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# Journal of Undergraduate Health Research UNIVERSITY OF WATERLOO

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APPLIED HEALTH SCIENCES AHSEE ENDOWMENT FUND

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# Dear Reader...

 ${
m A}$  fter a brief absence, we are pleased to bring you the third issue of the University of Waterloo (UW) Journal of Undergraduate Health Research (JUHR).

In these past few terms, we faced several challenges, one of which being a large turnover of our original student body as results of folks graduating. For this reason, we tirelessly worked to re-hire creative and literary talent to reestablish the foundation necessary for the release of our much anticipated third issue. With a majority of positions being filled with new talent, we are excited to share with you this the ideas, output and journal content.

Throughout this process, our executive team has learned to appreciate several lessons, first being Murphy's Law. In every phase of bringing you this issue, there were no shortage of challenges which momentarily impaired the progression of this journal's activity.

However, it was equally true that resilience and collaboration remained the only effective antidote each of the challenges we encountered. We are proud of how well our team was able to communicate and navigate through challenges while maintaining a sharp conviction to press on and deliver. We hope that our experience with adversity can resonate with you as you navigate challenges, planned and/or unforeseen, during your academic journey.

Our newest issue showcase manuscripts which have critically examined pressing community-based health issues using a sociological lens. Alexandra Pepetone's infographic for instance, highlights the unique challenge of food insecurity among UWaterloo undergraduates.

Sabrina D. Lutchmeah's manuscript titled "Review of DSM-5 Diagnostic Criteria for Anorexia Nervosa and Recommendations to Improve Inclusivity" went beyond reviewing the diagnostic criteria for Anorexia Nervosa (a lethal eating disorder) and discussed the current limitations and modifications which may enhance the inclusivity during the diagnostic process.

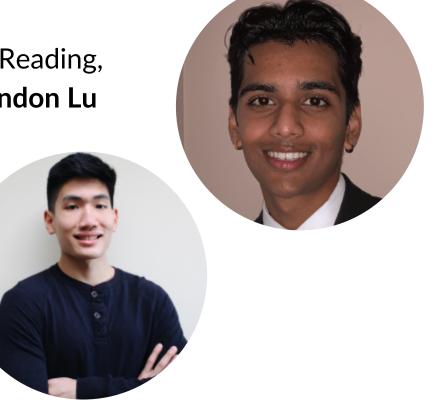
Building on community-based health issues, Wei et al.'s manuscript titled "Preferences of persons with memory changes and care partners for reducing barriers to community wellness programs" examined the preferences of individuals with memory changes and their care-partners to evaluate the needs and preferences in accessing community wellness programs that tendered to nutrition and exercise.

In a first for JUHR, we feature two submissions that bring attention to the health-issues experienced by Indigenous Women, a sub-group known to disproportionately experience a variety of health inequities in the Canadian context. Amanda Armstrong's opinion piece "A Gendered Perspective of the Lack of Justice for the Asubpeeschoseewagoon Anishinabek Women of Grassy Narrows" offers a critical examination and associated recommendations to the Ontario provincial government in the management of the health-issues experienced by the Asubpeeschoseewagoon Anishinabek women in relation to the mass mercury pollution encountered in the mid-1900s. Abeer Yusuf and Alysha Butt creatively summarize key findings of "Pregnancy, Maternal Health & Poverty in Indigenous Women". Lastly, to reflect the timely development and use of Artificial Intelligence tools in health research and academics, Elen Mullaj's manuscript "The Artificial Intelligence Dilemma: Navigating Ethics in Healthcare" highlights the implications of Al use in healthcare.

When consolidating these manuscripts, we hope that this issue emphasizes the importance, continuing need and future directions to pressing issues in community-based health issues. We sincerely hope that the content shared within this issue can leave an impression in your academic journey as future healthcare professionals.

We would like to express our heart-felt gratitude to the creative team (led by Angela Koehn), editorial team (led by Ainsely Durnin & Jaspreet Gill) and our administrative team (led by Rajnandini Ganguli). Also, the Faculty of Health senior advisor (Dr. Diane Williams) and the Applied Health Science Endowment Fund and to everyone else who have contributed to and encouraged the growth of our journal.

Warm Regards & Happy Reading, Francis Fernandes & Brandon Lu Co-Editors of Chief



Francis Fernandes

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# Review of DSM-5 Diagnostic Criteria for Anorexia Nervosa and Recommendations to Improve Inclusivity

Sabrina D. Lutchmeah

BA Honors Psychology (Research Intensive), Department of Psychology, University of Waterloo, slutchme@uwaterloo.ca

## ABSTRACT

This article reviews issues with the diagnostic criteria for anorexia nervosa. This article discusses how the diagnostic criteria for Anorexia Nervosa (AN) can be vague and exclude specific populations who can be affected by this eating disorder. After this discussion, suggestions are made to improve inclusivity in the AN diagnostic criteria. This article is meant to provide a new perspective on how the current diagnostic criteria have some limitations. This implies that all the affected individuals who need help are not receiving it. In addition, the current criteria are directed towards a particular subset of the population who live with anorexia nervosa, and do not include other subsets who present with different symptoms.

## INTRODUCTION

Anorexia nervosa (AN) is an eating disorder estimated to have a mortality rate of 5.1 to 5.8%,<sup>1</sup> making it the most lethal psychiatric disorder.<sup>2</sup> Current literature on anorexia nervosa within adolescents focuses primarily on females since males tend to have

no specific guideline for clinicians to follow to determine the required energy intake of an individual. The clinician must decide the appropriate energy intake based on growth expectations, weight, and age.<sup>7</sup> There are several approaches and tools that clinicians may use in addition to the DSM-V criteria when assessing and diagnosing individuals with eating

a later onset.<sup>3</sup> With the current diagnostic criteria for AN, three conditions need to be met in order to receive a diagnosis: "significantly low weight due to restriction of energy intake relative to requirements", "intense fear of gaining weight", and "disturbance in the way in which an individual views their body weight or shape".<sup>4</sup> Furthermore, severity is based on body mass index (BMI), with a BMI of 17 viewed as mild AN while a BMI of 15 is considered extreme AN.<sup>4</sup> The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) criteria for AN has faced controversies due to its ambiguous nature and the fact that it does not consider individual differences, such as differences in body mass index at the onset of symptoms of disorder into consideration.<sup>5</sup>,<sup>6</sup> This article will review the literature to discuss difficulties that arise from the current diagnostic criteria for AN. The paper will then conclude with suggestions to promote inclusivity within the criteria for AN.

#### **1.1 Energy requirements for a patient.**

Criterion A of the diagnostic criteria for AN states that the person must demonstrate "restriction of energy intake relative to requirements, leading to significantly low body weight".<sup>4</sup> There is disorders. Some examples include conducting clinical interviews, psychological testing, and taking family histories, among others. However, the DSM-V does not mention a standard procedure providers can follow to determine the required amount of energy intake for an individual and it is unclear how to determine whether the person's energy intake is too low. Additionally, the criterion does not consider children's developmental level. According to Knoll et al,<sup>8</sup> children often struggle with understanding the concept of required energy intake, which could make it even more difficult to determine the amount of energy they are taking in.

#### **1.2 Agreeable Restlessness.**

There is also the implication within the standard diagnosis criteria for AN that reduced energy intake would lead to decreased activity,<sup>8</sup> thus ignoring the subset of AN patients who experience hyperactivity due to their state of energy restriction. This hyperactivity has been termed "agreeable restlessness" and it seems to have an evolutionary basis whereby a scarcity of food results in more physical activity in foraging for food.<sup>9</sup> In particular, male patients with AN tend to



experience more of this hyperactivity compared to their female counterparts, often engaging in exercise as a means to reduce the hyperactivity they experience.<sup>10</sup> Thus, the diagnosis criteria is not inclusive of those patients who experience hyperactivity due to their limited intake of energy.

#### **1.3 Severity of Anorexia Nervosa.**

AN severity should not be based on body mass index (BMI) since individuals with low BMI and those within or above the normal range face the same physical and psychological consequences.<sup>11</sup> According to Sawyer et al.,<sup>12</sup> people with normal or high BMI might experience more significant distress regarding body image, thus showing more eating disorder psychopathology. Basing the severity of the disorder on BMI can have damaging consequences as patients might feel like they are not sick enough to qualify for a diagnosis of AN. Hence, they will not receive access to the appropriate treatment they need. The DSM-V severity marker fuels the idea that

#### **1.4 Suggestions to Improve the Criteria.**

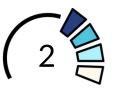
It is generally agreed upon in the medical community that selfreports can be useful for understanding an individual's thoughts, feelings, and behaviours, but they may be limited by

biases and may not provide a holistic understanding of the patient.<sup>17</sup> To ensure proper diagnoses of AN, self-reports can be supplemented with behavioural measures, but they cannot be alternatives to each other.<sup>17</sup> Behavioural measures that can be assessed include body-checking, which refers to the 'repeated checking of shape or weight", and food- and eating-related tendencies such as having meals alone.<sup>18</sup> The advantage to such measures is that they are examined from a patient's daily life, which paints a representative picture of the patient's behaviours in a natural setting.<sup>19</sup> By complementing selfreports with behavioural measures, providers can get a whole picture of what a patient feeling and how they are behaving, without the issue of biases in self-reporting. Behavioural measures can also fill in the gaps when younger children might not understand certain topics addressed in self-reports such as energy intake. Additionally, pediatricians should recognize that behavioural changes in children, such as food refusal, require nuanced approaches as they are complex and could reflect changes in mental status. <sup>20</sup> The severity marker for AN should be based on the speed and amount of weight loss in patients, rather than BMI. According to Garber,<sup>21</sup> adolescents who have lost a greater amount of weight at a faster rate over a longer period, present with worse medical and nutritional status, regardless of admission weight. This finding supports the suggestion that clinicians should pay attention to weight history prior to hospitalization, instead of focusing on admission weight. At the same time, basing severity on weight history will allow people who are in the healthy to obese weight range to feel more comfortable to reach out for help. There is an increasing prevalence of overweight and obese children and adolescents in the United States, <sup>22</sup> along with societal pressures to strive for thinness.<sup>2</sup>Correspondingly, it should be expected that many patients presenting for AN diagnoses will not have a low BMI and their weight loss might start from them being overweight or obese.<sup>24</sup>

AN is physically recognizable due to emaciation or malnutrition.

<sup>13</sup> However, people who do not fit this image might not reach out for help and are less likely to receive inpatient care.<sup>14</sup> In addition, family and peers might applaud weight loss, dieting, and restrictive eating behaviours for these people due to the societal appreciation for thinness<sup>15</sup>. This focus that the DSM-V severity marker has on an individual's physical appearance is a clear limitation that has many unintended consequences.

The DSM-V criteria also do not present considerations for patients in partial remission.<sup>4</sup> Partial remission refers to patients previously diagnosed with AN who no longer meet the diagnostic criterion of being at a significantly low body weight.<sup>4</sup> The criteria for AN promotes the idea that BMI should be very low to be treated, which could potentially be life-threatening for patients in partial remission who may still experience the negative effects of AN fully despite not meeting criterion A. This could lead to patients restraining their energy intake and cause even more distress regarding their body image and fear of gaining weight. Moreover, individuals who do not present with low BMI often endure a longer duration of illness, which leads to a poorer prognosis.<sup>16</sup> The focus of the DSM-V criteria on a very low BMI is a limitation that can cause patients' symptoms to worsen.



