk, and were relatively more aware of these risks, but their awareness did not necessarily lead to a reduction in their vulnerability.

Reducing vulnerability

Many risk mitigation initiatives focus on informing seniors of their risk and encouraging them to take personal actions to reduce it. This was reflected in participants' comments about the personal responsibility to be aware of their wellbeing, to push through discomfort and to take action on their self-care. Knowledge and self-care are important components of risk mitigation, and our results show that participants could be better informed about the symptoms of heat-related illness and resources in their community to help them take care of their health. However, many participants in this study reported that they were unlikely to make use of community resources or ask for help during a heat wave, and some suggested that social stigma, perceptions of personal responsibility, and fear of being perceived as vulnerable may be barriers to seniors' use of resources to stay healthy during heat waves. Risk factors such as social isolation, lack of social support and lack of access to cooling and other protective resources also played important roles in risk, and are more difficult for seniors to change for themselves.

Knowledge of risks and resources

Seniors in this sample had gaps in their knowledge of the symptoms of heat-related illnesses, and were open to receiving more information about the risks of heat and resources for coping. Having information that is directly relevant to seniors, particularly those with specific risk factors, disseminated through trusted sources such as community nurses, general practitioners and family doctors, local clinics, pharmacists and community centres could increase the accessibility, relevance and trustworthiness of heat-related resources to seniors. Finding out which local media outlets seniors favour, through community consultation and by ensuring that heat alerts and resources are disseminated through the best channels, could also increase the likelihood of important heat-related information reaching seniors.

Communication

Using language that is relevant, accessible and engaging for seniors is critical for the uptake of information.[22,34] Since many seniors in our sample learned the Imperial system before Canada switched to the metric system, communicating weather alerts in both Celsius and Fahrenheit degrees could help seniors recognize when the temperature puts them at risk. Avoiding technical, scientific language, referring to weather rather than climate and referencing the experience of humidity rather than heat are also recommended findings. Using strength-based language and avoiding language that may be disempowering or socially stigmatized is also important for supporting seniors' independence and sense of agency.[22,37] This could include avoiding the use of climate change terminology in broader alerts or preparedness resources, and avoiding terms that seniors may dislike or do not identify with, such as "vulnerable" or "elderly." Community consultation and stakeholder engagement is a vital tool for learning best practices for communication with local seniors.

Access to resources

While many seniors in our study felt they had the resources they needed to stay well during a heat wave, those who were socially isolated or living on low incomes often felt unprepared. Broader social determinants of health such as livable incomes and social support are important to address over the long-term,[41] but there are more immediate things that can be done to support seniors whose social location puts them at additional risk. Ensuring there are community resources such as cooling centres or other air-conditioned spaces available throughout the region, and that these sites are well-communicated and accessible by local transit could support seniors who do not have air conditioning or access to other spaces to stay cool. Water fountains or temporary water stations can also be helpful for anyone who cannot stay indoors during a heat wave, along with public washrooms, as many seniors mentioned avoiding drinking water out of fear they may not be able to access a washroom away from home.

Social networks

A lack of social connections and the stigma surrounding accessing support are important barriers to resilience that were identified by our participants. Many seniors did not have access to emergency resources, and others who did have access to additional support stated they were unlikely to ask for help. However, many seniors in our study and other research have reported supporting other seniors or people who may be at risk by sharing information and checking on them during heat waves.[22] This peer support could be a helpful and empowering tool to leverage to increase seniors' resilience to extreme heat. For instance, the San Jose Buddies Program[42] and the Netherlands Red Cross[43] local branches have established peer volunteer networks where seniors check on their peers, help with errands and provide assistance during heat waves and other emergencies. Implementing similar systems in Ontario could help improve social connections among seniors, increase knowledge among both low- and high-resource seniors, and help de-stigmatize their access to social support. To support these goals, it is critical to effectively engage stakeholders and include local community-based organizations. It is also important to understand the relative strengths and weaknesses of social networks for seniors, and to establish volunteer-based programs.

Strengths and limitations

Recruitment was a challenge throughout this study, and while our community partners were extremely helpful in recruiting participants from their networks, this may have contributed to a skewed sample. One particular strength of this study was our partnerships with community organizations, which allowed us to recruit participants for both the interview and survey components who had experiences, risks and resources relevant to our research, including low-income seniors, seniors with disabilities, senior community leaders and newcomers. The majority of our participants were women, and while gender-based analyses have revealed important differences in the ways men and women cope with heat,[44] our unbalanced sample did not allow for reasonable comparison. Our participants were predominantly white and Canadian-born, which, while representative of previous generations in Waterloo Region, does not represent the area's current overall diverse cultural and linguistic groups. Our sample was also skewed in terms of income, with clusters at the high and low end of the income spectrum, which made it challenging to accurately assess the contribution of demographic factors to vulnerability across a broad spectrum of seniors' experiences. People's perspectives on climate change and controllability of risk also influenced their willingness to participate, with many of the seniors we spoke to declining to participate because they did not believe in climate change or were not worried because they had air conditioning. Finally, our sample was geographically limited to seniors in Waterloo Region. However, because the municipality includes three cities as well as a number of rural townships, it is representative of many other districts within the province. While this regional focus may limit the generalizability of our results, the data we collected were relevant and useful for local planners and community, social service and public health organizations, and may be particularly useful to other nearby communities. Consequently, we believe that most of our findings are transferable beyond this region.

Conclusion

Unlike previous studies indicating that the dangers posed to seniors by environmental stressors such as heat waves are heightened by seniors' inaccurate perceptions of the risk to themselves and by their lack of response to risk, our study showed that Waterloo Region seniors' assessments of their risks from heat waves were relatively realistic. Instead, both their actual risk and their resilience were impacted more by social location and coping resources. Even in those with higher incomes, greater social support and better housing, resilience tends to depend heavily on the availability of coping resources such as air conditioning and running water. During prolonged heat waves, those resources could temporarily become unavailable because of power outages or freshwater sources. Communication about community resources, such as cooling centres and emergency water access, could help seniors better prepare in the event of a prolonged extreme heat wave.

More generally, different communication strategies may be used for those who have access to appropriate resources and those who do not. This targeted approach would avoid the quick dismissal of the public health communication as irrelevant by those with resources, and the feeling that they are being blamed for their lack of resources by those without them. Realizing that seniors are capable and active partners in the response to heat waves will help prevent them from feeling like vulnerable individuals who have lost their ability to deal with such challenges. Peer-based approaches seem to be highly suitable for this purpose; peer support not only de-stigmatizes the act of asking for help, it is likely to increase the efficacy of information about risks by increasing openness on the part of seniors who attend to this information not only for themselves, but also to offer support to others.

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Conflicts of interest

The authors have no conflict of interest to report.

Authors' contributions and statement

AE contributed to project design, participated in qualitative and quantitative data collection and analysis, and led the drafting and revision of the paper. BD contributed to project design, participated in quantitative data collection and qualitative and quantitative analysis, and contributed to the drafting and revision of the paper. BH contributed to recruitment strategy, qualitative data collection, qualitative and quantitative analysis, and to the drafting and revision of the paper. MR co-led project conceptualization and design, co-supervised qualitative and quantitative data collection and analysis, and contributed to drafting and revision of the paper. AW co-led project conceptualization and design, co-supervised qualitative and quantitative data collection and analysis, and contributed to drafting and revision of the paper.

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Original quantitative research

Regional variation in multimorbidity prevalence in British Columbia, Canada: a cross-sectional analysis of Canadian Community Health Survey data, 2015/16

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This article has been peer reviewed.

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Abstract

Introduction: Multimorbidity represents a major concern for population health and service delivery planners. Information about the population prevalence (absolute numbers and proportions) of multimorbidity among regional health service delivery populations is needed for planning for multimorbidity care. In Canada, health region–specific estimates of multimorbidity prevalence are not routinely presented. The Canadian Community Health Survey (CCHS) is a potentially valuable source of data for these estimates.

Methods: Data from the 2015/16 cycle of the CCHS for British Columbia (BC) were used to estimate and compare multimorbidity prevalence (3+ chronic conditions) through survey-weighted analyses. Crude frequencies and proportions of multimorbidity prevalence were calculated by BC Health Service Delivery Area (HSDA). Logistic regression was used to estimate differences in multimorbidity prevalence by HSDA, adjusting for known confounders. Multiple imputation using chained equations was performed for missing covariate values as a sensitivity analysis. The definition of multimorbidity was also altered as an additional sensitivity analysis.

Results: A total of 681 921 people were estimated to have multimorbidity in BC (16.9% of the population) in 2015/16. Vancouver (adj-OR = 0.65; 95% CI: 0.44–0.97) and Richmond (adj-OR = 0.55; 95% CI: 0.37–0.82) had much lower prevalence of multimorbidity than Fraser South (reference HSDA). Missing data analysis and sensitivity analysis showed results consistent with the main analysis.

Conclusion: Multimorbidity prevalence estimates varied across BC health regions, and were lowest in Vancouver and Richmond after controlling for multiple potential confounders. There is a need for provincial and regional multimorbidity care policy development and priority setting. In this context, the CCHS represents a valuable source of information for regional multimorbidity analyses in Canada.

Keywords: *multimorbidity, prevalence, British Columbia, Canada, cross-sectional studies, surveys and questionnaires*

Highlights

- Multimorbidity prevalence is a growing phenomenon with major cost and service delivery planning implications for health systems.
- This paper presents methods and results for analysis of Canadian Community Health Survey data for British Columbia (BC) during 2015/16.
- Estimated multimorbidity prevalence was lower in Vancouver and Richmond compared to other regions in BC, after adjusting for multiple confounding factors.
- Future research may seek to integrate multiple health administrative and survey datasets to better characterize multimorbidity among BC health regions.
- Policy development and priority setting for multimorbidity care in BC are warranted provincially and within each RHA.

Introduction

Globally, the prevalence of multimorbidity is rising.[1,2] Definitions of multimorbidity have proliferated in the past decade, and vary in terms of the conditions included and the populations considered, without a clear consensus.[3,4] However, systematic review guidance suggests that multimorbidity should be defined from a minimum of 12 candidate chronic health conditions and requires two or more chronic conditions (2+ conditions) to be present.[5] Furthermore, multimorbidity prevalence estimates should include all members of the population.[5] Finally, defining multimorbidity as 3 or more chronic conditions (3+ conditions) has been established as more meaningful for clinicians and linked to greater need for care coordination.[5]

In Canada, multimorbidity is a major cost driver for provincial health insurance plans.[6] British Columbia (BC) has the lowest prevalence of chronic diseases of Canadian provinces and territories.[7] However, Feely et al. estimated that the prevalence of multimorbidity (3+ chronic conditions) in BC increased 75% over ten years, from 5.2% in 2001/02 to 9.1% in

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2011/12, based on health administrative data.[7] Within BC, the prevalence of chronic diseases, and therefore multimorbidity, is expected to vary regionally, but the extent of that variation is unknown.

The BC Centre for Disease Control (BCCDC) has developed a Chronic Disease Dashboard (CDD) that is able to display incidence and prevalence of major chronic diseases, from mood and anxiety disorders to osteoporosis, across health regions, time, age and sex. The CDD is derived from the BC Ministry of Health's Chronic Disease Registry (CDR), which gathers data from multiple health administrative databases.[8] Currently, work is underway at BCCDC to include a multimorbidity indicator in the CDD to facilitate analysis of multimorbidity in BC by health professionals.[9] Information systems based on administrative data are powerful and cost-effective, with virtually complete follow-up (i.e. offering the ability to track long-term health care use) in Canada. However, lack of data on health behaviours and social determinants, such as smoking, household income, highest household education level, body mass index (BMI), diet and physical activity, reduces analysts' ability to explain differences between health regions.[7,10] Administrative data–based systems only capture treated conditions, rather than population prevalence of those conditions, which has led to underestimates of multimorbidity prevalence in Canada.[11]

There is a need for health region–specific multimorbidity prevalence estimates to inform health policy, programming and resource allocation within BC, as well as health promotion and chronic disease prevention activities.[9] In BC, five Regional Health Authorities (RHAs) exist as entities of the provincial government that coordinate and develop health services tailored to regional population needs.[12,13] The RHAs are composed of 16 Health Service Delivery Areas (HSDAs), which are further subdivided into 89 Local Health Areas (LHAs).[14] As multimorbidity increases in the aging BC population, the need for health region–specific multimorbidity prevalence estimates will grow.[9] Surveys may offer important data for multimorbidity research and surveillance within BC. Surveys can incorporate questions on health determinants, and are not affected by physician billing and reimbursement policies and practices or health care access issues, which makes survey data a valuable resource for health service planners seeking to address the prevalence of multimorbidity in Canada. The Canadian Community Health Survey (CCHS) is a nationally representative survey that contains data on health determinants at individual and household levels and includes a range of health outcome measures, including self-reported diagnoses of specified chronic diseases. These data have been used previously for chronic disease and multimorbidity research.[15-19]

This study examined the prevalence of multimorbidity within BC by HSDA using the most recently available CCHS data. The objectives of this study were to analyze the total burden of and variation in multimorbidity prevalence by HSDA, to determine how much variation could be explained by known risk factors for multimorbidity and to develop methods for regional analysis of multimorbidity in BC using survey data.