## CONCLUSION

The DSM-V diagnostic criteria for AN does not provide a specific guideline that providers can follow to measure energy intake and it does not consider the developmental levels of children. The DSM-V criteria do not consider the subset of AN patients who present with agreeable restlessness or are in partial remission, and the severity of AN is primarily based on patient's BMI at admission. This article recommends that self-reports can be supplemented with behavioural measures such as body-checking and food- and eating-related tendencies to provide a more comprehensive understanding of an individual's functioning and may be particularly useful for younger children or adolescents who may not easily understand certain topics addressed in self-reports. This report also suggests basing the severity marker of AN on weight loss and weight history, rather than solely on BMI. Further investigations need to be carried out to determine an appropriate standard that clinicians can follow to measure the energy intake of patients with AN. More research is also needed to explore hyperactivity within a subset of patients with AN to conclude whether this subset needs to be added as a subtype to the diagnostic criteria of AN.

**Acknowledgements:** I would like to thank Dr. Pamela Seeds for the opportunity to work on this piece, and the JUHR team to make this work into a publication.

8. Knoll S, Bulik CM, Hebebrand J. Do the currently proposed DSM-5 criteria for anorexia nervosa adequately consider developmental aspects in children and adolescents? European Child & Adolescent Psychiatry. 2010;20(2):95-101. doi:10.1007/s00787-010-0141-5

9. Scheurink AJW, Boersma GJ, Nergårdh R, Södersten P. Neurobiology of hyperactivity and reward: Agreeable restlessness in Anorexia Nervosa. Physiology & Behavior. 2010;100(5):490-495. doi:10.1016/j.physbeh.2010.03.016

10. Murray SB, Griffiths S, Rieger E, Touyz S. A comparison of compulsive exercise in male and female presentations of anorexia nervosa: what is the difference? Advances in Eating Disorders. 2013;2(1):65-70. doi:10.1080/21662630.2013.839189

11. Olivo G, Solstrand Dahlberg L, Wiemerslage L, et al. Atypical anorexia nervosa is not related to brain structural changes in newly diagnosed adolescent patients. International Journal of Eating Disorders. 2017;51(1):39-45. doi:10.1002/eat.22805

 Sawyer SM, Whitelaw M, Le Grange D, Yeo M, Hughes EK. Physical and Psychological Morbidity in Adolescents With Atypical Anorexia Nervosa. PEDIATRICS. 2016;137(4):e20154080-e20154080. doi:10.1542/peds.2015-4080

13. Eiring K, Wiig Hage T, Reas DL. Exploring the experience of being viewed as "not sick enough": a qualitative study of women recovered from anorexia nervosa or atypical anorexia nervosa. Journal of Eating Disorders. 2021;9(1). doi:10.1186/s40337-021-00495-5

14. Kennedy GA, Forman SF, Woods ER, et al. History of Overweight/Obesity as Predictor of Care Received at 1-year Follow-Up in Adolescents With Anorexia Nervosa or Atypical Anorexia Nervosa. Journal of Adolescent Health. 2017;60(6):674-679. doi:10.1016/j.jadohealth.2017.01.001

15. Puhl RM, Lessard LM. Weight stigma in youth: Prevalence, consequences, and considerations for clinical practice. Current Obesity Reports. 2020;9. doi:10.1007/s13679-020-00408-8

16. Treasure J, Russell G. The case for early intervention in anorexia nervosa:
theoretical exploration of maintaining factors. British Journal of Psychiatry.
2011;199(1):5-7. doi:10.1192/bjp.bp.110.087585

17. Lounes N, Khan G, Tchanturia K. Assessment of Cognitive Flexibility in Anorexia Nervosa - Self-Report or Experimental Measure? A Brief Report. Journal of the International Neuropsychological Society. 2011;17(05):925-928. doi:10.1017/s1355617711000671

18. Lavender JM, De Young KP, Wonderlich SA, et al. Daily patterns of anxiety in

Keywords: eating disorder, anorexia nervosa, health, diagnosis, psychology, psychological disorder

## REFERENCES

1. Arcelus J, Mitchell AJ, Wales J, Nielsen S. Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies. Archives of general psychiatry. 2011;68(7):724-731. doi:10.1001/archgenpsychiatry.2011.74

Kaye WH, Bulik CM. Treatment of Patients With Anorexia Nervosa in the US-A
 Crisis in Care. JAMA Psychiatry. Published online February 24, 2021.
 doi:10.1001/jamapsychiatry.2020.4796

3. Gueguen J, Godart N, Chambry J, et al. Severe anorexia nervosa in men: Comparison with severe AN in women and analysis of mortality. International Journal of Eating Disorders. 2012;45(4):537-545. doi:10.1002/eat.20987

4. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th ed. American Psychiatric Association; 2013.

5. Soon, S. P. Anorexia nervosa: controversy regarding diagnostic criteria and evidence for control-related cognitive and metacognitive mechanisms maintaining the disorder (Doctoral dissertation). 2012.

6. Brown TA, Holland LA, Keel PK. Comparing operational definitions of DSM-5 anorexia nervosa for research contexts. International Journal of Eating Disorders. 2013;47(1):76-84. doi:10.1002/eat.22184

7. Moskowitz L, Weiselberg E. Anorexia Nervosa/Atypical Anorexia Nervosa. Current Problems in Pediatric and Adolescent Health Care. 2017;47(4):70-84. doi:10.1016/j.cppeds.2017.02.003 anorexia nervosa: Associations with eating disorder behaviors in the natural environment. Journal of Abnormal Psychology. 2013;122(3):672-683. doi:10.1037/a0031823

McDonald JD. Measuring personality constructs: The advantages and disadvantages of self-reports, informant reports and behavioural assessments. Enquire.
2008 Jan;1(1):1-9.

20. Berksoy E, Özyurt G, Anıl M, Üzüm Ö, Appak YÇ. Can Pediatricians Recognize Eating Disorders? Early Onset Anorexia Nervosa in a Male Child. Nutrición Hospitalaria. Published online February 27, 2018. doi:10.20960/nh.1744

21. Garber AK, Cheng J, Accurso EC, et al. Weight Loss and Illness Severity in Adolescents With Atypical Anorexia Nervosa. Pediatrics. 2019;144(6). doi:10.1542/peds.2019-2339

22. Skinner AC, Ravanbakht SN, Skelton JA, Perrin EM, Armstrong SC. Prevalence of Obesity and Severe Obesity in US Children, 1999–2016. Pediatrics. 2018;141(3):e20173459. doi:10.1542/peds.2017-3459

23. Rajagopalan J, Shejwal B. Influence of Sociocultural Pressures on Body Image
Dissatisfaction. Psychological Studies. 2014;59(4):357-364. doi:10.1007/s12646-0140245-y

24. Swenne I. Influence of premorbid BMI on clinical characteristics at presentation of adolescent girls with eating disorders. BMC Psychiatry. 2016;16(1). doi:10.1186/s12888-016-0788-7

#### SENIOR EDITOR AINSLEY DURNIN EDITOR AINSLEY DURNIN GRAPHIC DESIGNER NIKKI NGUYEN

DOI: 10.15353/juhr.v1i3.5154

## PREGNANCY, MATERNAL HEALTH AND POVERTY IN INDIGENOUS WOMEN

Abeer Yusuf & Alysha Butt, Hon. Health Sciences, School of Public Health Sciences, Faculty of Health

Indigenous women in Canada face a number of unique challenges during pregnancy that pose a threat to the wellbeing of themselves and their infant.

> More likely for Indigenous women to be required to travel ~200km to deliver her baby.<sup>1</sup>





16x

## **ACCESS TO HEALTHCARE**

#### **Racism in Healthcare**

Indigenous women in Canada experience the effects of both interpersonal and structural racism in the form of mistreatment and segregation.<sup>2</sup>

#### Miscarriage and Infertility

Receive inconsistent health instructions leading to adverse events

Rate of infant mortality is 2x higher for Indigenous women.<sup>3</sup>

- ex. whether smoking cessation is beneficial during pregnancy or would result in more stress for the infant.<sup>3</sup>
  - ex. stillbirth, perinatal birth, low birth weight, or prematurity.<sup>3</sup>

#### Access to Resources

Factors that contribute to poor health outcomes: 4

geographical location

lack of knowledge about services

• cost

- language barriers
  - transportation

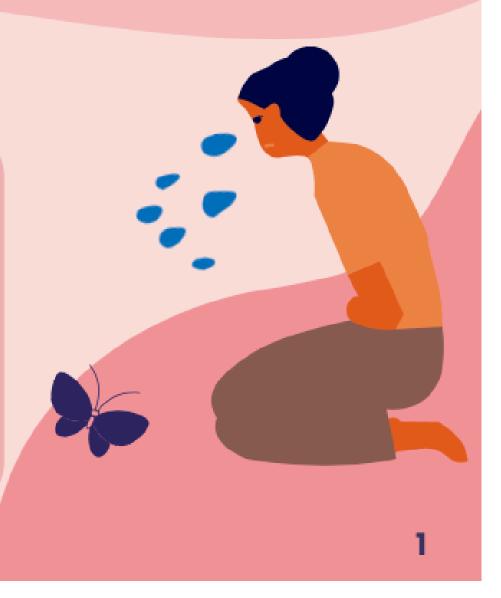
## **EXTERNAL STRESSORS**

#### Mental Health

- Indigenous mothers have higher risks for postpartum depression
  - Due to risk factors such as low education, lack of social support, abuse trauma and antidepressant use.<sup>5</sup>

#### Substance Abuse

- Higher rates of alcohol and drug consumption are reported in Indigenous women
  - Due to living in high-risk environments where there are overwhelming amounts of socioeconomic issues.<sup>6</sup>







## **ENVIRONMENTAL HAZARDS**

#### **Toxic Hazards and Exposures**

- Poor access to clean drinking water.
- Exposure to toxic chemicals.
- Poor air quality.
- Close proximity to industrial facilities.<sup>7</sup>

#### Living Conditions and Communities in Poverty

- Low socioeconomic status is a key determinant of structural safety.
- Safety is diminished by factors such as high crime and poor infrastructure.<sup>8</sup>

1 in 5 Indigenous communities in Canada are under water advisories which require residents to boil or stop drinking water.<sup>8</sup>

## HEALTH DETERMINANTS

#### Access to Food

- Low income causes a lack of healthy food sources and high food costs
  - Leads indigenous people to resort to non-nutritious and poor food options
    - Causes poor mental and physical health.<sup>9</sup>

#### **Chronic Diseases**



 Higher rates of chronic diseases such as renal failure, renal disease and especially diabetes due to deficiencies in their diets.<sup>7</sup>

## WHERE DO WE GO NEXT?

#### Support Groups



Provide space for new mothers to share insights.
Fill gap of support that may exist in a new mother's life.<sup>5</sup>

#### **Prenatal Care Services**



#### Allow women to receive information and care.

 Reduce incidence of infant complications.<sup>3</sup>

#### Food Programs



- Supply mothers with nutritional care needed to nurture baby.
- Reduce severity of nutritional disparities for Indigenous women.<sup>9</sup>