Methods

Data source and analytic sample

CCHS Public Use Microdata File (PUMF) data for 2015/16 (two years) were analyzed. The CCHS is a complex, nationally representative sample based on a cluster-randomized, multistage sampling framework. The PUMF dataset contains survey weights for each participant based on this framework that can be used to produce statistical estimates generalizable to 98% of the Canadian population.[20] Sample size calculations are based on health region–specific sampling frames.[20] Participants are weighted according to the number of people they represent in the Canadian population. Males are weighted more heavily than females due to lower participation in CCHS. Final weights are derived in a series of steps that involve integration, nonresponse adjustments, Winsorization and calibration.[20]

Analysis variables

The outcome variable, multimorbidity, was defined as three or more (3+) chronic conditions from a list of 17 candidate health conditions that were self-reported by respondents with a physician diagnosis, and included asthma, COPD, sleep apnea, scoliosis, fibromyalgia, arthritis, back problems (excluding scoliosis, fibromyalgia and arthritis), osteoporosis, high blood pressure, heart disease, stroke effects, diabetes, cancer, migraine headaches, multiple chemical sensitivities, mood disorder (e.g. depression, bipolar, mania, dysthymia) and anxiety disorder (e.g. phobia, obsessive-compulsive disorder, panic). An indicator variable was created for each condition and was assigned a value of 0 or 1, with 1 indicating that the condition was present, 0 that it was not. These indicator variables were summed for each participant to create a multimorbidity index. This index was then dichotomized into a categorical outcome variable indicating multimorbidity (3+ chronic conditions vs. 2 or fewer chronic conditions), based on a survey-weighted histogram of the multimorbidity index generated during exploratory data analysis (Figure 1), as well as literature suggesting that people with 3+ conditions have a greater need for coordinated clinical management.[4,5,21]

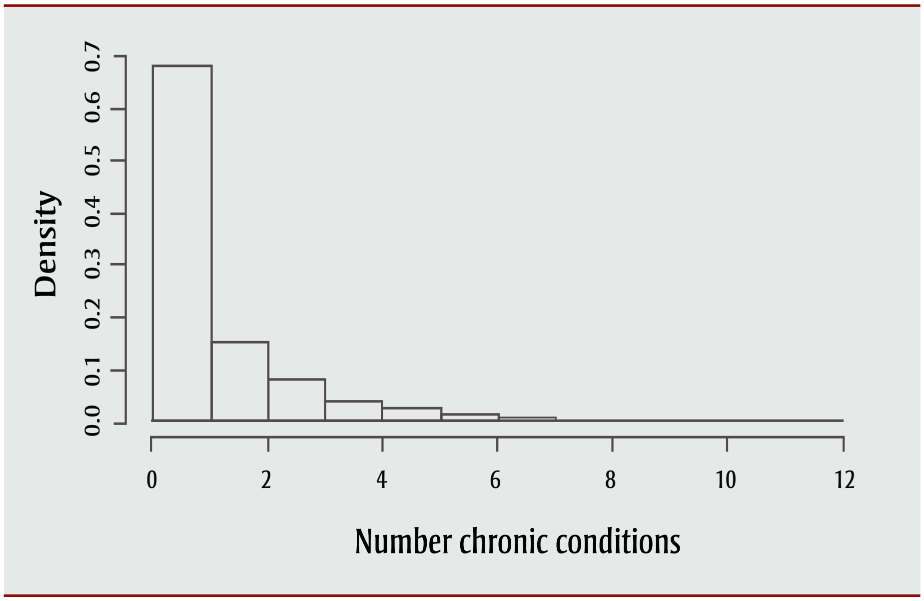
For an understanding of regional variation in multimorbidity prevalence estimates, HSDA was used as the key question predictor. HSDAs represent the most granular level at which data from the CCHS are available.

Statistical analysis

Descriptive statistics

The survey-weighted proportion and number of BC residents with multimorbidity were estimated by HSDA and by a series of sociodemographic factors identified in the literature as predictors of multimorbidity.[3,5,16,22-24] The sociodemographic factors included age group (12–29, 30–49, 50–64, 65–79, or 80+ years); sex (male or female); total household income group (< \$20 000, \$20 000–\$39 999, \$40 000–\$59 999, \$60 000–\$79 999, or \$80 000+); alcohol consumption (regular, occasional or not at all); current smoking status (daily, occasionally or not at all); daily fruit and vegetable consumption (< 5 servings or 5+ servings); highest household education level (< secondary, secondary graduate, or postsecondary certificate/diploma/degree); self-reported height and weight, converted to body mass index (BMI; categorized as under/normal weight, overweight, or obese classes I, II, III); and World Health Organization (WHO) physical activity level (active, moderately active, somewhat active, or inactive). Rao-Scott tests were used for equality of proportions for multimorbidity across covariate categories, incorporating the complex survey design weights.[25]

FIGURE 1
Histogram of multimorbidity index used to create dichotomous indicator variable for multimorbidity: Canadian Community Health Survey 2015/16, British Columbia subpopulation



Data source: Survey-weighted histogram, Canadian Community Health Survey, 2015/16.

Inferential statistics

For the inferential analysis comparing HSDAs within BC, adjusting for the covariates described above, survey-weighted logistic regression was used.[26] Univariable models were fit for the key question predictor, HSDA, as well as for each potential confounder listed above. An age- and sex-adjusted model was then fit to compare HSDAs. A full main effects model that included all potential confounders was fit to provide covariate-adjusted odds ratios (adj-ORs) for comparison of multimorbidity prevalence estimates across HSDAs. All models incorporated the survey weights supplied with the CCHS data to produce results generalizable to the population of BC, within the bounds of the sampling frame for the CCHS. Fraser South was used as the reference HSDA as it had the largest sample size (n = 1376), providing more stable OR estimates.

Interaction models (considered separately) included smoking status by alcohol consumption, smoking status by physical activity and smoking status by income. Each of these interaction terms was added to the covariate-adjusted main effects model. It was hypothesized that smoking status would have a stronger effect with regular alcohol consumption, low physical activity and low income level. Furthermore, age group by household income group and age group by smoking status were also considered potential interactions, with the hypothesis that the effect of income would be more pronounced in younger than older age groups, and that the effect of smoking would be less pronounced in younger age groups. No effect modification terms were considered as a theoretical justification was not clear for testing any interaction between HSDA and the covariates.

Missing data analysis

The proportion of participants with missing covariate values was assessed for each covariate separately and then multiple imputation using chained equations with five iterations of 20 imputations was performed for each participant with a missing value.[27] These imputed datasets were combined and analyzed to produce a pooled estimate and adjusted OR of multimorbidity for each HSDA compared with the reference HSDA, including all participants excluded due to missing values for one or more covariates for the final main effects model. This pooled and adjusted OR was compared with the results of the main effects model as a sensitivity analysis to assess robustness to missing data.

Sensitivity analysis

In the sensitivity analysis, the multimorbidity index definition was varied by combining four chronic pain conditions (scoliosis, fibromyalgia, arthritis and back problems) into a single indicator variable. Because arthritis and back problems were very common conditions in the sample, with 25.4% and 20.8% of the population reporting these conditions, respectively, these variables were combined with two other potentially related chronic pain conditions (scoliosis and fibromyalgia). The population prevalence of one or more of these four chronic pain conditions in BC was 38.2%. This chronic pain indicator variable was used as one condition within a revised multimorbidity index. From this revised multimorbidity index, the proportion of people with 3+ chronic conditions was recalculated to obtain a more conservative estimate of multimorbidity. The data was then reanalyzed using this revised multimorbidity definition.

Data management was conducted in SAS software, University Edition (SAS Institute Inc., Cary, NC, USA), while analyses and some final data management were conducted in R version 3.4.4 (R Core Team, Vienna, Austria).

Results

Data description

In BC, the estimated prevalence of multimorbidity (3+ chronic conditions) in 2015/16 was 17% (95% CI: 16%–18%) with the total number of people affected estimated at 681 921 (Table 1). Significant variation was observed in the estimated prevalence of multimorbidity by HSDA within BC. Richmond and Vancouver had the lowest prevalence at 10.2% and 11.6%, respectively, while Okanagan, North Vancouver Island and Central Vancouver Island had the highest at 22% (Table 1).

There was statistically significant variation (Rao-Scott test-based $p < .05$) in estimated multimorbidity prevalence across all sociodemographic characteristics of participants, except fruit and vegetable consumption (Table 2). By age group, multimorbidity prevalence estimates rose from 5% for ages 12 to 29 years up to 38% for those aged 80 years and over. By sex, females in BC had higher prevalence of multimorbidity than males (20% vs. 14%). Multimorbidity estimates were associated with income group: the highest income group (≥ $80 000) had the lowest prevalence (12%) while the lowest income group (< $20 000) had the highest prevalence at 27% (Table 2). Daily smoking status was related to higher estimated prevalence of multimorbidity (27%) than occasional/no smoking (16%). People

TABLE 1
Multimorbidity prevalence by health service delivery area: CCHS 2015/16, British Columbia subpopulation

Health service delivery area	Multimorbidity (n; sample)	Multimorbidity (N)[a]	Multimorbidity (%)[a]	95% CI
Central Vancouver Island	232	119 267	21.9	18.1–25.6
East Kootenay	141	50 253	18.0	14.6–21.3
Fraser East	215	12 031	19.6	16.0–23.1
Fraser North	237	47 739	15.1	12.4–17.7
Fraser South	294	86 445	17.5	14.8–20.1
Kootenay-Boundary	158	13 542	19.6	15.9–23.4
North Shore/Coast Garibaldi	188	35 216	15.0	12.0–17.9
North Vancouver Island	200	22 615	22.0	18.2–25.9
Northeast	127	9 435	16.3	12.5–20.0
Northern Interior	210	24 480	21.3	17.7–24.9
Northwest	123	9 942	19.3	15.0–23.5
Okanagan	285	67 901	22.3	19.0–25.5
Richmond	108	19 252	10.2	7.7–12.6
South Vancouver Island	237	56 317	17.2	14.5–19.9
Thompson/Cariboo	207	37 773	20.4	16.9–23.9
Vancouver	173	69 714	11.6	9.0–14.2
British Columbia (total)	3135	681 921	16.9	16.0–17.8
British Columbia (sensitivity analysis definition)	2615	576 075	14.3	13.4–15.0

Abbreviations: CCHS, Canadian Community Health Survey; CI, confidence interval.
Note: Multimorbidity is defined as the presence of 3 or more chronic conditions.
[a] N and % are weighted to the total British Columbia population using CCHS sample weights.

in households where the education level was less than secondary school had the highest estimated prevalence of multimorbidity (39%) of any covariate group. People classified as obese had an estimated higher prevalence of multimorbidity (26%) than people in overweight and under/normal BMI groups (14%–16%).

Results from statistical analysis

The univariable analysis of multimorbidity by HSDA showed significant variation in the estimated prevalence of multimorbidity, with two HSDAs (Richmond and Vancouver) being lower than the reference HSDA (Fraser South), and three HSDAs (Central Vancouver Island, North Vancouver Island and Okanagan) being higher than the reference HSDA (Table 3). After adjusting for multiple potential confounders, Richmond and Vancouver HSDAs still had significantly lower multimorbidity prevalence than Fraser South, while others did not differ significantly from Fraser South or each other (Table 3).

Missing data analysis

Three covariates had over 5% of participants with missing values: BMI (13.6%), physical activity (11.6%) and fruit and vegetable consumption (6.8%), while the other three variables with missing values—smoking status, alcohol consumption and household income group—had fewer than 4% missing. Multiple imputation was performed twenty times on seven variables (smoking, income, education, fruit and vegetable consumption, alcohol consumption, physical activity and BMI) using HSDA, age group, sex, income, physical activity, alcohol consumption, fruit and vegetable consumption, BMI, education and smoking status to predict the missing values. The results of the survey-weighted logistic regression of the imputed data showed similar results to the final main effects analysis, with Richmond and Vancouver HSDAs having significantly lower adjusted prevalence of multimorbidity than Fraser South (reference HSDA) (Table 3).

Sensitivity analysis

Using the more conservative definition of multimorbidity, the prevalence of multimorbidity in BC was estimated at 14.3%, with an estimated 576 075 people living with multimorbidity (Table 1). Estimated prevalence across all HSDAs was lower in the sensitivity analysis than in the main analysis; however, it did not decline equally across the HSDAs. Richmond and Vancouver had smaller proportionate decreases than other HSDAs (Figure 2). Crude and adjusted logistic regression analyses showed similar differences in multimorbidity prevalence estimates across HSDAs. Richmond's adjusted OR was 0.49 (95% CI: 0.32–0.75); however, Vancouver's adjusted OR was 0.69 (95% CI: 0.45–1.06) and was not statistically significant (p = .09) (results of sensitivity analysis available on request).

Discussion

This is the first study to estimate the proportion and number of BC residents living with multimorbidity in each HSDA and to compare multimorbidity prevalence estimates across HSDAs after controlling for potentially confounding variables. A large number of people in BC are estimated to be affected by multimorbidity (between 576 075 and 681 921 people; 13.4%–16.9% of the population). The main finding of this study was that Vancouver and Richmond had significantly lower prevalence of multimorbidity, compared to the reference HSDA, after control of multiple known confounders. None of the other HSDAs had a significantly different prevalence of multimorbidity from the reference HSDA (Fraser South) or from one another.

The lower estimated prevalence of multimorbidity may be due to residual confounding (e.g. income level; the highest level was $80 000+, which does not take into account advantages of increasing income beyond $80 000). The differences in multimorbidity estimates may also be due to unmeasured confounders such as ethnic origin or immigration status, which are known to vary across regions. Persons born outside of Canada tend to experience lower levels of multimorbidity (healthy immigrant effect) while Indigenous populations tend to face higher levels of multimorbity.[24,28] The differences in the proportions of immigrant and Indigenous populations between HSDAs may, therefore, be able to explain differences in multimorbidity across HSDAs. Differences in urban form may also explain differences in multimorbidity prevalence. Urban form has complex and poorly understood effects on chronic disease incidence and prevalence. Features of urban form, for example, transportation systems, act upon

TABLE 2
Multimorbidity prevalence by sociodemographic factors: CCHS 2015/16, British Columbia subpopulation

Sociodemographic factor	N	Multimorbidity (%)	95% CI
Age (years)			
12–29	409 015	4.6	2.6–6.6
30–49	1 235 321	7.1	5.9–8.3
50–64	958 272	14.6	12.7–16.6
65–79	920 341	26.0	23.8–28.1
80+	514 512	38.2	35.5–40.9
Sex			
Females	2 045 234	19.9	18.6–21.2
Males	1 992 228	13.8	12.6–15.0
Household income ($)			
< 20 000	292 057	26.7	23.4–30.0
20 000–39 999	632 028	27.5	24.8–30.1
40 000–59 999	615 696	19.4	17.3–21.6
60 000–79 999	591 057	13.3	11.2–15.4
≥ 80 000	1 902 665	12.2	10.9–13.4
Current smoking			
Occasionally/not at all	3 667 207	15.9	15.0–16.8
Daily	367 369	26.9	23.2–30.5
Alcohol drinking (past 12 months)			
Regular	2 427 755	15.5	14.4–16.6
Occasional	624 794	18.2	16.0–20.5
Not at all	954 734	19.8	17.7–21.8
Fruit and vegetable consumption (daily)			
< 5 servings	2 591 313	16.2	15.2–17.3
≥ 5 servings	1 154 123	16.3	14.7–18.0
Physical activity (WHO guidelines)			
Active	182 751	14.4	13.1–15.7
Moderately active	586 983	18.7	16.2–21.2
Somewhat active	620 207	17.9	15.8–19.9
Inactive	567 953	27.3	24.3–30.2
Household education			
< Secondary	150 780	39.0	34.3–43.7
Secondary graduate	62 232	21.1	18.7–23.4
Postsecondary graduate	3 081 325	14.9	13.9–15.9
Body mass index			
Under/normal weight	1 509 166	14.1	12.6–15.6
Overweight	1 237 534	15.9	14.3–17.4
Obese	747 209	26.2	23.9–28.6

Abbreviations: CCHS, Canadian Community Health Survey; CI, confidence interval; WHO, World Health Organization.
Note: Crude survey-weighted denominators and percentages are presented.

multiple potential risk factors, such as physical activity or sense of community, which in turn could affect multimorbidity prevalence.[29]

A recent analysis by BCCDC scientists of age-adjusted multimorbidity prevalence in BC by HSDA showed similarly low prevalence in Richmond and Vancouver, although not as pronounced a difference as in the estimates in the present study.[9] The BCCDC estimates were higher, averaging 29% across BC, due to the use of a 2+ chronic condition definition of multimorbidity, and restriction to persons aged ≥ 20 years.[9] The Feely et al. multimorbidity (3+ chronic conditions) prevalence estimate for BC (9.1%) was lower than the multimorbidity prevalence estimates from the main analysis (16.9%) and sensitivity analysis (13.4%), likely due to different conditions included, data sources and time period.[7] Compared to Roberts et al., who also used CCHS to estimate the prevalence of 3+ chronic conditions in BC (3.9%) in 2011/12, the multimorbidity prevalence estimates in this paper appear high.[24] The exclusion of hypertension, the most prevalent chronic condition in CCHS, and use of nine conditions from the CCHS to define multimorbidity may explain the lower prevalence finding of Roberts et al.[24]

Patterns in multimorbidity prevalence across known confounders, such as age group, sex, income, smoking status, education and physical activity were consistent with the literature.[3,5,30] Regular and occasional drinkers had a lower estimated prevalence of multimorbidity compared to nondrinkers. This relationship has been explored elsewhere,[31] with the “sick-quitter” hypothesis offered as a potential explanation. Fruit and vegetable consumption (< 5 vs. 5+ servings per day) was not related to multimorbidity prevalence in crude analysis (Table 2) or adjusted analyses (results not shown), which was not consistent with the literature.[5,32] People classified as obese had a higher prevalence of multimorbidity (Table 2), and the BMI variable was significant in univariable and multivariable models (data not shown). Recent literature on BMI and multimorbidity has shown a large and significant effect of obesity on multimorbidity prevalence, and this study’s findings were consistent (adj-OR for multimorbidity between obese and normal/under weight was 2.14 [95% CI: 1.76–2.60]; data not shown).[22,33]

Strengths and limitations

All members of the population aged 12 years and older, with the exception of First Nations communities, were included in this study. Multimorbidity was defined from 17 candidate conditions using the more clinically relevant definition of 3+ conditions. Multiple risk factors for multimorbidity were adjusted for in the analysis, which studies and surveillance systems employing administrative data generally cannot do. Findings from the main analysis were robust to missing data for covariates and were also substantially similar

TABLE 3
Logistic regression analysis of multimorbidity prevalence by health service delivery area: CCHS 2015/16, British Columbia subpopulation

Health service delivery area	Crude OR (95% CI)	Age/sex-adjusted OR (95% CI)	Covariate-adjusted OR (95% CI)	Multiple imputation pooled OR (95% CI)
Central Vancouver Island	**1.33 (1.00–1.76)**	1.07 (0.79–1.45)	1.18 (0.56–1.44)	1.07 (0.79–1.45)
East Kootenay	1.04 (0.77–1.39)	0.89 (0.65–1.23)	0.84 (0.58–1.21)	0.82 (0.59–1.13)
Fraser East	1.15 (0.86–1.54)	1.15 (0.84–1.57)	1.12 (0.77–1.63)	1.04 (0.74–1.45)
Fraser North	0.84 (0.64–1.11)	0.85 (0.64–1.13)	0.89 (0.63–1.25)	0.84 (0.62–1.13)
Fraser South	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)
Kootenay-Boundary	1.15 (0.86–1.56)	0.96 (0.70–1.32)	0.83 (0.57–1.20)	0.82 (0.59–1.14)
North Shore/Coast Garibaldi	0.83 (0.62–1.12)	**0.71 (0.52–0.97)**	0.79 (0.55–1.14)	0.80 (0.58–1.11)
North Vancouver Island	**1.34 (1.00–1.79)**	1.09 (0.80–1.48)	1.11 (0.78–1.58)	1.02 (0.75–1.38)
Northeast	0.92 (0.66–1.28)	1.10 (0.80–1.52)	0.92 (0.62–1.36)	0.93 (0.66–1.32)
Northern Interior	1.28 (0.97–1.70)	1.28 (0.95–1.74)	1.19 (0.84–1.67)	1.14 (0.84–1.56)
Northwest	1.13 (0.84–1.57)	1.07 (0.76–1.51)	0.89 (0.59–1.35)	0.98 (0.68–1.40)
Okanagan	**1.36 (1.04–1.77)**	1.13 (0.85–1.50)	1.13 (0.81–1.56)	1.11 (0.83–1.47)
Richmond	**0.53 (0.39–0.74)**	**0.47 (0.34–0.66)**	**0.55 (0.37–0.82)**	**0.50 (0.35–0.71)**
South Vancouver Island	0.99 (0.76–1.28)	0.85 (0.64–1.13)	0.92 (0.67–1.28)	0.87 (0.66–1.16)
Thompson/Cariboo	1.21 (0.91–1.61)	1.02 (0.76–1.37)	0.93 (0.66–1.31)	0.88 (0.64–1.20)
Vancouver	**0.62 (0.45–0.85)**	**0.62 (0.45–0.87)**	**0.65 (0.44–0.97)**	**0.64 (0.45–0.90)**

Abbreviations: CCHS, Canadian Community Health Survey; CI, confidence interval; OR, odds ratio.

Notes: Covariate-adjusted models controlled for age group, sex, household income group, smoking status, alcohol consumption, physical activity level, fruit/vegetable consumption, household education and BMI.

Bolded values are significant at α =.05.

when a revised definition of multimorbidity was used in the sensitivity analysis.

This study carries the limitations of the CCHS as well as some specific to this analysis. First, the definition of multimorbidity used here was based on self-reported diagnoses of the chronic conditions included in the CCHS, as were covariates. This may introduce some differential misclassification bias across HSDAs, although the extent of this potential misclassification bias cannot be assessed within the present study. A further limitation of the multimorbidity definition used here is the equal weighting of all cancers. Because CCHS does not provide information about cancer site, differential weighting of cancer sites could not be addressed in this study's multimorbidity index.

Second, the CCHS excludes First Nations reserve communities by design, limiting interpretation to off-reserve populations. In 2016, there were an estimated 172 520 First Nations persons living in BC, of whom 40.1% (69 180) were estimated to live on-reserve.[34] The adjusted odds ratio for multimorbidity (3+ conditions) has been estimated at 2.7 (95% CI: 2.2–3.4) among Indigenous compared to non-Indigenous Canadians.[24] Therefore, this study may have underestimated the true prevalence of multimorbidity in BC. Potential solutions are discussed later on.

Third, people who do not have a permanent dwelling or access to a regular telephone are excluded from the sampling frame. These populations may be at particular risk for multimorbidity, given its socioeconomic dimensions.[35]

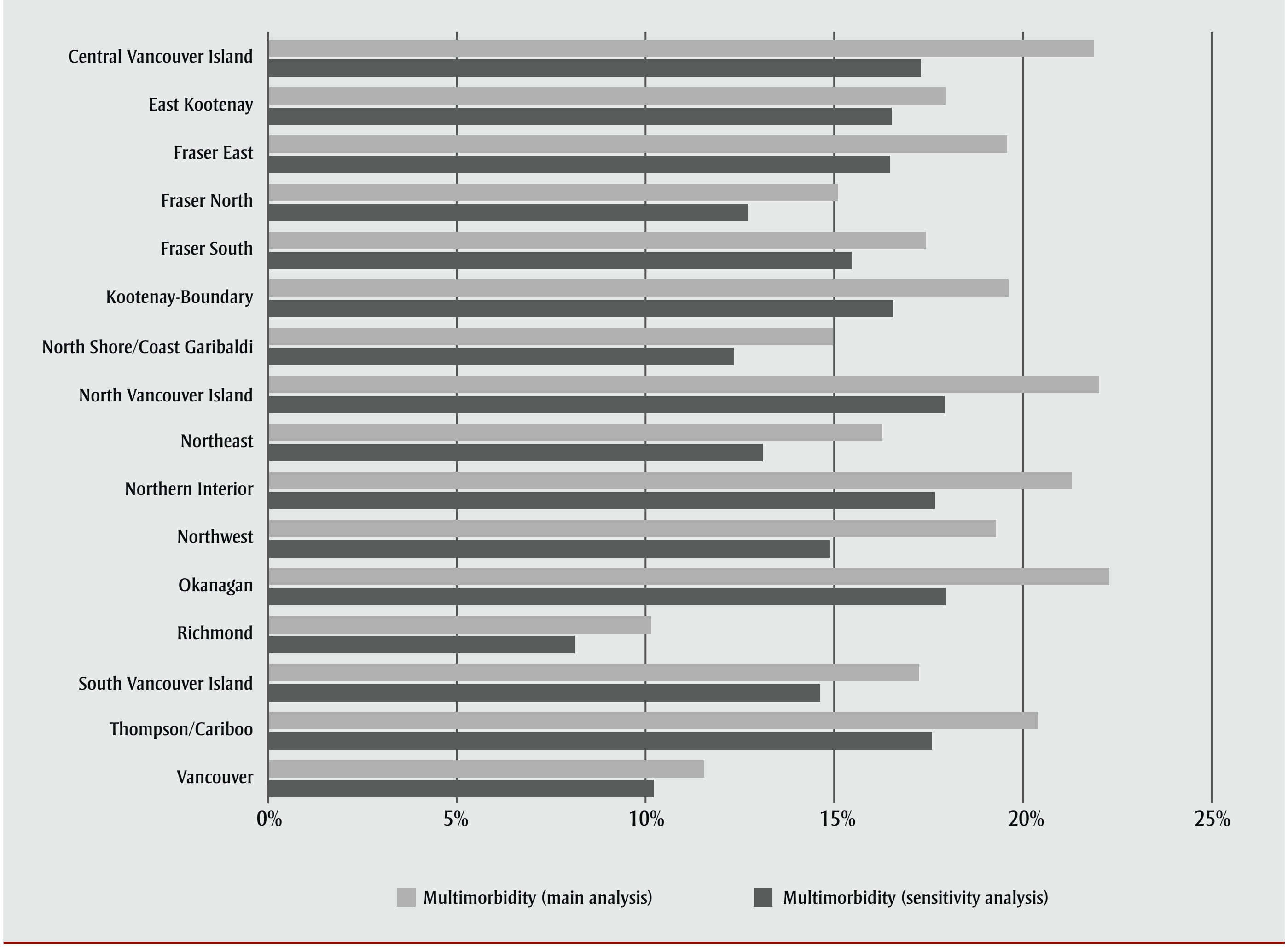
Fourth, CCHS data is collected cross-sectionally, which means temporality cannot be established. For example, in the relationship between BMI and multimorbidity, obese persons were found to have higher estimated prevalence of multimorbidity; however, it is not known whether multimorbidity preceded obesity, or vice versa. Because of the way it is collected, multiple years of cross-sectional data, such as the CCHS provides, could be assembled longitudinally, yet the data will remain cross-sectional.

Implications and applications

The main implication of this study, given the substantial number of people estimated to be living with multimorbidity in BC in each HSDA, ranging from 9435 to 119 267 people in 2015/16, is that policy and program development for integrated patient-centred care coordination are warranted. In BC, RHAs are tasked with developing policy and setting priorities for regional health, as well as developing regional health plans for health services, facilities, programs, human resource requirements and activities in support of regional health.[12] RHAs could explicitly incorporate multimorbidity as a focal point for integrated patient-centred care within these functions. Patients with multimorbidity report concerns with disease-centred rather than patient-centred care and desire that patient priorities be given more consideration in planning, and that patients are involved in care decisions.[36]

A starting point for integrated patient-centred care planning may be as simple as developing a policy and setting multimorbidity care as a priority within each RHA, considering both case complexity and care complexity in such policies.[37,38] Models for and effective elements of integrated patient-centred care for multimorbidity have been reviewed elsewhere and would need consideration within the BC context

FIGURE 2
Multimorbidity prevalence by health service delivery area: Canadian Community Health Survey 2015/16, British Columbia subpopulation



Note: Multimorbidity is defined as the presence of 3 or more chronic conditions.

and within each RHA.[39,40] Multimorbidity care coordinators that could listen to the concerns of patients and help coordinate their experience and involvement in care decisions across facilities and providers may be a valuable place to begin for tangible service delivery to older patients with multimorbidity.[41]

In addition to addressing integrated patient-centred care for patients with multimorbidity explicitly, RHAs could also use these results to justify upstream prevention activities. Conducting predictive modelling would help determine how health promotion strategies could be targeted to those at greatest risk of multimorbidity provincially, by RHA or by HSDA. The CCHS would be a valuable data source for multimorbidity predictive modelling, and such modelling would be a natural extension of this study. Briefly, from the crude prevalence estimates (Table 2), it appears those with lowest education levels, those in low-income households, people with obesity, those who are inactive physically and daily smokers are groups that would benefit from targeted prevention programming.