#### References

- 1. Smylie J, O'Brien K, Beaudoin E, Daoud N, Bourgeois C, George EH, et al. Long-distance travel for birthing among indigenous and non-Indigenous pregnant people in Canada. Canadian Medical Association Journal. 2021 Jun 20;193(25). doi:10.1503/cmaj.201903
- 2. Boyer Y. Healing racism in Canadian health care. Canadian Medical Association Journal. 2017 Nov 19;189(46). doi:10.1503/cmaj.171234
- 3.Sharma S, Kolahdooz F, Launier K, Nader F, June Yi K, Baker P, et al. Canadian Indigenous womens perspectives of maternal health and Health Care Services: A systematic review. Diversity & Equality in Health and Care. 2016;13(5). doi:10.21767/2049-5471.100073
- 4.Jawad Z, Chugh N, Daddar K. Barriers to access among indigenous women seeking prenatal care: A literature review. Undergraduate Research in Natural and Clinical Science and Technology (URNCST) Journal. 2022 Sept 22;6(9):1–7. doi:10.26685/urncst.389
- 5. Daoud N, O'Brien K, O'Campo P, Harney S, Harney E, Bebee K, et al. Postpartum depression prevalence and risk factors among indigenous, non-Indigenous and immigrant women in Canada. Canadian Journal of Public Health. 2019 Feb 14;110(4):440–52. doi:10.17269/s41997-019-00182-8
- 6.Shahram SZ, Bottorff JL, Kurtz DL, Oelke ND, Thomas V, Spittal PM. Understanding the life histories of pregnant-involved young Aboriginal women with substance use experiences in three Canadian cities. Qualitative Health Research. 2016 Jul 11;27(2):249–59. doi:10.1177/1049732316657812
- 7. Christensen J. Indigenous Housing and Health in the Canadian North: Revisiting cultural safety. Health & Place. 2016 Jul; 40:83-90. doi:10.1016/j.healthplace.2016.05.003
- 8. Sarkar A, Hanrahan M, Hudson A. Water insecurity in Canadian Indigenous communities: Some inconvenient truths. Rural and Remote Health. 2015 Oct 25; doi:10.22605/rrh3354
- 9. Skinner K, Hanning RM, Desjardins E, Tsuji LJ. Giving voice to food insecurity in a remote indigenous community in Subarctic Ontario, Canada: Traditional ways, ways to cope, Ways Forward. BMC Public Health. 2013 May 2;13(1). doi:10.1186/1471-2458-13-427

#### SENIOR EDITOR JASPREET GILL EDITORS NYLE FARAN, RONALDO RILEY GRAPHIC DESIGNER NIKKI NGUYEN

#### DOI: 10.15353/juhr.v1i3.6104

Journal of Undergraduate Health Research



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# Perspectives of Persons with Memory Changes and Care Partners for Reducing Barriers to Community Wellness Programs

#### Cindy Wei<sup>1</sup>, Vanessa Trinca<sup>2</sup>, Laura E. Middleton<sup>3</sup>, Heather Keller<sup>4</sup>

1 Department of Kinesiology and Health Sciences, Faculty of Health, University of Waterloo. 2 Department of Kinesiology and Health Sciences, Faculty of Health, University of Waterloo. 3 Department of Kinesiology and Health Sciences, Faculty of Health, University of Waterloo. 4 Department of Kinesiology and Health Sciences, Faculty of Health, University of Waterloo.

## ABSTRACT

Existing research demonstrates that community-dwelling persons with memory changes (PWMC) (including dementia) and care partners (CPs) benefit from nutrition and exercise, especially for frailty and sarcopenia prevention. However, needs and preferences for wellness programs are still unknown. The objective of this eight-month online survey study was to explore PWMCs' (n=24) and CPs' (n=46) perspectives on nutrition/exercise barriers and their preferences for program content and format to inform a community wellness program. PWMC self-reported, while CPs reported for themselves and their cared-for person with dementia (CPWD). Descriptive analyses revealed that 78% of PWMC, 64% of CPs, and 39% CPWDs were interested in a wellness program that combined nutrition and exercise. Content preferences varied (e.g., 45% of CPs were interested in yoga/Pilates, but only five percent of CPWD were interested). Over half of the participants preferred online delivery for nutritional information (55% PWMC, 54% CP). Group fitness was popular for exercise among all groups. In addition, participants prioritized attending as dyads twice or more per week, closeness to home, reasonable cost, knowledgeable instructors, a fun social environment, and beginner-friendliness. To conclude, greater consideration for flexibility in program content and format will help to meet these diverse needs and preferences.

## INTRODUCTION

Globally, dementia is one of five major causes of death.<sup>1</sup> Healthy diet and exercise are associated with improved well-being of persons living with dementia, mild cognitive impairment (MCI), or other memory changes (together referred to as persons with memory changes (PWMC)).<sup>2'3</sup> Almost 60% of PWMC and one-third of their paid or family/friend care partners (CPs) are at nutrition risk, which is associated with higher levels of required care and hospitalization.<sup>4</sup><sup>5</sup> Nutritional concerns for PWMC include, but are not limited to weight loss, forgetting/refusing to eat, dysphagia, and appetite loss, which can lead to sarcopenia and frailty.617 Foodrelated activities comprise a large proportion of CPs' care burden due to stress, tension, anxiety, and negative attitudes from pressure to provide nutritious meals for their loved one with dementia.<sup>8-10</sup> Furthermore, many older adults today are inactive, including those with memory changes<sup>11</sup>, yet, both aerobic and resistance exercise improve functional abilities, cognitive function, mental health, and body composition, regardless of cognitive status.<sup>12-14</sup> Exercise is a key strategy in preventing sarcopenia and frailty<sup>15,16</sup>, and programs that promote wellness and reduce

frailty risk in PWMC are crucial.<sup>17</sup> Establishing a community program that unites exercise, nutrition, and social well-being can be beneficial for PWMCs and their CPs. Moreover, understanding CPs' and PWMCs' barriers to and preferences for wellness programs will help develop interventions that are likely to be adopted in practice.<sup>18</sup> This study explored perspectives on barriers for exercise/wellness programs, challenges in eating well and being active, and wellness program content and format preferences to inform a future community program.

## METHODS

#### Population

A convenience sample of persons self-identifying as either a PWMC (dementia, MCI, or memory changes) or family or friend CP (unpaid, informal) was recruited using snowball and convenience sampling, a method used to identify hard-to-reach groups.<sup>19</sup> Notice of the online surveys was disseminated through stakeholders (e.g., the Alzheimer Society of Canada, Active Aging Canada, the Research Institute for Aging, and a Neurological Patient Database), Twitter, member email blasts, newsletters, and website postings. Telephone or mail questionnaire options were provided. Ethics clearance was provided by an ethics review board at the University of Waterloo (ORE# 40753). A checkbox on the online form was used to indicate informed consent, and respondents were directed to the appropriate survey after identifying as a PWMC or a CP. As part of the ethics requirement, respondents could opt out of completing specific questions.

#### Design

After providing informed consent, respondents were directed to the appropriate survey: (1) PWMC survey and (2) CP survey wherein CPs provided answers for themselves and on behalf of their cared-for person with dementia (CPWD). A literature review informed questionnaire content (e.g., potential eating challenges) and program delivery modes (e.g., group vs. individual). Questions were vetted by the research team (authors of this study), doctorate-holding dementia experts, the Waterloo Regional Dementia Advisory Group, and researchers experienced in question construction.

For both PWMC and CPs, the survey consisted of three sections: demographics, food and nutrition, and exercise. The CP questionnaire also included items specific to their CPWD, which were consistent with questions from the PWMC version. The survey consisted of 24 (PWMC version) and 26 questions (CP

#### Analyses

Question responses were summed for analyses where appropriate by totalling frequencies for each response per multiple choice question. Program preference was categorized as nutrition only, exercise only, combined lifestyle approach, and not interested. Exercise types were grouped as: classbased exercise, other structured exercise, other independent exercise (including walking), and sport-like exercise. Statistical analysis was primarily descriptive; associations explored whether desired program content and format varied by age, gender, and length of time since diagnosis, using the Fisher-Freeman-Halton test with adjusted standardized residuals (ASRs) for post-hoc testing. Statistical significance was determined by ASR>[1.96]. To determine differences in the number of challenges between PWMC and CPWD, independent t-tests were used (p<0.05). Researchers employed Microsoft® Excel Version 16.35 and IBM SPSS® Statistics Version 26. Content of open response text responses were also analyzed by grouping together similar responses (e.g staff, lack of time, scheduling, etc.) into descriptive categories (e.g., ability levels, staff, etc.).

## RESULTS

Of the respondents, 46 were CPs (66%) and 24 were PWMCs (34%). All respondents completed online surveys, with the vast majority being completed (95%) in English. Response rates varied by question as participants were given the opportunity to opt out of any question. Table 1 summarizes demographic characteristics. About one-third (35%) of PWMC reported not being formally diagnosed with dementia/MCI, and 40% had been living with memory changes for under five years. Fortyfive percent of PWMC were women and most CPs were women (93%). Most CPWD had been formally diagnosed (93%) with dementia/MCI, with 63% having received a diagnosis within the past five years. Approximately 45% of PWMC self-reported daily exercise, while CPs reported that only 14% of CPWD exercised daily. For a few of the respondents, exercise and nutrition were reported as having worsened after being a CP (82% excellent/good nutrition rating before and 73% rating after becoming a CP). Open text responses indicated that this change in self-rated nutrition for these CPs was due to lack of time and decreased motivation to cook.

version); demographic-related questions included gender, ethnicity (multiple select), age, time of dementia diagnosis (or time living with memory changes), province/territory of residence, and living arrangements. These questions had multiple choice answers for participants to select. There was one open-ended question at the end of the questionnaire. Nutrition challenges were self-reported from a list of 15 items. Exercise frequency was evaluated using a five-point scale (never to daily). Respondents also selected barriers to participation in exercise and reported preferences for exercise type, location, and format. An open-ended question allowed respondents to describe their ideal community wellness program. Questionnaires were uploaded to Qualtrics XM Survey Software, pretested by six older adults from a local care home (including one CP), and published in English and French on May 27th, 2019 (closed January 31st, 2020). Data collected did not encompass challenges that people may have faced due to the pandemic or associated countermeasures. Our survey did not include any pandemic-specific questions (e.g., challenges exercising due to recreation facility closures). As there was no primary outcome, a sample size estimation was not conducted; limitations of this small sample are discussed after Results.

Nutrition challenges and exercise barriers for PWMC and CPWD are indicated in Figure 1a, 1b, and 1c. Interest in making meals (69%), increased or decreased appetite (69%), difficulty deciding what to make (65%), and weight change (65%) were the most frequent nutritional challenges for CPWD. Common challenges reported by CPs were: stress affecting motivation to eat well (19%), poor appetite (8%), lack of time for exercise (45%), low motivation (14%), and physical limitations (9%). PWMC reported weather (60%), limited mobility (47%), health condition(40%) and cost (40%) as key barriers to exercise, and difficulty in deciding what to eat/cook was their most common nutrition challenge (65%). Based on a Fisher-Freeman-Halton test, longer time since dementia diagnosis (more than five years, compared to being diagnosed within the past five years) was significantly associated with more overall reported nutritional or exercise challenges (p=0.049).