To help fill gaps in multimorbidity surveillance and research in BC, administrative health data may be combined with survey and census data, and more participatory approaches adopted for policy and program development. A recent request-to-contact study initiated in BC used administrative data to identify a large number (n = 12 000) of people with and without systemic autoimmune rheumatic diseases (SARDs) and then subsequently contacted them for enrollment in a cohort study.[42] This was the first instance of this form of research in Canada. This method could be valuable in recruiting regionally representative numbers of people with multimorbidity, using the numbers presented in this paper as a sampling frame. This method could support involvement of patients in epidemiological and health service research that could be incorporated into policy development and the setting of priorities by RHAs.

Collaboration with First Nations in BC who are excluded from the CCHS could improve the representativeness of regional estimates of multimorbidity prevalence as well as the appropriateness of any policies to address multimorbidity developed with RHAs. This could involve collaboration with the First Nations Health Authority of BC in multimorbidity surveillance and research through the First Nations Regional Longitudinal Health Survey (RHS). The RHS is a First Nations–owned survey conducted across Canada that provides high-quality data with the ability to assess multimorbidity among First Nations communities and the potential for linkage with administrative data.[43-46] Multimorbidity could be a lens through which to examine known challenges in care coordination among First Nations peoples, as there are substantial numbers of First Nations people on- and off-reserve living with multimorbidity who are facing such challenges.[46,47] If BC's Ministry of Health and RHAs decide to address multimorbidity directly through policy and program development, a consultation process with First Nations would be an important component of this work. If First Nations in BC agreed to participate in such a consultation, it could provide a stronger basis for policy and program development that legitimately meets the needs of First Nations in BC for integrated patient-centred care for people living with multimorbidity.

Conclusion

This study demonstrates the usefulness of survey data in estimating the prevalence of multimorbidity for health services researchers within BC. Adjustment for key risk factors for multimorbidity affected prevalence estimates but did not explain the significantly lower estimated prevalence of multimorbidity in Vancouver and Richmond. Ongoing multimorbidity surveillance and research are needed in BC to provide support to practitioners and policy makers seeking to influence the prevalence and incidence of multimorbidity, and the care of people living with multimorbidity. The CCHS represents a valuable source of data for such analyses, and may be integrated with other surveys, administrative data and census data to provide a more complete picture of regional multimorbidity prevalence within BC. Given the large number of people living with multimorbidity in BC, policy development and priority setting for multimorbidity are warranted in all RHAs and throughout the province.

Conflicts of interest

None.

Author contribution and statement

CAB designed the study, conducted the analysis, and drafted the manuscript and takes complete responsibility for its contents.

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Original qualitative research

Hacking systemic lupus erythematosus (SLE): outcomes of the Waterlupus hackathon

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Abstract

Introduction: There is a growing literature demonstrating the benefits of engaging knowledge-users throughout the research process. We engaged a multi-stakeholder team to undertake a hackathon as part of an integrated knowledge translation (iKT) process to develop nonpharmacological interventions to enhance the economic lives of people with systemic lupus erythematosus (SLE). The aims of this research were to (1) increase understanding of the economic challenges of living with SLE through stakeholder engagement at a research hackathon; (2) investigate possible interventions to improve the economic lives of individuals affected by SLE in Canada; and (3) document the outcomes of the Waterlupus hackathon.

Methods: Waterlupus was held at the University of Waterloo in May 2019, attended by lupus advocacy organization representatives, researchers, physicians, individuals with lived experience and students. We conducted participant observation with participants' understanding and consent; notes from the hackathon were qualitatively analyzed to document hackathon outcomes.

Results: At the conclusion of the 28-hour hackathon event, five teams pitched nonpharmacological interventions to address the economic challenges of living with SLE. The winning team's pitch focussed on increasing accessibility of affordable sun-protective clothing. Other Waterlupus outcomes include increased awareness of SLE among participants, and professional and informal networking opportunities.

Conclusion: This paper contributes to a limited literature on health hackathons. The successful outcomes of Waterlupus emphasize the value of hackathons as an iKT tool. Research about how knowledge-users perceive hackathons is an important next step.

Keywords: *integrated knowledge translation, systemic lupus erythematosus, hackathon, social innovation*

Highlights

- Waterlupus was an integrated knowledge translation health hackathon held in May 2019 in Waterloo, Ontario.
- Multiple end-users participated in Waterlupus, including lupus advocacy organizations' representatives, researchers, physicians, individuals with lived experience and students.
- The primary outcome of Waterlupus was the five innovative pitches aimed at improving the economic lives of individuals with systemic lupus erythematosus (SLE) in Canada.
- Additional outcomes included increased awareness of SLE, and professional networking opportunities among participants.

Introduction

Integrated knowledge translation (iKT) is an approach to doing research that involves a collaboration between researchers and knowledge-users; it has gained attention as an approach for enhancing the relevance of research outcomes.[1] There is a large and growing literature demonstrating the benefits of engaging knowledge-users as equal contributors throughout the research process,[1-3] and it is believed that iKT has potential to generate more relevant scientific outcomes (e.g. through engaging knowledge-users in research design), and to create better scientists (e.g. through improved communication skills).[4] Although health research is conducted to improve health systems and population health, major challenges exist in that findings often do not address problems identified by knowledge-users, and are often not applied in a timely manner.[3,5] While best practices in iKT are yet to be established,[1] hackathons are one possible approach to involve end-users in generating timely, useful and innovative health care solutions.

Understanding health hackathons

Health hackathons are events that bring together diverse stakeholders to focus on complex health challenges. The term "hackathon" combines "hack" (a solution reached through intense innovation) and "marathon" (an event of defined length and concentrated effort).[6,7] These events offer participants an uninterrupted period in which to work on a defined problem.[8] Hackathons champion the process of

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co-creation among stakeholders from a range of geographies and disciplines (e.g. health care, design, engineering, business; those with lived experience, end-users, scientists, health care professionals, entrepreneurs).[6] Hackathons are often forums where teams (either pre-established or formed at the event) can present innovative solutions to specific problems.[9] Many hackathons offer awards or prizes for the most promising ideas to help encourage solution development, and some offer funding opportunities to propel solutions forward.

While hackathons are well-established practices in software companies and are commonly associated with programming and computer science,[7-10] health hackathons first appeared in 2011 through the Massachusetts Institute of Technology (MIT).[7] MIT Hacking Medicine, a group that organizes health hackathons based at MIT, aims to accelerate medical innovation and energize the health care community. This group has organized more than forty events across nine countries and five continents (themes include reproductive, maternal, newborn and child health, diabetes, and Ebola), and offers its *Health Hackathon Handbook* online, detailing timelines, marketing, logistics, prizes and other organizational considerations.[11]

The first Canadian health hackathon was called Hacking Health, and was conducted in an attempt to narrow the gap between frontline health professionals and technology experts. It took place in Montréal in 2012, with over 200 health professionals and technical experts in attendance; 19 working prototypes were produced over this two-day event. Hacking Health have now conducted 58 events since 2012.[12]

The University of Waterloo hosts Hack4Health, a hackathon that focusses on improving the lives of those living with degenerative neurological conditions, primarily multiple sclerosis and dementia. The inaugural event took place in 2015; four iterations of Hack4Health have since been completed. The involvement of those with lived experience of the disease and other speakers at the two-day events has enabled participants to generate ideas and create workable solutions for challenges encountered by people living with these conditions.[13] For example, the fourth Hack4Health saw two winning teams: one focussed on tackling social isolation through the creation of a baking social media app, while the other aimed to promote safe and independent cooking using a mat sensor that detects when a stove is left unattended (see https://uwaterloo.ca/hack4health/about-hack4health/hack4health-40-winners).

Health hackathons carry particular significance for addressing health challenges in resource-limited settings, where there is a need for cost-effective innovations that can positively impact health in an affordable and sustainable manner.[6,14] Health hackathons typically focus on social rather than technological innovation,[15] and can result in the development of small but realistic projects that can be refined and scaled up (e.g. funds raised, business plans created, start-up companies formed[6]). Olson et al.[6] reviewed the outcomes of 12 health hackathons (from 2012–2015) in the USA, India and Uganda, and found that one year post-event, 30% of projects had progressed, 25% of teams had begun pilot testing, and of these, 12% and 7% had piloted their innovation with care providers and patients, respectively. Notably, 15 new companies were formed and 22 patents were filed from the hackathons reviewed. The overwhelming majority (87%) of hackathon participants surveyed stated they would attend again, indicating both the potential for successful and innovative outcomes, and worthwhile participant experiences.

Hacking for SLE

In this research, we implemented a hackathon aimed to enhance the economic lives of individuals with systemic lupus erythematosus (SLE) and promote public understanding of the disease. SLE is a chronic autoimmune disease in which the immune system mistakenly attacks the body's tissues and organs, and can damage the skin, joints, blood vessels, brain, heart and muscles.[16] It commonly manifests as alternating periods of flares and remissions. Individuals with SLE are at increased risk of developing diabetes, heart disease and neurological and renal dysfunction.[17] SLE is among the leading causes of death in females aged between 10 and 44 years in the US.[18] Symptoms (e.g. fatigue, joint pain, sun sensitivity) vary based on the individual, and for this reason SLE has been called the "disease of a thousand faces."[19] While worldwide incidence and prevalence rates vary by sex, age and ethnicity (e.g. disease severity and frequency is estimated to be greater in people of African descent),[19,20] it is estimated that approximately one in every 1000 Canadians is affected by SLE;[19] and females are more frequently affected at a 9:1 ratio.[20] Women of child-bearing age (15–45 years) are most frequently affected; SLE is 8 to 13 times more common in females in this age range. Nevertheless, men, children and individuals above age 45 may all be diagnosed with lupus.[19] Those with SLE experience distinct physical, emotional and social challenges; like other chronic illnesses, SLE has been associated with the contraction of social networks and loss of identity.[21,22]

Previous research undertaken using a mixed-methods approach illustrates that affected individuals and their families experience considerable economic challenges, both direct and indirect.[23] A recent Canadian study estimated that direct costs (i.e. health care resources used by a patient with SLE) averaged over $10 000 per patient per year.[24] Other research shows that indirect costs (e.g. time missed from paid work) are four times that of direct costs, and—unlike direct costs—are not related to illness severity.[25] Despite all of this, knowledge about interventions to improve the economic lives of these individuals is limited.[24-27] Furthermore, affected individuals often experience a less satisfying working life.[26] This is partially explained by the complex characterization of the illness, which is episodic (i.e. with fluctuating periods of illness and wellness), gendered, idiosyncratic, racialized and invisible.[27]

For those with SLE, pharmacological treatment options remain limited and are often poorly tolerated or ineffective.[28] We must therefore look beyond individual solutions and focus on broader, nonpharmacological interventions. Bisung et al.[26] conducted a systematic review of existing nonpharmacological interventions to improve the economic lives of individuals with SLE. Four published and two ongoing studies were identified.[29-34] Of the four completed studies, all were conducted in 2005 or earlier. While the completed studies included individuals with SLE, SLE was not necessarily the primary focus; of the 979 participants across the four studies, only 9% had SLE, as each study primarily involved patients with rheumatoid arthritis or osteoarthritis. This is limiting, as arthritis is only one of the many manifestations of SLE that can impact individuals at home or in the workplace. The interventions studied included job accommodations,[29,31,32] vocational guidance[32], education,[29,31,32] support with transportation,[32] and skills training.[30] While three studies demonstrated positive effects on return to work and job retention,[29,30,32] the evidence remains dated, and comparison of effectiveness across studies is challenging due to variability in duration and study design.[26]

In an attempt to effect change in the lives of people living with SLE, the Waterlupus hackathon was held, attended by a multistakeholder group of lupus advocacy organization representatives, researchers, physicians, individuals with lived experience and students, over a period of 28 hours at the University of Waterloo. The research presented in this manuscript was aimed at fulfilling three objectives: (1) to increase understanding of the economic challenges of living with SLE through stakeholder engagement at a research hackathon; (2) to investigate possible interventions to improve the economic lives of individuals affected by SLE in Canada; and (3) to document the outcomes of the Waterlupus health hackathon.

Methods

Waterlupus hackathon

The Waterlupus hackathon was held on 24–25 May, 2019, at the University of Waterloo in Waterloo, Ontario. Our research team consisted of three principal investigators, and four other researchers from the University of Waterloo, Queen's University and the University of Calgary. During the planning process, the research team partnered closely with two representatives from the GreenHouse, a community for social and environmental innovation at the University of Waterloo (https://uwaterloo.ca/stpauls/greenhouse). The GreenHouse staff has extensive experience in planning and executing successful hackathons, including those related to chronic illness (e.g. Hack4Health).

A multi-stakeholder group of participants concerned with addressing the economic needs of individuals with SLE attended the hackathon. Advocacy group participants included Lupus Canada, the Lupus Foundation of America, Lupus Ontario, the Lupus Society of Alberta and the Canadian Arthritis Society (n = 9). Participants with lived experience (n = 5) attended from Ontario and Alberta. Multiple advocacy organization representatives also acted as individuals with lived experience.

Members of the research team conducted stakeholder recruitment using multiple methods. Provincial and national SLE advocacy organizations were contacted by email to describe the purpose of the research and ask if their organization would be interested in participating. To recruit mentors with lived experience, one member of the research team who works as a medical doctor shared the hackathon details with her network. In addition, we consulted a list of participants from previous qualitative research undertaken by our research team. We contacted policy mentors (n = 2) based on their public health expertise. Finally, we used snowball sampling, asking potential participants if they knew others that might be interested in participating.

To provide a valuable interdisciplinary learning opportunity, student participants (n = 25) were recruited from both graduate and undergraduate programs across all six faculties (Arts, Engineering, Environment, Science, Math, Applied Health Sciences) at the University of Waterloo. First, summer classes were reviewed for themes related to health or social impact (e.g. Social Determinants of Health, Connections to Ethical Context, Social Research). Professors were asked if a representative could attend a lecture to describe the event, and provide an EventBrite registration link to students. Professors were also asked to post an advertisement on their course website. In addition, the University of Waterloo Federation of Students posted advertisements in preapproved campus locations. Finally, poster advertisements were distributed around the GreenHouse and the research team's personal and professional networks.

Before Waterlupus, three webinars were held to provide background research results to the hackathon stakeholders and others. All confirmed hackathon participants were invited to attend the webinars, and webinar links were provided at the hackathon as a resource. Webinar recordings remain available to the public (https://uwaterloo.ca/geographies-of-health-in-place/events/lupus-hackathon/pre-hackathon-webinars). The first webinar (held on 30 April, 2019) presented the results of quantitative surveys previously undertaken with lupus patients documenting both direct and indirect costs of SLE, and the relationship of these costs with sociodemographic characteristics and illness severity. The second webinar (7 May, 2019) presented qualitative results from interviews with patients, physicians and lupus advocates on the lifecosts (perceptions or experiences of economic and other costs) of SLE. The third (14 May, 2019) presented the results of a review of disability and employment policies across Canada at national and provincial levels. This data sharing was broken into three segments (i.e. three webinars) to make it manageable for a heterogeneous stakeholder group.

To kick off Waterlupus, one mentor participant spoke of her lived experience of SLE. This introduction engaged mentors and students, and helped participants gain a deeper understanding of the economic challenges related to living with SLE. GreenHouse staff then facilitated a "World Café," a method for conducting large-group discussions whereby smaller subgroups discuss questions in a comfortable, café-like atmosphere. During the World Café, student participants discussed a series of questions with lived experience mentors. In addition, members of the research team gave three short presentations (mirroring the webinars) of previous research to help contextualize the research problem, and answer any research-related questions. Based on their interests and initial ideas, student participants then formed teams, guided by the policy, lived experience and advocacy mentors.

In addition to multiple unique workshops held by the GreenHouse and the research team (with names such as "Deep Dive into Research"), most of the time was spent as an interactive working period, during which teams and mentors discussed their "hacks."

At the end of the working period, five student teams pitched their solution ideas. Three judges (a research mentor, a research director from a lupus advocacy group, and a GreenHouse pitch expert) deliberated with the support of the other GreenHouse expert for about one hour before selecting a winner and runner-up. Judging criteria were based on previous GreenHouse best practices and included four categories: problem identification; problem–solution fit; impact, feasibility, and viability; and additional criteria (Table 1). No numerical scores were attached to the judging criteria, and the final decision was based on a group discussion and consensus by the judges.

Data collection and analysis

This research was granted ethics approval from the University of Waterloo Office of Research Ethics, and conducted with all participants' consent. Data was collected in multiple ways. First, during the World Café discussions, hackathon participants were asked to record their responses and related notes for each question presented; this was collected for thematic analysis.

During the World Café and throughout the hackathon, multiple members of the research team conducted participant observation. Designated notetakers were present to record the event proceedings, summarize plenary discussions, and document outcomes (e.g. pitches, judge feedback).

Members of the research team discussed and recorded the major outcomes immediately following the hackathon. The first author reviewed all notes in the following weeks, and consulted other members of the research team. All notes were recorded into NVivo 10 for Mac (QSR International Americas Inc., Burlington, MA, USA) for subsequent analysis. Themes emerged inductively (based on researcher and chart paper notes and hackathon conversations) throughout analysis. The first author led the analysis, and noted any differences between themes identified in the notes taken at the event for further discussion with other team members. To enhance consistency and reliability in thematic analysis, the authors discussed the results, and consulted other members of the research team to ensure agreement in interpretation.

TABLE 1
Waterlupus[a] hackathon judging criteria

Judging criteria	Considerations
Problem identification	Is the problem specific? Is it real? Do you have quantitative/qualitative data to support the problem?
Problem–solution fit	Does the chosen solution address the identified problem? Is the solution useful to the specific user?
Impact, feasibility, viability	What is the potential impact of the solution? Is it scalable? Is it feasible to implement in the timeframe suggested? Is it viable? Do you see it implemented successfully?
Additional criteria	Did the team deliver an interesting and captivating pitch? Was the team/their ideas well organized? Did the team follow the guidelines for the presentation?

[a] Waterlupus health hackathon event held 24–25 May, 2019, at the University of Waterloo, Waterloo, Ontario.

Results

Hackathon results are reported in three distinct sections: World Café discussions, intervention pitches, and additional outcomes of Waterlupus.

World Café discussions

The first day of the hackathon included a World Café to increase student understanding of the economic challenges of SLE through engagement with diverse stakeholders. This activity contextualized the research problem and previous research results, served as an icebreaker and provided an opportunity for student participants to engage with mentors before joining their teams. Participants were enthusiastic about the World Café, and the questions generated engaging discussion between mentors and students. The lived experience, policy and lupus advocacy organization mentors were split between 7 tables to ensure a range of perspectives in each discussion. Students were divided into groups and rotated through the tables following each question, while mentors remained seated.

The first question, "What does economic quality of life mean to you?", generated in-depth discussion, and several common themes emerged across the groups (Table 2). The most frequent theme identified (by 6 groups) was the impact of a reduced income on quality of life. Lived experience and advocacy mentors discussed the importance of having disposable income to afford life necessities (e.g. shelter, healthy food, medication), as well as activities for entertainment and pleasure (e.g. to take holidays or give gifts). The potential impacts on mental health related to a reduced income were discussed by 5 groups. Each group spoke of the stress and worry associated with limited financial freedom and accumulating monthly bills. Conversely, the positive "state of mind" experienced when expenses are managed was discussed by one group. The connection between economic quality of life and relationships/social support (e.g. family, friends, spouse) was described by five groups. Participants discussed the economic and emotional familial impacts of a reduced income; for example, increased reliance on a spouse or other family member to support dependants, guilt associated with inability to support family members, and the possible relationship stress when an individual does not feel supported or understood by family or friends. The potential for social isolation due to job loss or early retirement was also identified.

Other themes discussed included the need to access satisfying and accommodating employment to maintain an income, pension and the sense of meaning that comes from fulfilling work (4 groups), and the potential loss of identity when an individual is no longer able to work, experiences reduced personal independence or does not feel meaningfully engaged in society (4 groups). Finally, the direct relationship between income and accessing medical care (e.g. alternative care practitioners), and the accessibility of resources that can support financial planning were identified by 3 and 2 groups, respectively.

Following this discussion, the students rotated tables, and the groups were asked "How has lupus affected your economic quality of life in the past, present or future?" (Table 3). After the hackathon,

TABLE 2
Themes emerging from the Waterlupus World Café[a] discussion, "What does economic quality of life mean to you?"

Subtheme	Number of tables where mentioned[b]
Impact of a reduced income on quality of life	6
Mental health impacts (positive/negative)	5
Relationships/social support	5
Need for satisfying and accommodating employment	4
Loss of identity	4
Relationship between income and accessing medical care	3
Accessibility of financial planning resources	2

[a] Small group breakout session at the Waterlupus hackathon event held 24–25 May, 2019, at the University of Waterloo, Waterloo, Ontario.

[b] A total of seven separate tables were involved in this discussion.

the research and the GreenHouse teams reflected on the similarities between the first two questions and discussed increasing variation in questions in future hackathon iterations. In this context, as often happens in qualitative research, themes in these discussions overlapped. Not surprisingly, the most common theme surrounded the impacts of lupus on employment (6 groups). Groups discussed uncertainty about sharing their diagnosis with or asking for accommodations from their employer, the need for accessible and flexible workplaces, challenges related to progressing in their career, and forced medical retirement. The resulting financial impacts were described by 4 groups (e.g. less security in retirement, reduced pension, difficulties finding health coverage). Other themes included the need to access quality health care and medication (3 groups); and the impacts on mental health (e.g. anxiety related to flares or future plans or career, lack of sleep, irritability from treatment) and the physical symptoms that can impact employment (e.g. inability to drive, organ damage from medication) (2 groups).

After the final rotation, groups discussed the question, "What ideas do you have to address some of these challenges?" (Table 4). Ideas varied more between groups relative to the previous two questions. Four groups described the need to increase access to resources, and the value of creating a tool or platform to facilitate access to relevant information (e.g. support groups, medical information following diagnosis, employment resources). One group spoke of the need for information to come from a credible source (e.g. medical professional) to reduce the spread of inaccurate information, and another group described the value of counsellors in sharing support and information with patients. Three groups discussed the need for medical interventions (e.g. lupus screening tools). Two groups each identified workplace-specific interventions (e.g. scale to subjectively rate symptoms for employers, flexibility in work schedule/hours), increasing workplace awareness (e.g. for improved accommodations), and interventions that went beyond the workplace (e.g. for policy change, increased research funding). The value in organizational collaboration (e.g. between advocacy organizations at the provincial and national levels), increased financial support for medical-related transportation, and increased physician education (e.g. to provide employment-related resources) were each identified by one group.

TABLE 3
Themes emerging from a Waterlupus World Café[a] discussion, "How has lupus affected your economic quality of life in the past, present or future?"

Subtheme	Number of tables where mentioned[b]
Impacts of lupus on employment	6
Workplace challenges and financial impacts	4
Access to quality health care and medication	3
Mental and physical impacts	2

[a] Small group breakout session at the Waterlupus hackathon event held 24–25 May, 2019, at the University of Waterloo, Waterloo, Ontario.

[b] A total of seven separate tables were involved in this discussion.

Intervention pitches

The primary outcome of Waterlupus was the interventions generated during the event: at the end of the hackathon, five teams pitched interventions to address the economic challenges associated with living with SLE. The winning team, called "Shine On," pitched their idea to collaborate with Lupus Canada (and other advocacy organizations) and Canadian clothing brands to increase accessibility of affordable sun-protective clothing suitable for different environments (e.g. work, school). SLE patients are encouraged to minimize their exposure to sunlight, as it may aggravate their illness. The judges thought this pitch was especially innovative, because it had the potential not only to change the lives of those with lupus, but also the lives of other sun-sensitive individuals, such as those on certain medications. It could also reduce UV exposure among the general population, and it had economic potential for the innovators. As one participant with SLE described, this innovation was attractive due to the stigma associated with their "lupus clothes," since, although available, sun-protective clothing is extremely limited and costly.

The runners up, "Team Purple," pitched their idea for a professionally moderated online social network to connect patients to relevant employment-related information and resources, and offer a space for meaningful social interaction with others impacted by SLE. This pitch was recognized by the judges for considering and applying mentor feedback, and for having a clear connection to economic quality of life. While it would be important for the platform to be professionally moderated in order to ensure credibility, the feasibility of this was identified as challenging.

Another team, "Lup4Help," also pitched an online platform to create awareness, share stories and provide employment opportunities for individuals with SLE. A fourth team, "Purple Monarch," similarly pitched an online platform designed to provide information for treatment and symptoms, a social feature (e.g. to coordinate meet-ups) and financial and employment resources and opportunities. This platform was especially accessible (e.g. the group created the platform in multiple languages, which is relevant given that

TABLE 4
Themes emerging from a Waterlupus World Café[a] discussion on ideas for addressing economic challenges associated with SLE

Subtheme	Number of tables where mentioned[b]
Increase access to resources and information	4
Need for interventions (e.g. medical, workplace-specific interventions)	3
Need for increased awareness in the workplace	2
Need for broad awareness (e.g. for policy change)	2
Organizational collaboration	1
Financial support for medical-related transportation	1
Increased physician education	1
Need for communication from credible sources	1
Role of counsellors for support and resources	1

Abbreviation: SLE, systemic lupus erythematosus.

[a] Small group breakout session at the Waterlupus hackathon event held 24–25 May, 2019, at the University of Waterloo, Waterloo, Ontario.

[b] A total of seven separate tables were involved in this discussion.

SLE has higher prevalence rates among minority populations[35]), and was also user-driven, increasing feasibility. Finally, the fifth team, "Lupus@Work," pitched an online platform to bridge employees and employers with respect to possible workplace accommodations. While this platform had the potential to be incredibly useful and was heavily informed by mentors' lived experiences, it would require employer buy-in to be implemented successfully. Table 5 provides a detailed summary of each pitch.

Based on their pitches, the winning teams were awarded the opportunity to continue to work on their innovations in collaboration with the Workplace Innovation Program (WIP), developed and implemented by the GreenHouse with the support of Geographies of Health in Place (GoHelP) Lab (https://uwaterloo.ca/geographies-of-health-in-place/about) and the research team, along with other stakeholders (e.g. lupus organization representatives). The conclusion of the hackathon saw support and enthusiasm from advocacy and lived experience mentors, who will continue to support the winning teams throughout the WIP. The WIP guides students for 8 to 12 months in the development of their solutions through ongoing capacity-building exercises.