Respondent program preferences are indicated in Table 2. Over half of PWMC and CPs were interested in learning about nutrition, especially identifying nutritious food (53% and 52% respectively) and cooking easy, healthy meals (53% and 44% respectively). The preferred delivery method for nutrition education was online (PWMC 55%; CPs 54%). Print (50% PWMC, 38% CP) and in-person delivery with health professionals (40% PWMC, 38% CP) were also highly ranked. More than half of PWMC (58%) and most CPs (82%) were interested in being more active. Exercise preferences were diverse (e.g., 45% of CPs were interested in yoga or Pilates, but only 5% of CPWD reported this interest), although tretching, balance, walking, and lifting weights were most favoured across all three groups (PWMC, CPs, and CPWD). Many wanted to participate in an exercise group two or more times a week (61% of PWMC, 50% of CPs, and 47% of CPWDs, as reported by their CPs). PWMC were interested in group exercise classes (56%), although training with a friend (39%) or loved one (39%) was also popular. Similarly, most CPs (64%) preferred exercising with their CPWD. The most popular exercise locations for PWMC were fitness centres (61%), outdoors (44%) and community centres (44%). Ultimately, 78% of PWMC, 64% of CPs, and 39% CPWDs were interested in a wellness program that combined nutrition and exercise. Open-text responses provided further insight into participant views. As with all questions on the survey, completion of open-text responses was optional. PWMC reported that their mental/emotional health challenges could influence participation in a community program. Social aspects, including supportive, understanding, and friendly instructors and classmates, were considered essential. CPs commented on lack of time, noting that appropriate scheduling was essential due to other commitments (e.g., work, children, etc.). The ideal community wellness program would be: age-appropriate; cater to different ability levels; close to home; taught in small groups by kind, helpful staff; and offer

social opportunities. Some CPs indicated in this section that they would prefer a split program, where CPs and their CPWD learn different exercises.





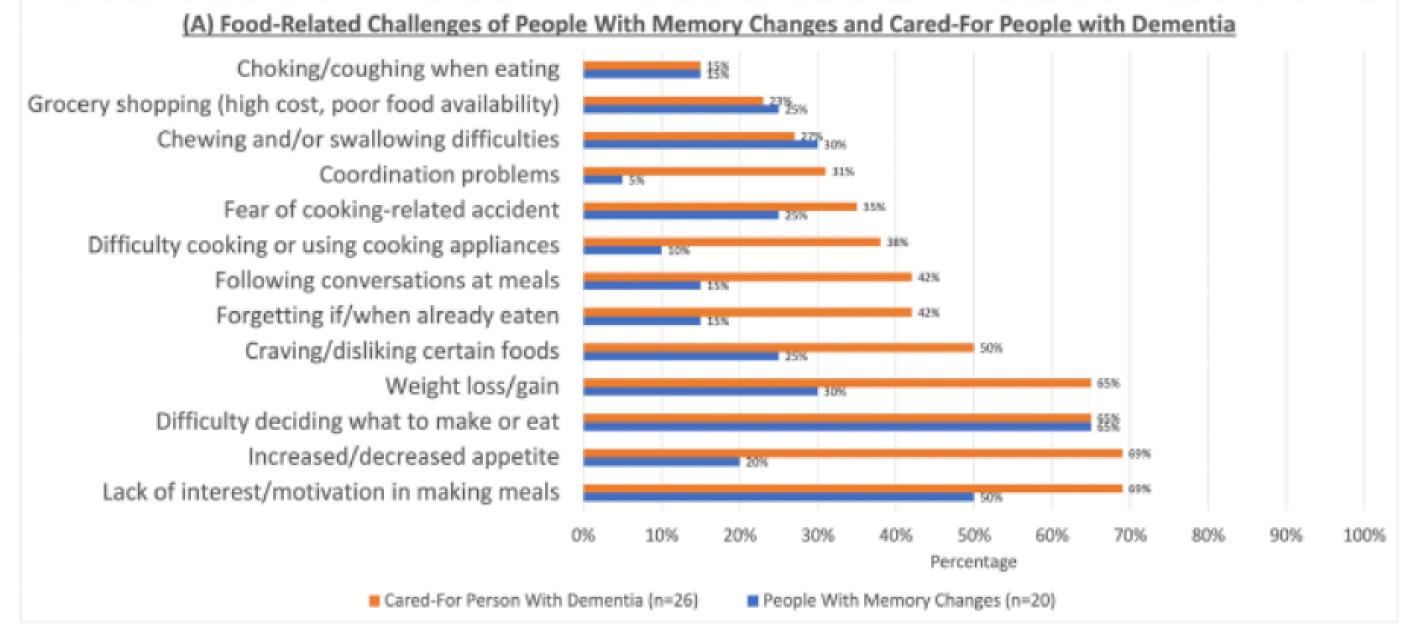
	Persons with memory changes (%)	Care partners (%)	Cared-for persons with dementia, as reported by care partners (%)
Time since formal dementia diagnos			
>5 years	25ª		30 <sup>b</sup>
<5 years	40		63
Not formally diagnosed	35		7
Age			
<60 years	40 <sup>a</sup>	32°	4d
60-79 years	45	61	44
>80 years	15	7	52
Gender			
Women	45ª	93°	39°
Ethnicity <sup>e</sup>			
Canadian	75ª	68°	68°
European	45	50	64
Province or territory			
Ontario	90ª	76 <sup>f</sup>	
Another Canadian province	5	24	
Not from Canada	5	—	—
Living situation			
With spouse	40 <sup>a</sup>		
Alone	30		
With spouse and other family	15		_
Other	10	_	
With other family member(s)	5	_	—
Living situation			
Living with cared-for person		52 <sup>f</sup>	
Not living with cared-for person	—	48	—
Urban or rural dwelling			
Urban	80 <sup>a</sup>	89°	—
Perception of current nutrition			
Excellent	21g	33 <sup>h</sup>	23 <sup>i</sup>
Good	47	40	19
Average or fair	32	9	39
Poor or terrible	—	18	19
Exercise over the past month			
Every day or almost every day	45ª	50j	14 <sup>k</sup>
A few times a week	55	29	54
Once per week	0	8	18
Never	0	13	14
Self-reported nutrition status before	becoming a care par	tner	
Excellent/good		82 <sup>1</sup>	
Self-reported nutrition status after be Excellent/good	coming a care partn	er 73 <sup>h</sup>	
Self-reported exercise status before b Excellent/good	becoming a care part	ner 64 <sup>1</sup>	
Self-reported exercise status after be	coming a care partne		
Excellent/good	g a vare parak	57 <sup>h</sup>	

#### **TABLE 1.** Demographic characteristics of respondents

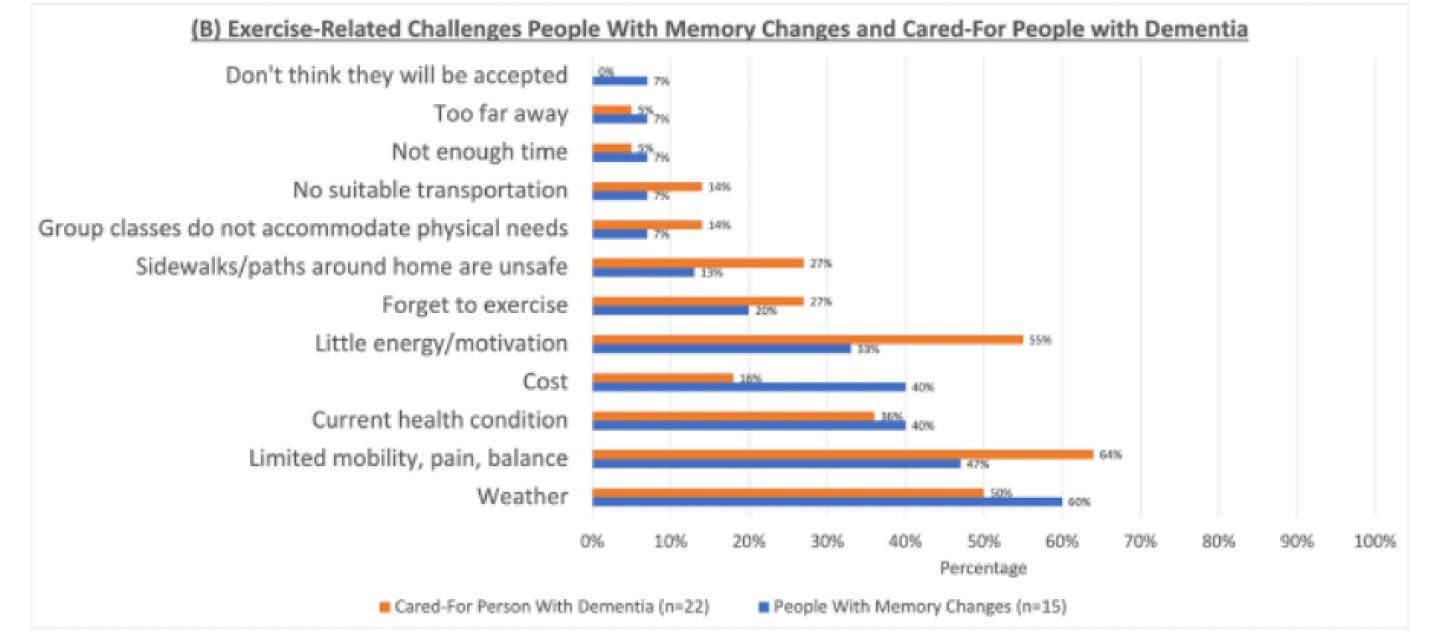
— indicates that this question or option was not available Number of respondents: <sup>a</sup>20; <sup>b</sup>30; <sup>c</sup>28; <sup>d</sup>27; <sup>e</sup>Text box for respondents to complete with categories not mutually exclusive; <sup>f</sup>29; <sup>g</sup>19; <sup>h</sup>33; <sup>i</sup>26; <sup>j</sup>24; <sup>k</sup>22; <sup>l</sup>34



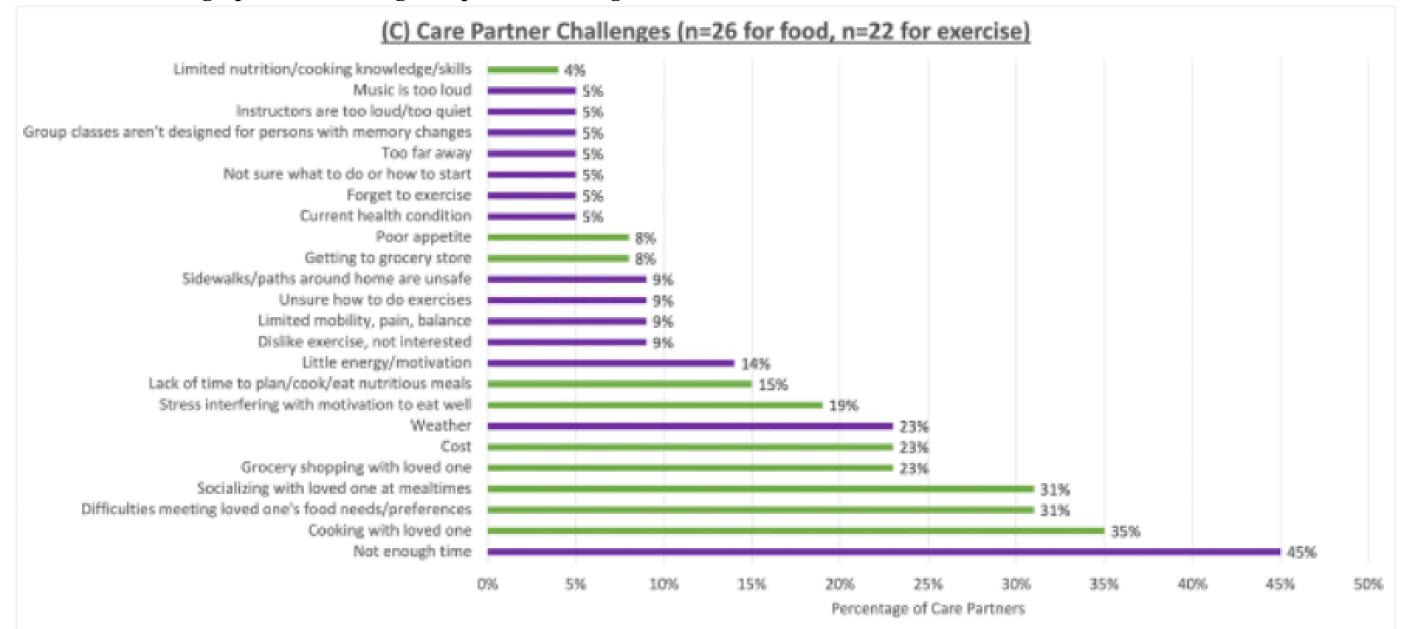
#### FIGURE 1a - Bar graph demonstrating food-related challenges of people with memory changes and cared-for people with dementia