The winning teams moving forward in the program are focussed on two distinct ideas. Shine On are proceeding with their idea to develop fashionable and affordable UV-protective clothing, and are currently working with three mentors with lived experience and a local fashion designer to design templates for clothing that is comfortable, desirable for a work environment, and made from sun-protective fabric. Team Purple are moving forward with their idea to create an online space for individuals with SLE to share useful employment-related resources. They are in the process of exploring the market to understand what other online resources exist for individuals with chronic illness; they are currently consulting with another WIP team (unrelated to the hackathon) to explore whether there is any overlap with their project (developing a digital space for individuals with chronic illness to access disability-related resources).

While both teams generated initial ideas at the hackathon, participation in the WIP is iterative, and the teams are currently reviewing the literature, patents, current market and stakeholder feedback to determine how to best generate interventions that differ from what currently exists. In this way, these innovations will continue to evolve over the course of the program.

Additional outcomes

Additional outcomes of Waterlupus were also documented. A major outcome relates to increased awareness of the economic challenges of those with SLE. Not only did the webinars and hackathon increase awareness among participants (especially the students, many of whom had no prior knowledge of SLE), but the innovations have the potential to increase awareness of SLE and the associated economic challenges of living with the disease among employers, colleagues and the Canadian population more broadly. Indeed, multiple lived experience and advocacy mentors spoke of the students' increased knowledge of SLE, and the potential for the innovations to continue to increase understanding of the economic impacts of SLE and other invisible and episodic illnesses.

The lived experience, policy and advocacy mentors also described the positive experience of spending extended time with students interested in SLE. During the informal working periods, students worked on their "hacks" with the mentor participants. Not only was this a productive time for the teams to receive feedback from mentors, but the mentors spoke of the energy and innovative ideas generated while engaging with students. Similarly, the educational opportunity provided to the students was positive, as they had the opportunity to work on a real-world problem and develop their skillset with a group of stakeholders that would otherwise be inaccessible in a university setting. Their participation offered an unbiased and future-oriented vision to this health and social challenge.

Finally, a very positive but unintended outcome was the feedback received from mentors, who genuinely appreciated the time they had to share their experiences. This provided professional networking opportunities and encouraged development of informal support networks, both for mentors representing advocacy organizations as well as for patients who connected across provinces.

Discussion

This paper documents the outcomes of the Waterlupus hackathon conducted at the University of Waterloo in May 2019. Not only does this paper report outcomes from the event, but it contributes to a limited literature about the use of health hackathons for social innovation. The Waterlupus hackathon was a useful iKT tool, generating innovative ideas to address a complex health challenge.

While the World Café itself did not generate the interventions, it was an opportunity for students to increase their understanding of the economic challenges of living with SLE by hearing from those with lived experience; it contextualized

TABLE 5
Summary of Waterlupus[a] hackathon innovations

Team name	Place finished	Target population	Problem identified	Summary of innovation
Shine On	1st	• Canadians with SLE, specifically those with sun-sensitivities • Other sun-sensitive individuals	• Sun-sensitive individuals must limit exposure to sun, which can impact quality of life • Lack of affordable everyday clothing for sun-sensitive individuals; UPF clothing exists but is limited to specialized clothing (e.g. athletic wear)	• Create accessible and affordable sun-protective clothing suitable for work and school • Develop clothing templates, approach Canadian clothing brands to increase accessibility of UPF sun-protective clothing
Team Purple	2nd	• Canadians with SLE • Presentation specifically identified users under age 45	• Need to improve economic quality of life of individuals with SLE, through reducing time it takes to access relevant resources • Need to reduce physical pain and emotional challenges of an SLE diagnosis	• Professionally moderated online social network to connect patients to employment resources • Ensure valid and relevant information, provide a positive community and meaningful interactions • Platform offers opportunities to organize threads and sub-threads, connect people and provide in-person meetups through message board and hashtags
Lup4Help	N/A	• Canadians with SLE	• Individuals with SLE often have to limit or leave employment following diagnosis • As a result, SLE can lead to reduced income and quality of life, and increased reliance on disability benefits • Need to increase social and economic impact	• Online platform to create awareness, share stories and provide employment resources • Aim to create job opportunities for individuals affected by connecting to flexible employers, and create awareness among employers • Aim to build a community to increase awareness and raise funds by organizing community events (e.g. marathons, camping)
Purple Monarch	N/A	• Canadians with SLE	• Continuously declining economic quality of life • Overwhelming for individuals with SLE to find resources and receive support • Current sources are limited or not user-friendly	• Online platform to provide resources to individuals with SLE • Tailored and curated financial assistance • Frequent updates on optimal care and specialist availability • Access to peer support and community building • Accessibility challenges identified (e.g. website provided in multiple languages)
Lupus@Work	N/A	• Canadians with SLE • Specifically focusses on those of working age	• Many with SLE cannot continue in employment following diagnosis, and those that do face stigma, fear disclosing their illness or are unable to access job accommodations to prolong their ability to work • With appropriate accommodations, increased productivity, improved interactions with coworkers, and long-term employment are possible	• Online platform to bridge employees and employers related to possible workplace accommodations • Engage variety of stakeholders (e.g. employers, employees, family members, advocacy representatives), and collaborate with software providers to create a prototype platform • Need to enable open discussion about workplace opportunities

Abbreviations: SLE, systemic lupus erythematosus; UPF, ultraviolet protection factor.

[a] Waterlupus health hackathon event held 24–25 May, 2019, at the University of Waterloo, Waterloo, Ontario.

the results of the previous qualitative and quantitative research; and it provided energy and momentum early in the event.

With respect to the interventions, the winning pitch and the runner up both offered solutions with the potential to positively impact the economic and the social challenges faced by individuals with SLE (e.g. workplace barriers, stigma, social isolation).[23-27] These innovations may also be beneficial for those impacted by other chronic diseases (e.g. accessible sun-protective clothing for other sun-sensitive individuals).

The two winning teams are currently moving forward with the development of their ideas in the WIP. In so doing, they will work through an iterative innovation cycle with both the research team and hackathon organizers from the GreenHouse to explore and develop their solutions. This involves following a multistage process that ensures teams identify and define a problem, conduct a needs identification and generate an implementation plan. In addition, in-depth training on a range of topics (e.g. giving an effective pitch) will be provided. Funding opportunities to move their projects forward and disseminate results will also be offered by the research team.

Documented successful outcomes from previous health hackathons include increased passion, community engagement and sustainable, culturally appropriate solutions;[14] generation of ideas and enthusiasm for innovation;[36] establishment of networks to inspire future work and collaboration;[14] and the start of new innovations, solutions and companies.[6] Waterlupus also had numerous successful outcomes. For example, multiple and diverse end-users (e.g. patients, advocacy representatives) were included, and provided their perspectives to ensure long-term and sustainable innovations that satisfy end-user needs. In addition, multiple participants expressed excitement with the energy generated at the event, and were impressed with the passion of both mentors and students. Finally, new professional and social networks were created, as multiple stakeholders reported connecting with individuals from different geographic locations. Multiple participants exchanged contact details, and every lived experience, policy and advocacy mentor expressed interest in receiving research results and updates with respect to the WIP teams' progress.

While SLE disproportionately impacts working-age females,[20] the innovations generated at Waterlupus were not necessarily designed to be age- or gender-specific. The hackers did, however, draw on previous research results (e.g. qualitative interviews, primarily with females impacted by SLE), and on the feedback from lived experience mentors at the event (who, with one exception, were all female). In this sense, the teams' innovations implicitly considered age and gender in that they were intended to improve economic (which often means employment) outcomes for individuals with SLE. For example, a professionally moderated online social network to connect patients with employment-related resources is relevant to females and males impacted by SLE, but may be used more frequently by females of working age (15–64 years) because they are disproportionately affected. Exploring how innovations can be developed to suit different subpopulations affected by SLE—for example, by increasing the number of languages available in an online platform or by creating sun-sensitive clothing that goes beyond athletic-wear and is suitable for both females and males—is certainly an avenue for future work.

Multiple challenges emerged in the execution of Waterlupus. First, using the term "hackathon" in the advertisement may have attracted students expecting a software hackathon, or deterred other potential participants assuming who assumed the event was a traditional hackathon. Second, a larger number of students was anticipated, based on previous hackathons held by the GreenHouse. Waterlupus was the first hackathon the GreenHouse had conducted during the summer term, though, when there are fewer students on campus available for recruitment. Other factors beyond the research team's control, such as seasonably pleasant weather, could also have deterred students from participating. The students in attendance, however, were extremely engaged and the research team were impressed with their commitment.

Third, throughout the recruitment process, by the questions that the research team were asked about SLE, it was evident that lay understanding of SLE is limited. The lack of awareness of the disease and its associated challenges may have reduced interest in the event. Fourth, with respect to the pitch outcomes, geography likely influenced the results. If this hackathon had been held outside of Canada, the pitches may have focussed on different economic challenges. In Canada, the health care system is publicly funded, offering universal coverage for medically necessary services.[37] While health care access challenges do exist in Canada in the context of SLE (e.g. appointment waiting times, accessing specialist care),[23,38] alternative economic challenges to accessing health care may have been identified elsewhere (e.g. in the US).

A primary criticism of hackathons is that they can develop short-lived excitement, yet lack a pathway to generate sustainable solutions with long-term impact.[14] Similarly, and outside of the hackathon literature specifically, there have been calls for researchers to consider the success of iKT beyond the short-term timelines of any one research project, as an avenue to build long-term partnerships and inspire innovative thinking.[2] In consideration of these criticisms, one of the primary outcomes of Waterlupus is the formation of WIP teams that are provided a pathway to continue their innovation beyond the short term with lupus organization advocacy groups, members of the research team and the GreenHouse. By moving these teams' solutions forward and involving multiple stakeholders in the process, we aim to go beyond awareness-raising to attitude, behaviour and, ultimately, social change.

Conclusion

This paper describes what is, to our knowledge, the first iKT activity focussed on the co-production of knowledge to improve the economic lives of individuals with SLE and increase public understanding of the disease. Waterlupus generated feasible and actionable nonpharmacological intervention ideas, established partnerships and facilitated networking and leveraged expertise between those living with SLE, advocacy organizations, policy makers and student participants. While these successful outcomes emphasize the value of hackathons in the iKT toolbox, the next step of this research involves increasing our understanding of how the hackathon participants themselves (e.g. knowledge-users) perceived the hackathon as an iKT initiative. Not only will this increase our understanding of how Waterlupus itself was valued, but acknowledging the perspectives and voices of knowledge-users is an important step in ensuring that future iKT science, and hackathons specifically, can help meet their needs.

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Conflicts of interest

There are no conflicts of interest to disclose.

Authors' contributions and statement

SE, AC and EB conceptualized the work; FC, SE, AC and EB acquired, analyzed and interpreted the data; FC drafted the paper; FC, EB, AC and SE revised the paper.

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At-a-glance

Initial evaluation of Manitoba's cannabis surveillance system

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Abstract

The Government of Manitoba created a cannabis public health surveillance system in 2018 in preparation for nonmedical cannabis legalization on 17 October, 2018. An initial evaluation was conducted to assess the usefulness, flexibility and simplicity attributes of the system, using an online stakeholder survey, website metrics, system analysis and interviews. Resulting recommendations included creating a detailed communication plan for surveillance products, changing the format and frequency of reporting, maintaining strong relationships with partners and building towards a centralized provincial substance use surveillance database and surveillance system.

Keywords: *cannabis, public health surveillance, evaluation, Manitoba*

Highlights

- Evaluating public health surveillance systems is essential for understanding system performance and providing guidance for improvement.
- An initial evaluation of Manitoba's cannabis surveillance system showed that the system was moderately useful, highly flexible and moderately simple.
- Recommendations included creating a detailed communications plan prior to surveillance product release to increase the audience reach; producing a shorter infographic-style product that sets cannabis in context of other substances once or twice a year; and leveraging the existing provincial opioid misuse and overdose surveillance system to include cannabis and other substances.

Introduction

Nonmedical cannabis use was legalized in Canada on 17 October, 2018, when the *Cannabis Act* came into force.[1] To prepare for this event, the provincial department of health (Manitoba Health, Seniors and Active Living) created Manitoba's cannabis surveillance system. The purpose of the system was "… to manage, analyze, and interpret cannabis and related data from a range of stakeholders to provide epidemiologic evidence to inform policy and programs in Manitoba."[2] More specific objectives of the system were to

(1) monitor cannabis-use behaviour patterns among people in Manitoba;

(2) measure cannabis-related health impacts among people in Manitoba; and

(3) measure justice-related impacts of cannabis policy in Manitoba.

A list of indicators in the system can be seen in Table 1. An initial baseline report was released in November 2018,[2] and was modelled from existing opioid misuse and overdose surveillance reports.[3] In order to better understand the performance of the cannabis surveillance system, and to inform future development at this early stage, an initial evaluation of the system was conducted.

The objectives of this initial evaluation were to (1) understand if Manitoba's cannabis surveillance system was meeting its intended objectives, and (2) to define the direction that a sustainable and relevant provincial cannabis surveillance system should take going forward. Specifically, these objectives relate to the content of the system (i.e. which indicators should be used), the identification of stakeholders' needs and the format and frequency of reporting.

Methods

We undertook an evaluation using guidance from the Centers of Disease Control and Prevention[4] (CDC) and the European Centre for Disease Prevention and Control,[5] with specific direction from recent work from the CDC in evaluating behavioural health surveillance systems.[6,7] Three attributes, deemed to be the most relevant for a new and changing system, were selected for evaluation: usefulness, flexibility and simplicity. For each attribute, we used multiple evaluation methods (described below), and then made a global assessment based on these results to summarize and communicate our findings. For example, when assessing the overall usefulness (i.e. low, moderate or high), we considered results from an online survey and from website metrics to make a judgment within our organizational context.

Usefulness

This attribute measures whether the system and its outputs are helpful and important for stakeholders. We assessed usefulness through an online survey and website metrics. We conducted the survey using a snowball approach, whereby key stakeholders who received the survey were instructed to send it to others in their networks. The survey covered topics relating to the overall usefulness of the surveillance system baseline report, specific

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TABLE 1
Manitoba cannabis surveillance system indicators, by objective

	Indicator	Data source
Objective 1: To monitor cannabis use behaviour patterns among youth and adults in Manitoba		
Patterns of use	Percentage of youth who used cannabis in last year (Grades 7–12)	AFM's Student Survey (2007) Manitoba Youth Health Survey (2012/13)
	Percentage of youth who used cannabis in last 30 days (high school students)	AFM's Student Survey (2007)
	Quantity of cannabis used per session	Manitoba Cannabis Survey (2017)
	Percentage of cannabis users by type of product used (e.g. plant, edible)	Manitoba Cannabis Survey (2017)
	Percentage of cannabis users who frequently/often use cannabis alongside alcohol	Manitoba Cannabis Survey (2017)
Driving	Percentage of adults who have driven after using cannabis	Manitoba Cannabis Survey (2017)
	Percentage of adults with driver's licences who consumed cannabis within two hours of driving	Statistics Canada National Cannabis Survey
Objective 2: To measure the burden of cannabis-related health harms among youth and adults in Manitoba		
Poisoning	Rate of in-patient hospitalizations that include cannabis poisoning ICD-10-CA diagnosis code (T40.7)	DAD
	Number of cannabis-related calls to Health Links – Info Santé	Health Links – Info Santé
	Number of cannabis-related calls to Manitoba Poison Control Centre	MB Poison Control Centre
Mental wellness	Rate of in-patient hospitalizations that include cannabis-related disorder ICD-10-CA diagnosis codes (F12.x)	DAD
	Rate of in-patient hospitalizations that include cannabis abuse ICD-10-CA diagnosis code (F12.1)	DAD
	Rate of in-patient hospitalizations that include cannabis dependence syndrome ICD-10-CA diagnosis code (F12.2)	DAD
	Rate of in-patient hospitalizations that include cannabis-related psychotic disorder ICD-10-CA diagnosis code (F12.5)	DAD
	Proportion of clients with past-year cannabis use in publicly funded substance use treatment centres	Addiction Policy and Support Branch, MHSAL
Objective 3: To measure justice-related impacts of cannabis policy among youth and adults in Manitoba		
Justice	Number of samples that tested positive for THC or CBD	HC Drug Analysis Service
	Rate of charges for drug-impaired operation of vehicle/vessel/aircraft among youth (12–17 years)	Statistics Canada UCRS
	Rate of charges for drug-impaired operation of vehicle/vessel/aircraft among adults (18+ years)	Statistics Canada UCRS
	Rate of charges for cannabis possession among youth (12–17 years)	Statistics Canada UCRS
	Rate of charges for cannabis possession among adults (18+ years)	Statistics Canada UCRS
	Rate of charges for cannabis trafficking among youth (12–17 years)	Statistics Canada UCRS
	Rate of charges for cannabis trafficking among adults (18+ years)	Statistics Canada UCRS

Abbreviations: AFM, Addictions Foundation of Manitoba; AFM's Student Survey, Addictions Foundation of Manitoba's Alcohol and Other Drugs: Students in Manitoba - 2007 survey; CBD, cannabidiol; DAD, (hospital) Discharge Abstract Database; HC, Health Canada; MHSAL, Manitoba Health, Seniors and Active Living; THC, tetrahydrocannabinol; UCRS, Uniform Crime Reporting Survey.

indicator and content questions, and direction for the future. (A copy of the survey is available upon request.) The website metrics measured the number of users accessing the report landing page, and their characteristics in the three months following the release of the baseline report.

Flexibility

This attribute refers to the ability of the system to adapt to changes in stakeholder needs. We assessed flexibility by analyzing the system as a whole (i.e. is it possible to add, delete or modify indicators?). We also created hypothetical scenarios for adding a new indicator (cannabis poisoning in children) using each of the existing health-related data sources. We consulted external data providers about feasibility and process questions when required.

Simplicity

This attribute refers to the system structure and how easy it is to use. We assessed simplicity by analyzing the system as a whole (i.e. how many organizations, data types and human resources are needed) and by documenting and analyzing the data collection, management and analysis steps of the surveillance cycle for each data source.

Results

Usefulness

Initially, we sent the online survey to 52 stakeholders in Manitoba; after snowball sampling, there were 62 survey respondents. The largest proportion of respondents were from regional public health (44%), followed by provincial public health (21%), and other provincial departments (16%). The remainder were from other areas of the government or crown corporations, nongovernmental organizations and other agencies.

The key findings of the survey were as follows:

- Most respondents (55%) were not aware of the baseline report; 24% were aware but had not reviewed it, and 21% were aware and had reviewed it.
- Eighty-three percent of respondents said the overall report was somewhat or very useful; 63% said they already have used or plan to use the information in their work.
- The two most common intentions for using the baseline report were to influence education and awareness activities, and to provide general context to other work.
- Behavioural indicators were most highly rated for usefulness, followed by cannabis-related disorder hospitalizations (ICD-10-CA: F12). In general, poisoning information was rated to be less useful.
- Most respondents (74%) preferred to see the cannabis data in the context of other substances.
- Most respondents (65%) preferred a shorter, infographic style of reporting.
- Annual reporting was favoured by 41% of respondents, and semi-annual by 31%.

Available website metrics captured unique page views for the cannabis surveillance website. Metrics on the report access itself (PDF) were not available. Key findings of the website metrics assessment for usefulness were as follows:

- There were 191 page visits; 56% were internal government views, and 44% were external views.
- Almost all internal views were from a desktop computer; for external views, 55% were from a desktop computer, 38% from a mobile device and 7% from a tablet.
- Forty-five percent of all views were directed from a Google search, 26% were from a direct link and 7% were from the government search engine; 18% of external views came from a Facebook link.

Flexibility

Overall, the whole system is highly flexible. This is because the indicator groups operate independently, so changing one will have no effect on others (i.e. one indicator is not dependent on the presence of another). Also, indicator change decisions are informal and made through a limited group of stakeholders, which makes the process timely and flexible. However, this structure may pose threats, such as inconsistencies in data over time due to changes, in the absence of good documentation.

When hypothetically adding a new indicator about cannabis poisoning among children from existing poisoning data sources, flexibility differed depending on the data source. For example, for hospitalizations, because an ICD-10-CA code already exists for cannabis poisoning and there is direct access to the data source (including custom age queries), it is relatively simple to get this information. However, other queries outside of the current ICD-10-CA structure would require much more effort and time to modify coding. For other data sources, high level indicators were available but there was low flexibility for more specific information; challenges in current data structures, resources and data sharing agreements were identified. A common theme was that several data quality improvement initiatives were currently underway or planned in the near future, highlighting the importance of continued relationship building with data providers.

Simplicity

The overall system itself is complex due to the many data sources (ten data sources provided by eight organizations), and types of data included (survey data, administrative data and program data; Figure 1). In terms of resources, the system development and reporting took one full-time employee (FTE) approximately four months to complete, with additional support from a senior epidemiologist (about 0.33 FTE), and publication support for an additional 2.5 months.

For each data source, data collection ranges from downloading publicly available content, to making specific data requests, to accessing departmental data directly. Several file types are involved, including PDFs, Excel and CSV files and SAS code/extracts. In terms of management, these data are stored in different folders on a shared drive. As the number of reports increases, there is a risk that the volume of data will become difficult to manage and document in the current structure. However, the actual analysis of the data is simple; most data sources are already aggregated and analyzed, and a few only require manipulation for data visualization. One data source has an automated process (hospital discharge abstract database).

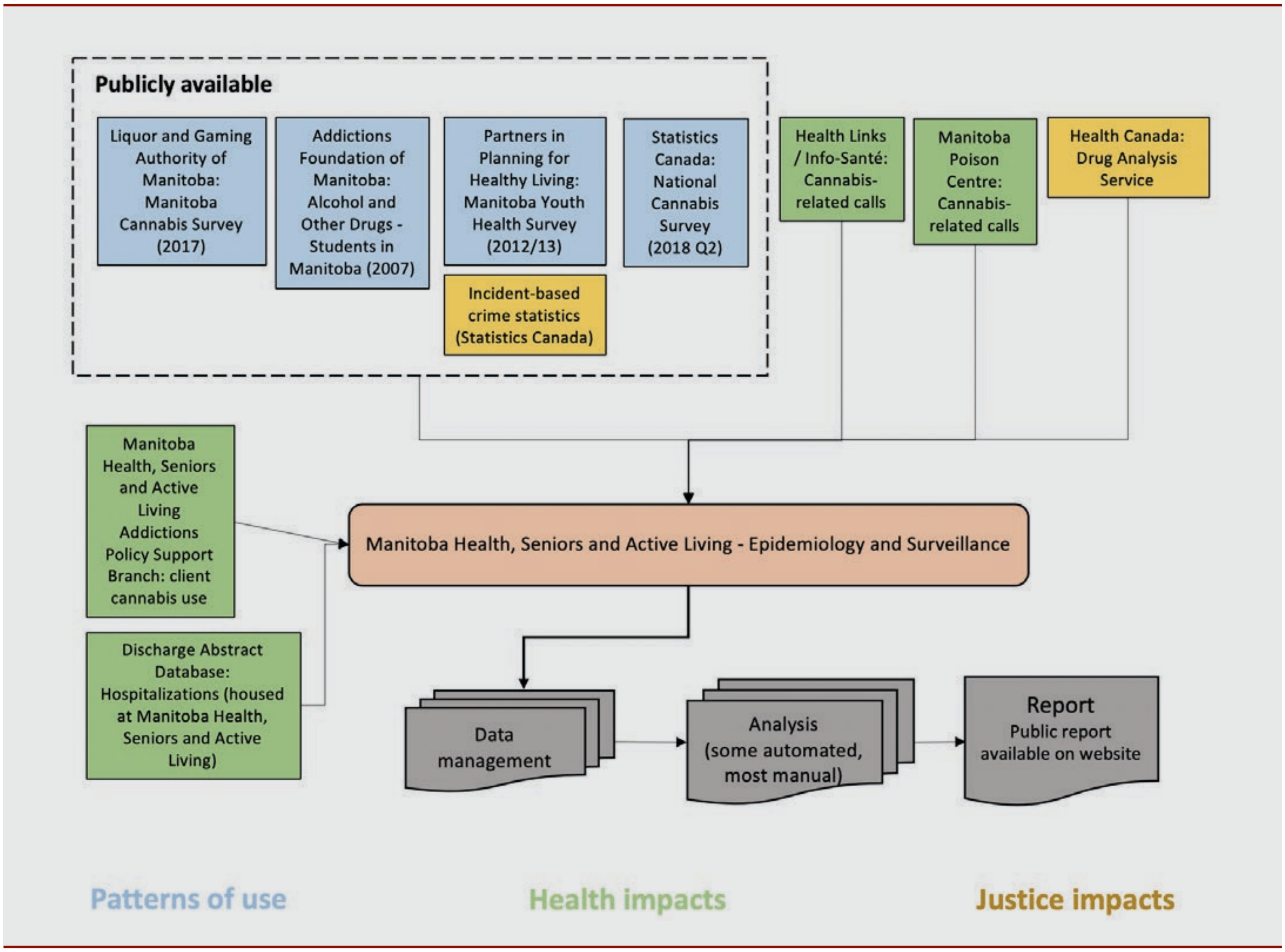
Recommendations

- Create a detailed communications plan prior to surveillance product release; consider new media accessing the products (e.g. mobile devices) and platforms (e.g. Facebook).
- Release surveillance products once or twice per year; include a shorter, infographic-style product, and set cannabis surveillance in the context of other substances.
- Review stakeholder indicator survey feedback and explore ways to measure suggested concepts.
- Document methodologies used by each data provider to maintain comparability across surveillance products in future.
- Maintain strong relationships with data providers in order to leverage future opportunities for improvements in data quality.
- Leverage opioid data management and analysis structure to standardize data management, reduce filing inconsistencies and increase automation.

Conclusion

Overall, this initial evaluation of Manitoba's cannabis surveillance system identified strengths, weaknesses and opportunities for its enhancement. Stakeholders identified useful indicators from all three objectives of the system, and provided feedback for content areas of interest. The system was found to be generally flexible, and to be relatively complex in terms of data volume and management. Key challenges were identified as the limited reach of the baseline report, and the risk of data management inconsistencies for the future.

FIGURE 1
Structure of Manitoba cannabis surveillance system: data flow



Our experience shows the importance of regular surveillance system evaluation. During the surveillance cycle, this is a step that is often overlooked but really should be a key consideration during design and planning of a surveillance system. It is important that the effort put into maintaining surveillance systems and the processes of sharing information be efficient and serve the information needs of users. Evaluation allows us to understand these needs better and informs how we can adapt and improve processes and surveillance products going forward.

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Conflicts of interest

The authors have no conflicts of interest to declare.

Authors' contributions and statement

AB conceptualized and designed the evaluation, analyzed and interpreted the data and drafted the manuscript. SBE reviewed the evaluation and contributed to the drafting of the manuscript.

The content and views expressed in this article are those of the authors and do not necessarily reflect those of the Government of Manitoba or of the Government of Canada.

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At-a-glance

Injuries and poisonings associated with e-cigarettes and vaping substances, electronic Canadian Hospitals Injury Reporting and Prevention Program, 2011–2019

Steven R. McFaull, MSc (1); Minh T. Do, PhD (2,3); André Champagne, MPH (1); Felix Bang, MPH (1)

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Abstract

Electronic cigarettes are devices that deliver nicotine to the user by heating an e-liquid. In Canada, the *Tobacco and Vaping Products Act* became law on May 23, 2018. The purpose of this study was to describe the cases of injuries and poisonings associated with e-cigarette and vaping substances that presented to Canadian emergency departments within the electronic Canadian Hospitals Injury Reporting and Prevention Program network between 2011 and 2019. A total of 68 cases were retrieved (54.4% males). Of the 68 cases, 8 occurred between 2011 and 2014, while 35 (51.5%) occurred in 2018 or 2019. Ingestions, inhalations and burns were observed.