#### TABLE 2. Respondent preferences for community food, nutrition, and exercise wellness programs

			Cared-for persons with dementia,
	Persons with		reported by care
	memory changes (%)	Care partners (%)	partners (%)
Nutrition topics of interest <sup>a</sup>			
Identifying nutritious foods	53 <sup>b</sup>	52°	
Cooking easy, healthy meals	53	44	
Weight loss/gain	37	40	
Hydration	37	44	
Understanding nutrition labels	32	24	
Managing eating challenges	32	36	
Evaluating different diets	11	40	
Preferred method of nutrition edu	cation delivery <sup>a</sup>		
Online	55 <sup>d</sup>	54 <sup>e</sup>	
Print	50	38	
In-person presentations	40	38	
Health professional	55	35	
Not interested	5	31	
Interest in being more active	-	-	
Yes	58 <sup>b</sup>	82 <sup>f</sup>	18 <sup>f</sup>
No	16	14	36
Not sure	26	4	46
Desired frequency of an exercise	-	-	
Never	17 <sup>g</sup>	18 <sup>f</sup>	31 <sup>b</sup>
<1 time per week	5	4	0
Once per week	6	14	11
≥2 times per week	61	50	47
Other	11	14	11
Exercises of interest <sup>a</sup>	11	1.	
Stretching	79 <sup>h</sup>	73 <sup>f</sup>	50 <sup>f</sup>
Balance exercises	68	68	41
Lifting weights	53	36	23
Walking	53	73	50
Cycling	47	14	0
Other strength exercises	32	55	36
Yoga or Pilates	32	45	5
Chair exercises	11	5	36
Most important factors for choosing	ng an exercise group/	programa	
Closeness to home	56 <sup>g</sup>	73 <sup>f</sup>	64 <sup>f</sup>
Knowledgeable instructors	56	50	32
Reasonable cost	50	55	50
Fun, social environment	44	64	59
Beginner-friendly	28	36	59
Degininer-menuty	20	50	57

Exercise companions <sup>a</sup>			
With loved one	39 <sup>g</sup>	64 <sup>f</sup>	
Alone	33	14	
Not interested		23	
Group classes	56		
Friend	39		
Personalized individual training	33		
Preferred exercise location <sup>a</sup>			
Fitness centre	61 <sup>g</sup>		
Outdoors	44		
Community centre	44		
Home or in my building	33		

 indicates that this question or option was not available <sup>a</sup>Multiple select Number of respondents: <sup>b</sup>19; <sup>c</sup>25; <sup>d</sup>20; <sup>e</sup>26; <sup>f</sup>22; <sup>g</sup>18; <sup>h</sup>19

## DISCUSSION

This study sought to investigate the perspectives of communitydwelling PWMC and CPs (reporting for themselves and CPWD) on nutrition/exercise challenges and wellness program preferences to inform a community program. For future planning of wellness programs, many participants were interested in attending as dyads two or more times per week, at sites that were close to home, and were of a reasonable cost. Having dementia progression.<sup>25,26</sup> Specifically, as dementia progressively worsens, cooking- and food preparation-related abilities for PWMC may change and become more difficult. Therefore, it is important to bear in mind the variable experiences of individuals in their dementia journey, thereby highlighting the need for dynamic, adaptable, and tailored programming. Consistent with past research, major exercise

knowledgeable instructors and a fun, social, and beginnerfriendly environment were also important to respondents.

In previous research, community wellness programs (although not always specific to PWMC and CPs) have improved mobility, functional ability, knowledge, confidence, and competence with healthy eating.<sup>20-23</sup> There also exists reasonable literature on exercise programming and their specific benefits for PWMC. With group classes, attendees would further benefit from social engagement and peer support, which increases feelings of inclusion (building a sense of community) and can improve quality of life.<sup>24</sup> CPs may also experience health benefits from such a program, especially since our survey results identified that perceived exercise and nutrition status worsened upon becoming a CP.

Moreover, in line with published literature, PWMC, CPs, and CPWD (CP-reported) listed challenges with appetite, weight change, low fruit and vegetable intake, chewing and swallowing, and dietary restrictions.<sup>17/25</sup> All three groups of participants (PWMC, CPs, and CPWD) may find strategy-driven education sessions useful and applicable. Mealtime routines and relationships between PWMC and their CPs change with barriers reported by PWMC and CPWD herein were consistent with those identified by a systematic review, including bad weather, poor health and function, decreased energy, and loss



of motivation and resources.22 In the present study, we observed that most of the challenges experienced by respondents regarding both food/nutrition and exercise—were individual-level barriers (e.g., lack of time). With thorough planning, a wellstructured and effectively delivered program may be able to overcome challenges associated with health and function, motivation, and energy.

Exercise barriers were similar among CPs and PWMC, although insufficient time was more frequently reported among CPs. Insufficient time is a common barrier reported by older adults more broadly.23 The most important factors for choosing an exercise group or program had varied between the three groups, although similiarities can be found between them as well. As all three groups (PWMC, CP, CPWD) valued having a program that was close to home, programs at specialty sites (rehabilitation or healthcare sites, for instance) are likely not sufficient to meet their needs. Therefore, all three groups (PWMC, CPs, and CPWD) may benefit from programs that take place in their local facilities, such as community or recreation centres. PWMC and CPs also prioritized the cost of the program, indicating the need for affordable and accessible community programming. CP and CPWD valued a fun and social environment. A beginner-friendly environment was most important among CPWD. Thus, it is important that program facilitators and instructors are welltrained in inclusive language and able to make new attendees feel

#### Limitations

Generalizability of these results is limited due to the small sample and that eligible participants required internet access and literacy.<sup>25</sup> Online questionnaires are a feasible method of surveying older adults, but they are limited in representing a sample size with internet access.<sup>31</sup> As such, due to the online nature of the survey, our findings may be biased towards tech-friendly solutions. Respondents were mostly Englishspeaking Ontarians (Table 1). Our sample is biased towards those already interested in health-particularly food, nutrition, and exercise. Self-report questionnaires are subject to social desirability bias and respondent interpretation. Furthermore, the predicted duration of our survey, according to Qualtrics Survey Software, was 15.5 minutes; Qualtrics indicates that questionnaires tend to have substantial respondent break-off if they take longer than minutes.<sup>32</sup> Online questionnaires twelve are also accompanied by the potential for misunderstanding. As there is no interviewer to make clarifications, questions may be interpreted differently by respondents. Due to limited research on community-dwelling PWMC, there is a need to recruit representative random samples of older adults in the community-especially from equity-deserving groups-in the future. Finally, our survey was created and conducted prior to the COVID-19 pandemic. Since then, online exercise programming, especially for groups with significant health or functional challenges, has seen ample improvement. Such improvements over the past two years have dramatically accelerated our ability to support persons living with dementia and their CPs in exercise programming online.33 Future researchers must be mindful of the aforementioned limitations and aim to recruit a more diverse sample in relation to technological literacy, geography, etc. Future studies may also wish to investigate how a low-cost program can be established and implemented to support this group.

welcome. These preferred elements should be taken into consideration for future program design and development to improve their feasibility and acceptability.

Ultimately, content and format of community programs to support PWMC, CPs, and CPWD need flexibility and tailoring to individual challenges and preferences.20,21,24 The CPs' role as a supportive partner for CPWD must also be considered in wellness programming.<sup>17,26</sup> In addition to adaptable content, these findings support the need to reduce barriers via flexible delivery (e.g., online). Technology-based tools as a means for educating PWMC and CPs on food, nutrition, and exercise may be of interest for future studies.

#### Strengths

Our online survey was available across Canada in both English and French (telephone and mail options also available), which addressed specific geographical and language barriers. Multipleselect answers provided respondents with the opportunity to choose all applicable answers. There are differences in the experience of living with dementia, and we addressed this by constructing one open-ended questions for respondents to elaborate on their own challenges and preferences surrounding food, nutrition, and exercise.

## CONCLUSION

This study aimed to understand nutrition and exerciserelated challenges and program preferences of PWMC and their CPs to guide wellness program planning. Many PWMC, CPs, and CPWD (reported by their CPs) experienced challenges surrounding food intake, meal preparation, time, and motivation. In terms of exercise, participants seeked to exercise twice or more times per week, though many experienced challenges with weather, mobility, balance, pain, energy, time, and existing health conditions. While most were interested in a community wellness program encompassing nutrition and exercise, specific preferences for activities and delivery modes were diverse; hence, future programs for this demographic require flexibility in both content and delivery.

#### ACKNOWLEDGEMENTS AND SUPPORT FROM OTHER FACULTY MEMBERS

Dr. Carrie McAiney, Dr. Celia Laur, Jill Morrison-Koechl, Dr. Sarah Wu, and senior advisors from the Village of University Gates supported survey design.

#### **FUNDING**

This research was funded by the University of Waterloo Hallman Undergraduate Research Fellowship in Health Promotion, as part of an undergraduate thesis.

#### **CONFLICTS OF INTREST**

The authors have no conflicts of interest to declare.

#### **OTHER DISCLOSURES**

The authors have nothing to disclose.

Key Words: Community-dwelling; Older adults; Dementia; Caregiver; Nutrition; Exercise  Keller HH, Smith D, Kasdorf C, Dupuis S, Schindel Martin L, Edward G, et al. Nutrition education needs and resources for dementia care in the community. Am J.Alzheimers.Dis.Other.Demen.2008.https://pubmed.ncbi.nlm.nih.gov/18276954/
 Kimura A, Sugimoto T, Niida S, Toba K, Sakurai T. Association between appetite and sarcopenia in patients with mild cognitive impairment and earlystage Alzheimer's Disease: a case-control study. Front Nutr. 2018. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6305366/

8. Atta-Konadu E, Keller HH, Daly K. The food-related role shift experiences of spousal male care partners and their wives with dementia. J Aging Stud. 2011. https://www.infona.pl/resource/bwmeta1.element.elsevier-ef5ad706-8dc9-3bbf-a20c-18196c7da1a3

9. Ball L, Jansen S, Desbrow B, Morgan K, Moyle W, Hughes R. Experiences and nutrition support strategies in dementia care: Lessons from family carers. Nutr Diet. 2015. https://onlinelibrary.wiley.com/doi/abs/10.1111/1747-0080.12107
10. Hsiao HC, Chao HC, Wang JJ. Features of problematic eating behaviors among community-dwelling older adults with dementia: family caregivers' experience.Geriatr.Nur.(Lond)..2013. https://pubmed.ncbi.nlm.nih.gov/23849671/
11. Miller MJ, Cenzer I, Barnes DE, Covinsky KE. Physical inactivity in older

adults with cognitive impairment without dementia: room for improvement. Aging Clin Exp Res. \2022;34(4):837-845. doi:10.1007/s40520-021-01999-5

12. Northey JM, Cherbuin N, Pumpa KL, Smee DJ, Rattray B. Exercise interventions for cognitive function in adults older than 50: A systematic review with meta-analysis. BJSM. 2018. https://pubmed.ncbi.nlm.nih.gov/28438770/