Keywords: *electronic cigarette, vaping, injury, surveillance, eCHIRPP*

Highlights

- Of 68 cases of injury or poisoning due to e-cigarette use or vaping between 2011 and 2019, 54.4% involved males.
- Of the 68 cases, 8 occurred between 2011 and 2014 while 35 (51.5%) occurred in 2018 or 2019.
- The annual percent change (APC) was 50.7% (95% CI: 15.9–96.1).
- Children under 5 years of age who either ingested the e-juice or vaping liquid or inhaled from the device accounted for 52.9% of incidents.
- In two cases, the device's battery exploded in the pocket of an adult male, causing a burn to the thigh.
- There were 3 traumatic brain injuries as a result of a fall subsequent to vaping.

Introduction

Electronic cigarettes (e-cigarettes) are devices that deliver nicotine, via an aerosol, to the user by heating an e-liquid that contains propylene glycol, nicotine and flavouring agents.[1,2] These devices were invented in the early 2000s in China and began to gain prominence in the North American marketplace in 2013, when the large tobacco companies entered the market.[1]

The prevalence of e-cigarette use among youth in Canada has increased between 2013 and 2018.[3,4] Reid et al.[3] indicated that in 2013, 8.5% of Canadians aged 15 years and older reported ever having tried an e-cigarette (1.8% reported use in the last 30 days). Prevalence was highest among youth aged 15 to 19 years (19.8% ever; 2.6% past 30 days). Hammond et al.[4] reported on vaping from a more recent survey of adolescents aged 16 to 19 years; in 2018, ever-prevalence was 37.0% and past-30-day use was 14.6%.

In Canada, the *Tobacco and Vaping Products Act*[5] (TVPA) became law on May 23, 2018. The TVPA replaced the *Tobacco Act,* which governed how tobacco products were sold, labelled, produced and promoted. Adults can now legally get vaping products with nicotine. In addition to the TVPA, vaping products are also subject to the *Canada Consumer Product Safety Act*,[6] the *Food and Drugs Act*[7] and the *Non-smokers' Health Act*.[8,9] Despite the TVPA becoming law only recently, there is evidence that vaping products containing nicotine were available at least three to four years prior to 2018.[10,11]

A recent outbreak in the United States of pulmonary illness associated with vaping has heightened awareness of the potential hazards associated with e-cigarette use.[12] While these cases would not necessarily be captured in an emergency department injury and poisoning surveillance system due to their differing presentation, there are reports of other injuries and poisonings that have been associated with vaping devices, including ingestions resulting in nicotine exposure by young children.[13-15] These reports included a fatality,[16] intentional ingestions,[17] inhalation effects[15] and burns due to explosions.[18,19]

The purpose of this study was to describe the circumstances of injuries and poisonings associated with e-cigarette and vaping substances that presented to Canadian emergency departments within the electronic Canadian Hospitals Injury Reporting and Prevention Program (eCHIRPP) network between 2011 and 2019.

Methods

Data source

The electronic Canadian Hospitals Injury Reporting and Prevention Program (eCHIRPP) is an injury and poisoning sentinel surveillance system operating in 11 pediatric and 8 general hospitals across

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Canada. The eCHIRPP is managed by the Public Health Agency of Canada (Centre for Surveillance and Applied Research).[20]

Extraction of cases

We searched the eCHIRPP database for cases (all ages) of injuries and poisonings related to e-cigarette and vaping substance use entered into the system between 1 April, 2011, and 4 October, 2019. Cases were identified using eCHIRPP factor codes "858F:e-cigarette" or "859F:e-cigarette fluid" and a bilingual text-based search of the eCHIRPP narrative fields (Narrative, Product, Substance ID) using a list of slang and brand-name terms such as: "Ecig", "e-cig", "nicotine", "Vapouriz", "e-juice", "JUUL", "lene glycol" and "myblu". The full list of search terms is available upon request. We cleaned the data by mining the narrative fields using practical extraction and report language (Perl) regular expressions[21] in SAS 9.4 (SAS Institute Inc., Cary, NC, USA). The clean dataset was manually reviewed and coded with further circumstantial detail. The temporal trend was assessed using Joinpoint software.[22]

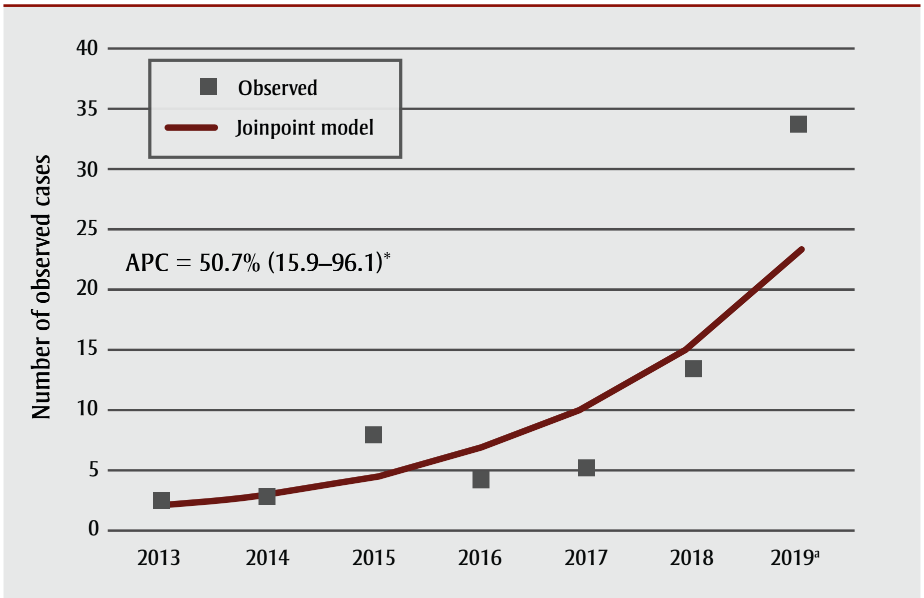
Results

We retrieved a total of 68 cases, of which 37 (54.4%) involved males. In the emergency department 26 patients (38.2%) were held for prolonged observation and 2 were admitted to hospital.

Of the 68 cases, 8 occurred between 2011 and 2014, while 35 (51.5%) occurred in 2018 or 2019. Figure 1 shows the trend over time and the results of the Joinpoint analysis. Since there was one case in 2011 and there were none in 2012, the analysis was limited to 2013 to 2019. The annual percent change (APC) was 50.7% (95% CI: 15.9–96.1). The number of cases were normalized to the proportion of eCHIRPP cases (per 100 000) in the same year.

Table 1 describes the circumstances and the injuries and poisonings associated with electronic cigarettes and vaping devices. Children under 5 years of age who either ingested the e-juice or vaping liquid or inhaled from the device accounted for 52.9% of incidents. A smaller number of children and youth aged between 5 and 19 years also ingested the vaping fluid; however, youth at this age vape (either with or without cannabis) and therefore may experience inhalation effects (as did 18 of the cases in our study).

FIGURE 1
Emergency department presentations for e-cigarette/vaping–related injuries and poisonings, eCHIRPP, 2013–2019



Abbreviations: APC, annual percent change; eCHIRPP, electronic Canadian Hospitals Injury Reporting and Prevention Program.
Note: Normalized proportion: number of cases/total number of cases in eCHIRPP in the given year (x 100 000).
[a] 2019 is incomplete.
[*] Significant at α = .05.

In two cases, the device's battery exploded in the pocket of an adult male, causing a burn to the thigh. The 68 patients suffered 71 injuries (3 had a second injury). There were 3 traumatic brain injuries as a result of a fall subsequent to vaping.

Discussion

In addition to the usual potential health effects of vaping, it is clear that injuries and poisonings related to vaping are a real concern. The large annual percent change depicted in Figure 1 likely reflects the increased marketing exposure of these devices in recent years, although increased awareness may also have contributed to the inflection. However, given the proximity of the May 2018 law to the cut-off date of the current study, changes may not be detectable and would require a longer post-law surveillance period.

Nicotine poisoning in children became an issue in the early 1990s, when transdermal nicotine patches became available in the US.[23] With the increasing prominence of e-cigarettes, the issue has re-emerged.[9-11] Because of their increased exposure to e-liquids and vaping devices, children under 5 years of age are at risk for unintentional ingestion or inhalation, resulting in a poisoning diagnosis. While these cases are overrepresented in this study due to the predominance of pediatric hospitals in the eCHIRPP system, it is still an important issue that requires continued surveillance. The study by Chang et al.[13] in the United States showed an increase in such cases between 2013 and 2015, and then a decrease to 2017. These researchers indicated that the *Child Nicotine Poisoning Prevention Act of 2015*,[24] which became effective in 2016 and which required child-resistant packaging for liquid nicotine, may have in part contributed to the awareness of state and federal legislation. While packaging/labelling requirements were being enforced since May 23, 2018, Health Canada published new regulations for the labelling and packaging of vaping products in December 2019.[25] Continued surveillance will be essential if we are to assess the effects of legislative measures.

A Canadian survey of pediatricians[15] reported 85 ingestion cases among children aged from 1 to 4 years and 135 cases of inhalation among youth aged 15 to 19 years. The difference between the results of this survey and the current study may be due to the fact that they each cover different points of care (ED vs. physician's office), although there will have been some overlap. Also, eCHIRPP underrepresents

TABLE 1
Characteristics of injuries and poisonings associated with e-cigarettes and vaping

Characteristics	Counts	Example narrative[a]
Circumstances		
0–4 years	**37**	
Unintentional ingestion of vaping solution	31	"Found with open bottle of e-cigarette solution. Drank entire bottle of solution and has been crying since."
Sucked/inhaled on vaping device	5	"Playing at home and mom found sucking on an e-cigarette."
Injured by piece of disassembled device	1	"Playing with e-cigarette. Dad was cleaning e-cigarette and had it apart. Child put ring on finger."
5–14 years	**14**	
Vaping nicotine—felt ill	5	"Nicotine poisoning from vaping all day with friends."
Vaping cannabis/marijuana—felt ill	4	"Smoking friend's e-cigarette. Took puff of vaporizer cigarette. It was laced with marijuana."
Unintentional ingestion of vaping solution	3	"Accidentally had a couple drops of e-cigarette oil into mouth. Was playing with mom's e-cigarette, and some oil leaked into mouthpiece."
Other or unknown circumstances	2	"Attending house party. Drinking. Vaping. Highly intoxicated."
15–19 years	**15**	
Vaping cannabis/marijuana—felt ill	6	"She was hanging out with a friend and took 2 'hits' of THC oil from a vape pen. Says she has never taken THC or cannabis before. Brought in by EHS."
Vaping nicotine—felt ill	3	"He was vaping, using nicotine. Felt nauseated and dizzy."
Unintentional ingestion of vaping solution	2	"Ingested 'purple glide' vape juice."
Vaping and using other substances	2	"Vaping with cannabis, and using LSD."
Intentional self-harm	1	"Vaping marijuana, threatening suicide."
Swallowed piece of vaping device	1	"Vaping; piece of device broke off and he swallowed it."
30–49 years	**2**	
Battery exploded in pocket	2	"Walking, battery of his vaping device exploded in his front pocket."
Injuries and poisonings	**71[b]**	
Poisonings	55	"Swallowed nicotine e-juice."
Traumatic brain injury	3	"Was vaping with THC; stood up and fainted; fell to the floor and struck head."
Thigh burn	2	"Walking, battery of his vaping device exploded in his front pocket."
FB in alimentary tract	1	"Vaping; piece of device broke off and he swallowed it."
Crushing injury to finger	1	"Playing with e-cigarette. Dad was cleaning e-cigarette and had it apart. Child put ring on finger."
No injury or poisoning detected	5	"In store, had been vaping marijuana; fainted and hit head on counter."
Unknown	4	"Playing. Took a sip of liquid for e cigarette. She was shaking, parents called poison control. Called paramedics. No shaking when they arrived."

Abbreviation: FB, foreign body.

Note: There were no cases among people aged 20–29 years.

[a] Identifying information has been removed.

[b] 3 patients had a second injury.

older teenagers who may go to a general hospital.

In this study, two cases of burns due to explosion or overheating of the device were identified. Both incidents resulted in a burn to the thigh. There have been other reported cases of significant burns to the face, mouth, thigh and genitalia.[18,19] Given the array of newer products appearing on the market, some with the ability to change the power capacity and voltage,[2] this aspect of injury due to e-cigarette use warrants serious attention.

Injuries and poisoning associated with e-cigarettes can be very serious, especially among children and adolescents. Ongoing surveillance is necessary to profile the Canadian experience and identify emerging trends. Since new brands with unique names are regularly introduced into the market, a continued evolution of the search strategy is necessary to accurately monitor these cases.

Strengths and limitations

The eCHIRPP narrative provides contextual information not available in administrative data sources. This additional information allows deeper analysis and can highlight opportunities for prevention.

However, eCHIRPP does not capture all incidents in Canada, only those presenting to the participating emergency departments. Because most of the eCHIRPP hospitals are pediatric (usually located in major cities), certain groups are under-represented in the data, including rural inhabitants (including some Indigenous peoples), older teens and adults. Also, while eCHIRPP captures people who are dead-on-arrival at the hospital, those who died at the scene or later in hospital are not included (although there have not been any deaths associated with vaping in Canada). In addition, patients who bypass the ED registration desk for immediate treatment may not be captured, as well as those who do not complete an injury/poisoning reporting form.

Conclusion

Injuries and poisonings related to e-cigarettes range from ingestions in young children to inhalation effects in adolescents and burns related to device explosion. Continued monitoring of the eCHIRPP text fields can help to focus mitigation efforts.

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Conflicts of interest

The authors declare no conflicts of interest.

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