13. Tremblay MS, Warburton DER, Janssen I, Paterson DH, Latimer AE, Rhodes RE, et al. New Canadian physical activity guidelines. APNM. 2011. https://pubmed.ncbi.nlm.nih.gov/21326376/

14. Forbes D, Forbes SC, Blake CM, Thiessen EJ, Forbes S. Exercise programs for peoplewithdementia.CDSR.2015.https://www.cochranelibrary.com/cdsr/doi/10.1 002/14651858.CD006489.pub4/full

15. Angulo J, El Assar M, Álvarez-Bustos A, Rodríguez-Mañas L. Physical activity and exercise: Strategies to manage frailty. Redox Biology. 2020. https://pubmed.ncbi.nlm.nih.gov/32234291/

## REFERENCES

1. Nichols E, Szoeke CEI, Vollset SE, Abbasi N, Abd-Allah F, Abdela J, et al. Global, regional, and national burden of Alzheimer's disease and other dementias, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016.LancetNeurol.2019.https://www.thelancet.com/journals/laneur/article/PIIS14 74-4422(18)30403-4/fulltext

 George EK, Hemachandra Reddy P. Can healthy diets, regular exercise, and better lifestyle delay the progression of dementia in elderly individuals? J Alzheimer's Dis.
 2019. https://pubmed.ncbi.nlm.nih.gov/31227652/

 Zhao C, Noble JM, Marder K, Hartman JS, Gu Y, Scarmeas N. Dietary patterns, physical activity, sleep, and risk for dementia and cognitive decline. Curr. Nutr. Rep. 2018. https://pubmed.ncbi.nlm.nih.gov/30413973/

4. Rullier L, Lagarde A, Bouisson J, Bergua V, Barberger-Gateau P. Nutritional status of community-dwelling older people with dementia: Associations with individual and family caregivers' characteristics. Int J Geriatr Psychiatry. 2013. https://pubmed.ncbi.nlm.nih.gov/22821728/

5. Enoki H, Sugiyama M, Izawa S, Hirose T, Hasegawa J, Iguchi A, et al. Factors associated with malnutrition in Community-Dwelling disabled Elderly (the Kanagawa-Aichi disabled elderly cohort (Kaidec) study). Jpn J Geriatr. 2014. https://pubmed.ncbi.nlm.nih.gov/25749326/ 16. Watanabe Y, Yamada Y, Yoshida T, Yokoyama K, Miyake M, Yamagata E, et al. Comprehensive geriatric intervention in community-dwelling older adults: a cluster-randomized controlled trial. J Cachexia Sarcopenia Muscle. 2020. https://pubmed.ncbi.nlm.nih.gov/31997543/

17. Mole L, Kent B, Abbott R, Wood C, Hickson M. The nutritional care of people living with dementia at home: A scoping review. Health Soc. Care Community. 2018. https://pubmed.ncbi.nlm.nih.gov/29365369/

18. Tatangelo G, McCabe M, Macleod A, You E. "I just don't focus on my needs." The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study. Int J Nurs Stud. 2018. https://pubmed.ncbi.nlm.nih.gov/28982034/

19. Shaghaghi A, Bhopal RS, Sheikh A. Approaches to recruiting "hard-toreach" populations into re-search: a review of the literature. Health Promot Perspect. 2011. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3963617/

20. Marshall S, Agarwal E, Young A, Isenring E. Role of domiciliary and family carers in individualised nutrition support for older adults living in the community. Maturitas. 2017. https://pubmed.ncbi.nlm.nih.gov/28274324/

21. Keller HH, Østbye T, Goy R. Nutritional risk predicts quality of life in elderly community-living Canadians. J Gerontol - Ser Biol Sci Med Sci. 2004. https://pubmed.ncbi.nlm.nih.gov/14718488/

22. Moreau M, Plourde H, Hendrickson-Nelson M, Martin J. Efficacy of nutrition education-based cooking workshops in community-dwelling adults aged 50 years and older. J Nutr Gerontol Geriatr. 2015. https://pubmed.ncbi.nlm.nih.gov/26571355/ 23. Seino S, Nishi M, Murayama H, Narita M, Yokoyama Y, Nofuji Y, et al. Effects of a multifactorial intervention comprising resistance exercise, nutritional and psychosocial programs on frailty and functional health in community-dwelling older adults: A controlled, cross-over trial. Geriatr Gerontol Int. 2017. randomized, https://pubmed.ncbi.nlm.nih.gov/28393440/

24. Pedersen MT, Vorup J, Nistrup A, Wikman JM, Alstrøm JM, Melcher PS, et al. Effect of team sports and resistance training on physical function, quality of life, and motivation adults. Scand in older J Med Sci Sports. 2017. https://pubmed.ncbi.nlm.nih.gov/28144978/

25. Kai K, Hashimoto M, Amano K, Tanaka H, Fukuhara R, Ikeda M. Relationship between eating disturbance and dementia severity in patients with Alzheimer's disease. PLoS ONE. 2015. https://pubmed.ncbi.nlm.nih.gov/26266531/

26. Johansson L, Björklund A, Sidenvall B, Christensson L. Spouses ' Experiences of mealtime with a partner suffering from dementia. J Ageing Res Clin Pract. 2014. https://www.jarlife.net/715-spouses-experiences-of-mealtimes-with-a-partnersuffering-from-dementia.html

27. Kai K, Hashimoto M, Amano K, Tanaka H, Fukuhara R, Ikeda M. Relationship between eating disturbance and dementia severity in patients with Alzheimer's disease. PLoS ONE. 2015. https://pubmed.ncbi.nlm.nih.gov/26266531/

28. van Alphen HJM, Hortobágyi T, van Heuvelen MJG. Barriers, motivators, and facilitators of physical activity in dementia patients: A systematic review. Arch Gerontol Geriatr. 2016. https://pubmed.ncbi.nlm.nih.gov/27295140/

29. Franco MR, Tong A, Howard K, Sherrington C, Ferreira PH, Pinto RZ, et al. Older people's perspectives on participation in physical activity: A systematic review and synthesis qualitative literature. BJSM. 2015. thematic of https://pubmed.ncbi.nlm.nih.gov/25586911/

30. Vanoh D, Ishak IH, Shahar S, Manaf ZA, Ali NM, Noah SAM. Development and assessment of a web-based intervention for educating older people on strategies promoting healthy cognition. 2018. Clin Interv Aging. https://pubmed.ncbi.nlm.nih.gov/30271134/

31. Remillard ML, Mazor KM, Cutrona SL, Gurwitz JH, Tjia J. Systematic review of the online questionnaires older adults. JAGS. 2014. of of use https://pubmed.ncbi.nlm.nih.gov/24635138/

32. Qualtrics. Survey methodology & compliance best practices: predicted duration [Internet].https://subjectguides.uwaterloo.ca/c.php?g=695555&p=4933491

Nora CD, de Lima JD, Teixeira IA, et al. Online physical exercise and the 33. neuropsychiatric symptoms in patients with dementia: a cross-sectional study during Neuropsychol. COVID-19 pandemic. Dement 2022;16(3):253-260. the doi:10.1590/19805764-DN-2021-0079

## **SENIOR EDITOR JASPREET GILL EDITORS** KARINA POPOVICI **JASPREET GILL GRAPHIC DESIGNER** KIRSTEN DOUGALL

DOI: 10.15353/juhr.v1i3.4967





# A Gendered Perspective of the Lack of Justice for the Asubpeeschoseewagoon Anishinabek Women of Grassy Narrows

Amanda Armstrong, BSc 4B Biological Sciences, Department of Biology, Faculty of Science

## ABSTRACT

From 1962 to 1970, the Reed Paper Mill dumped over 9000 kilograms of mercury into the English-Wabigoon

River system in Northern Ontario. The Grassy Narrows community, an Anishinabek First Nation, depend on this water system for sustenance and their livelihoods. Their reliance specifically on fish as a primary source of food and income increases their community's vulnerability to mercury poisoning, which has resulted in lasting impacts on the physical and mental health of their community. Grassy Narrows women are disproportionately impacted by mercury poisoning due to their gendered responsibility to protect water, care work, and child-bearing. This paper examines the failure of the Government of Ontario to uphold the foundational elements of environmental justice for Grassy Narrows women, including distributive fairness, procedural fairness, and corrective action. Recommendations for the Government of Ontario include listening to the needs of Grassy Narrows First Nations and including them in decision-making processes to help ease the generational pain caused by perpetual environmental racism.

## INTRODUCTION

"When the white man comes to my country, he leaves a trail of blood."<sup>1</sup> Arnold Pelly, a Grassy Narrows First Nations Chief, pointed to the disproportionate burden placed on his indigenous community caused by one of the largest cases of perpetual environmental racism in Ontario: the devasting mercury pollution that occurred within Grassy Narrows. <sup>2-5</sup> From 1962 to 1970, the Reed Paper Mill dumped over 9000 kilograms of mercury into the water system (English-Wabigoon River) of Grassy Narrows located in Northern Ontario. <sup>1/2/3/4/6</sup> The mercury created an "immense sickness in the Anishinabek community and negatively impacted their health and way of life. <sup>47677</sup> Due to high mercury concentrations in the water, the Anishinabek community was also forced by the Government of Ontario to halt the selling of all fish. This drastically impacted their community given that their primary source of income came from commercial and touristic fishing.<sup>476777</sup> Simultaneously, the government insisted the fish were safe for the community to eat, despite collective signs of mercury poisoning.<sup>15</sup> This contradiction raises the question of the government's intentions.<sup>15</sup> While acknowledging that mercury contamination was a concern for non-Indigenous



communities, they disregarded these same concerns impacting the Indigenous community. <sup>15</sup>

For decades, the Grassy Narrows people have been pursuing environmental justice,<sup>7</sup> defined as the equitable treatment and effective consultation with all people in respect to environmental decision-making.<sup>8-11</sup> In the case of Grassy Narrows, women have been disproportionately impacted by mercury contamination due to the failure of the Government of Ontario to uphold the three key pillars of environmental justice; distributive fairness, procedural fairness, and corrective action.<sup>718112</sup> Through this paper, the gendered impacts of mercury pollution will be explored through the foundations of justice to critique the action and inaction of the government of Ontario.<sup>8</sup>

#### **2.1 Distributive Fairness**

Distributive fairness refers to people equally sharing the burdens and benefits of environmental decision-making outcomes.<sup>22</sup> Specifically, the women of Grassy Narrows are more vulnerable to mercury due to their gendered responsibility to the land, water, and their nation.<sup>7</sup> Given that water is considered by the Anishinabek community as the "lifeblood" that brings health and nurtures unborn children and ecosystems, women are the primary caregivers responsible for meeting the needs of the family, children, and elders.7 Therefore, women are more vulnerable to the impacts of mercury pollution as monitoring the quality of food and water is an important part of a women's tasks.<sup>7,23</sup> Dietary exposure to unsafe mercury concentrations detrimentally impacts physical health and economic prosperity.<sup>16,23</sup> For example, fishing guide fathers are associated with lower economic stability and higher dietary mercury.<sup>23</sup> Moreover, studies have linked a fishing guide father to children with poor health, high psychological distress, poor results in school, and a higher poverty rate.<sup>23</sup> Similarly, consumption of dietary mercury during pregnancy is associated with higher blood concentrations in children.<sup>23</sup> This phenomenon can be explained by the vulnerability of children to chemical exposure due to their relative body weight to absorption ratio and rapid brain development.<sup>23</sup> Importantly, eating fish during pregnancy is a traditional medicine for the Anishinabek peoples.7,23,24 Grassy Narrows Elder Judy Da Silva explained, "The grandmothers used to say, 'Eat fish broth, and the breast milk will come out.' That's how important fish was to a woman's body."7'<sup>25</sup> Higher fish consumption increases mercury exposure during pregnancy and is linked to poor emotional, behavioural, and physical health in children.<sup>23</sup> As a result, mothers in Grassy Narrows have reported that 27.4 % of young adults have attempted suicide at least once, with the rate of girls attempting suicide being threefold the average for First Nations in Canada.<sup>16,23</sup> These health issues amplify the burdens on mothers

and women, who are already struggling with their own health concerns. 16,23 In Grassy Narrows, the mental health of mothers is greatly impacted by mercury exposure and is carried to future generations. 16,23 A mother's poor mental health is linked to struggling children, with more than 31% of children cared for by "Social Services". 16,23 Since the 1970s, a mounting burden has been building on the mothers of Grassy Narrows, with little help from the Government of Ontario concerning distributive fairness. 16,23

#### 2.2 Procedural Fairness

Procedural fairness refers to inclusion in the processes of environmental decision making.<sup>22</sup> The major role women play in care work and their responsibility to protect water leads to a greater vulnerability to mercury exposure.7'16'23 Therefore, women's voices need to be included throughout decisionmaking processes.<sup>7'16'23</sup> The women of Grassy Narrows have pushed their way to the forefront of advocacy, while the of Ontario continues to ignore Government their voices.4,7,16,23,25 In the 1970s, the Anishinabek peoples were not consulted on the harms of the Reed Paper Mill.4 Despite the high levels of mercury, Health Canada reported that they were unable to diagnose mercury poisoning due to the lack of symptoms.<sup>4</sup><sup>21</sup><sup>26</sup> Concurrently, a mercury expert, Dr. Masazumi Harada, investigated the residents and found symptoms of mercury poisoning including the loss of senses and motor functioning.<sup>4'21'26</sup> Furthermore, hair samples taken from residents confirmed the presence of mercury poisoning in 87 individuals.<sup>4)21)26</sup> Unsurprisingly, the Government of Ontario predicted that mercury remediation would take 30 years; however, increased logging in the area resulted in the increased movement of sediment, exposing mercury back into the water column.<sup>27,28</sup> As a result, it is predicted that restoration to safe levels will take more than a century.<sup>26</sup> In 2002, the women of Grassy Narrows initiated a youth and women led blockade to protect the water system from the impacts of logging.<sup>7</sup> After a year of blockade expansion, the logging company retreated.<sup>27</sup> The elders announced a prohibition on all industrial activities within their traditional land without community consent.<sup>29</sup> A decade later, the Government of Ontario promised no clearcutting for at least five years.29 However, the community's rights to consent were ignored by the current Premier Doug Ford.<sup>29</sup> Nine mining permits were issued for the traditional land, and the Grassy Narrows community were not informed of these permits.<sup>29</sup> Like logging, mining increases the remediation period for mercury due to disturbed sediment. As is evident, the Ontario Government refuses to practice procedural fairness and continues to reinforce injustice towards women who lead advocacy.



#### **2.3 Corrective Action**

Corrective action refers to the acknowledgment and reconciliation of past wrongs pertaining to distributive and procedural fairness.<sup>30</sup> Proper reconciliation requires a focus on social context; therefore, solely covering material costs is not enough.<sup>10</sup> From 1970 to 1984, the Reed Paper Mill operations received a net profit of \$235 million. <sup>4</sup><sup>31</sup> This dwarfs the \$17 million compensated to the Grassy Narrows community.<sup>4,31</sup> With this reparation, Grassy Narrows elders announced the purchase of a fishing lodge to help create opportunities for economic growth.<sup>4,31</sup> Fishing is predominantly completed by men, resulting in a gap for women.<sup>7</sup> Care-work and health care could not be targeted by corrective action, as money alone can not solve this issue. As a result, the Anishinabek community has continued to suffer, as seen by early deaths (less than 60 years of age) and high youth suicide rates.<sup>7'16'23</sup> In 2021, a \$90 million agreement was signed between the community and the Federal government with the promise of an operating long-term care home for residents with mercury poisoning.<sup>32</sup> However, in response to the COVID-19 pandemic the Grassy Narrows community anticipates it is unlikely to be developed.<sup>32</sup> Hopefully, the government will honour the rights of the Grassy Narrows community by providing the promised health care.<sup>32</sup>

## CONCLUSION

been suffering from the violence of environmental racism on their watershed for decades. This is an infringement of the Canadian Charter on the basis of rights to life, liberty, and security of the person (Section 7), as well as their rights to equality (Section 15).<sup>12</sup> It is time the Government of Ontario recognizes and acts towards environmental justice for Grassy Narrows through the incorporation of the foundations of environmental justice.

Acknowledgements: I would like to express my gratitude to my professor Dr. Andrea Collins for providing me with the framework and understanding for many of the key concepts in this paper and the unequivocal importance of "context matters". I would also like to thank Thomas Charky for his endless support with ideas and editing.

**Keywords:** Mercury Poisoning, Generational Impacts, Environmental Justice, Environmental Racism, Gendered Perspective, Grassy Narrows First Nations

## REFERENCES

1. McMonagle, D. (1986, Sep 12). Peterson hears litany of woe from Grassy Narrows band. The Globe and Mail, p. A3.

2. APA Dictionary of Psychology. (n.d.). Racism. In American

The disproportional gender impacts of mercury pollution on Anishinabek women of Grassy Narrows provides strong evidence that the Government of Ontario failed and continues to fail in addressing environmental justice for the community. A review of distributive fairness showed the impact of mercury exposure on the health and economic resources of women due to their responsibility of care work. These added stressors can lead to more mental health issues and higher rates of children raised by "Family and Social Services". Similarly, a review of procedural fairness provided evidence that the Government of Ontario has had a history of neglecting the rights of the Grassy Narrows women. Despite women's higher vulnerability to mercury exposure, their voices continue to be disregarded by the government as seen in new mining permits. Surprisingly, the Ontario government has contributed to some corrective action through monetary compensation. However, developments to address the increased burdens of mercury sickness has yet to be seen, and women continue to be left out of corrective action, as material value alone assist in implementing a health care facility. The Government of Ontario must respect and incorporate the perspectives of women and the community. Grassy Narrows has

Psychological Association. <u>https://dictionary.apa.org/racism</u>

3. Braveman, P. A., Arkin, E., Proctor, D., Kauh, T., & Holm, N. (2022). Systemic And Structural Racism: Definitions, Examples, Health Damages, And Approaches To Dismantling: Study examines definitions, examples, health damages, and dismantling systemic and structural racism. Health Affairs, 41(2), pp. 171-178. <u>https://doi.org/10.1377/hlthaff.2021.01394</u>

4. Ilyniak, N. (2014). Mercury Poisoning in Grassy Narrows: Environmental Injustice, Colonialism, and Capitalist Expansion in Canada. McGill Sociological Review, 4, pp. 43-66.

5. Tuncak B. (2020). Visit to Canada: report of the Special Rapporteur on the implications for human rights of the environmentally sound management and disposal of hazardous substances and wastes. (Geneva, Switz: United Nations Human Rights Council). <u>https://digitallibrary.un.org/record/3897911?ln=en</u>

6. Da Silva, J. 2008. Defenders of the Land: a network of Indigenous communities and activists in land struggle across Canada. [Interview by Jaggi Singh, Video]. Isuma TV: <u>http://www.isuma.tv/en/defenders-land/judy-dasilva</u>

7. Simpson, L., DaSilva, J. Riffel, B., & Sellers, P. (2009). The Responsibilities of Women:

8. Confronting Environmental Contamination in the Traditional Territories of Asubpeechoseewagong Netum Anishinabek (Grassy Narrows) and Wabauskang First Nation. Journal of Aboriginal Health, 4(2), p.6.



9. Kuehn, R. R. (2000). A taxonomy of environmental justice. Environmental Law Reporter, 30(9), 10681–10681

10. Willow, A. J. (2012). Re(con)figuring Alliances: Place Membership, Environmental Justice, and the Remaking of Indigenous-Environmentalist Relationships in Canada's Boreal Forest. Human Organization, 71(4), 371–382. <u>https://doi.org/10.17730/humo.71.4.x267775756735078</u>

11. Heyen, D. A. (2023). Social Justice in the context of climate policy: systematizing the variety of inequality dimensions, social impacts, and justice principles.ClimatePolicy,23(5),539-554.

https://doi.org/10.1080/14693062.2022.2142499

12. Collins Dictionary. (n.d.). Social Context. In Collins Cobuild. https://www.collinsdictionary.com/dictionary/english/social-context

13. Vallani, M. (2018). Sections 7 and 15 of the Canadian Charter of Rights and Freedoms in the Context of the Clean Water Crisis on Reserves: Opportunities and Challenges for First Nations Women. Master of Laws Research Papers Repository. 2. <u>https://ir.lib.uwo.ca/llmp/2</u>

14. Pellow, D. (2000). Environmental inequality formation - Toward a theory of environmental injustice. The American Behavioral Scientist (Beverly Hills), 43(4), pp. 581–601. <u>https://doi.org/10.1177/00027640021955441</u>

15. Haluza-DeLay, R., O'Riley, P., Cole, P., & Agyeman, J. (2009). Speaking for Ourselves, Speaking Together: Environmental Justice in Canada. UBC Press.

16. Vecsey, C. (1987). Grassy Narrows Reserve: Mercury Pollution, Social Disruption, and Natural Resources: A Question of Autonomy. American Indian Quarterly, 11(4), 287–314. <u>https://doi.org/10.2307/1184289</u>

17. Mergler, D., Philibert, A., Fillion, M. & Da Silva, J. (2023). The Contribution across Three Generations of Mercury Exposure to Attempted Suicide among Children and Youth in Grassy Narrows First Nation, Canada: An Intergenerational Analysis.EnvironmentalHealthPerspectives,131(7).

#### https://doi.org/10.1289/EHP11301

18. Kerr, S. J. (2010). This document should be cited as follows: Kerr, S. J.

24. Mergler, D., Ismawati, Y., Lemire, M., Miller, P., Bailey, M. [HEJSupport]. (2020, June 17). Women and mercury: new approaches to minimize mercury exposure [Video]. Youtube. <u>https://youtu.be/HslaAu-T9lQ</u>

25. Thompson, J. (2018). Why the people of Grassy Narrows are still eating the fish.TVO Today. <u>https://www.tvo.org/article/why-the-people-of-grassy-narrows-are-still-eating-the-fish</u>

26. Oved, M. (2022, December 2). Grassy Narrows just secured a 'major landmark': 20 years after its logging blockade began. Toronto Star. <u>https://www.thestar.com/news/canada/grassy-narrows-just-secured-a-major-</u> <u>landmark-20-years-after-its-logging-blockade-began/article\_67583630-45cb-</u> <u>52b1-a8d4-9fae2e039088.html</u>

27. Philibert, A., Fillion, M., & Mergler, D. (2020). Mercury exposure and premature mortality in the Grassy Narrows First Nation community: a retrospective longitudinal study. The Lancet Planetary Health, 4(4), pp. E141-E148. <u>https://doi.org/10.1016/S2542-5196(20)30057-7</u>

28. Wong, G. (2017). Mercury poisoning in the Grassy Narrows First Nation: history not completed. National Library of Medicine, 189(22). <u>https://doi.org/10.1503/cmaj.733011</u>

29. Anderson, C. (2009). Grassy Narrows. The Canadian Encyclopedia. <u>https://www.thecanadianencyclopedia.ca/en/article/grassy-narrows</u>

30. Turner, L. (2021, November 17). Grassy Narrows takes Ontario to court for issueingminingexplorationpermits.CBC.News

https:www.cbc.ca/news/Canada/thunder-bay/grassy-narrows-mining-legalaction-

<u>1.6251280#:~:text=The%20nine%20permits%20are%20held,Power%20Metals%</u> <u>20Croporation%2C%20one%20permit</u>

31. Law Insider. (n.d.). Environmental corrective actions. In Law Insider. <u>https://www.lawinsider.com/dictionary/environmental-corrective-actions</u>

32. Platiel. R. (1985, November 26). Indians offered \$16.7 million settlement. TheGlobeandMail.https://proxy.lib.uwaterloo.ca/loginurl=https://www.proquest.

2010. Fish and Fisheries Management in Ontario: A Chronology of Events. Biodiversity Branch. Ontario Ministry of Natural Resources. Peterborough, Ontario. In Fish and Fisheries Management in Ontario. Ontario Ministry of Natural Resources.

19. EPA. (2023, March). Health effects of exposures to mercury. United States Environmental.Protection.Agency.

https://www.epa.gov/mercury/health-effectsexposures-mercury

20. Saavedra, S., Fernández-Recamales, Á., Sayago, A., Cervera-Barajas, A., González-Domínguez, R., & Gonzalez-Sanz, J. D. (2022). Impact of dietary mercury intake during pregnancy on the health of neonates and children: a systematic review. Nutrition Reviews, 80(2), 317– 328. https://doi.org/10.1093/nutrit/nuab029

21. Mosa, A. & Duffin, J. (2017). The interwoven history of mercury poisoning in Ontario and Japan. National Library of Medicine, 189(5). <u>https://doi.org/10.1503/cmaj.160943</u>

<u>22</u>. Chojnacka, K. & Mikulewicz, M. (2014). Bioaccumulation. Encyclopedia of Toxicology, pp. 456-460.

https://doi.org/10.1016/B978-0-12-386454-3.01039-3

23. Bal, M., Stok, M., Bombaerts, G., Huijts, N., Schneider, P., Spahn, A., & Buskens, V. (2023). A fairway to fairness: Toward a richer conceptualization of fairness perceptions for just energy transitions. Energy Research & Social Science, 103. https://doi.org/10.1016/j.erss.2023.103213

<u>com/historical-</u> newspapers/indians-

33. Forester, B. (2023, June 20). Grassy Narrows chief questions federal commitment to mercury care home amid delays soaring costs. CBC News. <u>https://www.cbc.ca/news/indigenous/grassy-narrows-delays-mercury-care-home-1.6882699</u>.

## SENIOR EDITOR AINSLEY DURNIN EDITORS ARELLA CHAN RISHI LOGANATHAN GRAPHIC DESIGNER NIKKI LE NGUYEN

DOI: 10.15353/juhr.v1i3.6105

## The Artificial Intelligence Dilemma: Navigating Ethics in Healthcare

**Elen Mullaj** Bachelor of Computer Science, Artifical Intelligence Specialization & Bachelor of Science

## ABSTRACT

The integration of Artificial Intelligence (AI) into healthcare represents a transformative shift towards more accurate and efficient patient care, highlighted by advancements in disease detection, treatment adherence, and patient interaction. However, this technological evolution introduces significant ethical dilemmas, including concerns over empathetic care provision, data security, and bias in clinical decision-making. This literature review critically examines these ethical challenges and proposes potential solutions to ensure AI's beneficial integration into healthcare without compromising patient well-being. The exploration into AI's capacity for empathetic care reveals its limitations to cognitive empathy, suggesting a complementary role to human providers rather than a replacement. Data privacy concerns underscore the imperative for secure handling and consent mechanisms in the utilization of patient information, amidst the risk of misuse by large corporations. Furthermore, the review addresses AI-induced biases, advocating for diverse data representation and algorithmic transparency to mitigate discrimination and enhance treatment efficacy across varied populations. While acknowledging the potential of AI to revolutionize healthcare, this paper advocates for a cautious and ethically informed approach to its adoption, emphasizing the need for comprehensive legislation, stakeholder engagement, and ongoing scrutiny to safeguard against the erosion of trust and equity in patient care.

## INTRODUCTION

Artificial intelligence (AI), a term encompassing all computer systems that are able to perform tasks mimicking human intelligence, has ushered in a new era of healthcare by revolutionizing patient care with unparalleled accuracy and efficiency. Recent studies have shown revolutionary AI impacts, including 2-fold reductions in colorectal cancer detection, a 10% decrease in image analysis errors made by radiologists, the development of stress-reducing robotic pets, and more, positioning Al at the focal point of scientific discussions.<sup>1-3</sup> The body of literature on AI's revolutionary impacts in healthcare extends beyond early detection of diseases and improved diagnostic accuracy. For instance, AI has been instrumental in predicting patient outcomes by analyzing patterns in vast datasets that human experts may overlook. A notable study by Esteva et al. demonstrated AI's ability to accurately predict the prognosis of skin cancer patients, outperforming traditional prediction models.4 Moreover, AI applications have shown significant promise in personalizing treatment plans, where algorithms tailor treatment recommendations based on a patient's unique genetic profile, lifestyle, and disease characteristics,

leading to more effective and targeted therapies. This is exemplified in the work by Korach et al., where Al-driven analyses of patient data resulted in customized chemotherapy regimens for cancer patients, significantly improving survival rates compared to standard care.<sup>5</sup> Al has also been utilized in mental health care for addressing the global shortage of mental health professionals by offering innovative solutions such as chatbots and virtual therapists that provide psychological support and therapy.<sup>6</sup> These Al systems engage users in meaningful conversations, helping to alleviate symptoms of depression and anxiety with accessibility and anonymity that traditional therapy cannot always offer.

The diversity of AI's applications underscores its potential to revolutionize every aspect of healthcare, from preventive medicine and early detection to treatment personalization and mental health support. This highlights a future where AI will become a cornerstone of patient care and medical research. One question that needs to be asked, however, is how the benefits of AI can be harnessed while simultaneously addressing its associated ethical challenges such as the risk of apathetic care, biased solutions, and the unsafe handling of patient data,



the unauthorized access and leakage of personally identifiable information (PII), the misuse of sensitive health information for purposes not consented to by patients, security breaches).<sup>7</sup> The excitement surrounding AI has led to this field advancing faster than its ability to thoroughly consider these complexities. Thus, the purpose of this literature review is to highlight the ethical issues and potential solutions that need to be considered before incorporating AI into medical practices to preserve empathy, unbiased treatments, and safe data handling for patients.

## **METHODS**

#### **Literature Search Strategy**

A focused literature search was conducted exclusively on PubMed, chosen for its comprehensive collection of biomedical literature. Our search aimed to identify original research articles published in English within the past ten years, highlighting the latest advancements and ethical considerations in artificial intelligence (AI) within healthcare. Keywords included "Artificial Intelligence", "Healthcare", "Ethics", "Patient Data Security", "Empathetic Care", and "Bias in AI". These were combined using Boolean operators to refine searches, for instance, "Artificial Intelligence AND Healthcare" to locate studies specifically on AI's application in healthcare settings.

by the work of Suchman et al. and Kim et al., who respectively formulated a model of empathic communication in medical interviews and developed scales to measure empathy-related constructs, assessing their impact on patient satisfaction and compliance.<sup>9'10</sup> Their findings suggest that while AI can assist in healthcare, its capability to replace the human element in empathetic interactions remains questionable.

On the subject of data privacy, studies such as those by Trinidad et al. and Winkler et al. explore public comfort and ethical considerations associated with sharing patient data.<sup>11,12</sup> Trinidad et al. found varied levels of comfort among the U.S. public regarding the sharing of health data with third-party companies, influenced by the purpose of data sharing. Winkler et al. discuss the ethical conditions necessary for the reuse of such data, advocating for a balance between public health benefits and patient rights. These themes are echoed in the research by Gurevich et al. and Baowaly et al., who explore the ethical frameworks for AI in healthcare and the development of synthetic electronic health records, respectively.<sup>13,15</sup> These studies collectively highlight a critical tension between leveraging technological advancements for improved healthcare delivery and ensuring the protection of individual privacy and ethical standards.



#### **Selection Process**

A focused literature search was conducted exclusively on PubMed, chosen for its comprehensive collection of biomedical literature. Our search aimed to identify original research articles published in English within the past ten years, highlighting the latest advancements and ethical considerations in artificial intelligence (AI) within healthcare. Keywords included "Artificial Intelligence", "Healthcare", "Ethics", "Patient Data Security", "Empathetic Care", and "Bias in AI". These were combined using Boolean operators to refine searches, for instance, "Artificial Intelligence AND Healthcare" to locate studies specifically on AI's application in healthcare settings.

## **RESULTS**

The results section of our review synthesizes insights from various studies focusing on the ethical concerns of empathy and data privacy in the use of artificial intelligence (AI) in healthcare (Table 1). Montemayor et al. emphasize the limitations of Al in performing empathetic roles within healthcare settings, highlighting the moral and ethical implications of substituting human empathy with Al-driven processes.8 This is complemented

#### Can AI provide empathetic care?

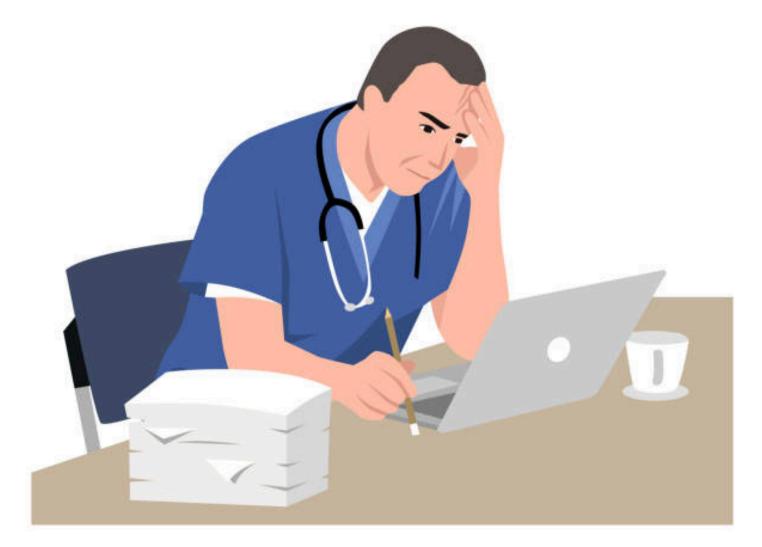
Empathetic care is one of the most essential pillars a healthcare professional can provide and is necessary for fostering patient trust and holistic well-being. Three types of empathy exist: emotional, cognitive, and motivational empathy.<sup>8</sup> Emotional and motivational empathy originate from instinctive or biological connections that fosters compassionate understanding and motivates people to support one another. These connections reflect our inherent capacity respond to others' emotional states, driven by to neurochemical reactions and evolutionary processes that have shaped human social interactions. For instance, witnessing someone in distress can trigger an empathetic response due to the activation of mirror neurons, which produces a shared feeling of concern and prompts actions aimed at alleviating the other's suffering.<sup>8</sup> This biological underpinning of empathy facilitates a depth of understanding and connection that is fundamental to compassionate care, underscoring the challenges AI faces in replicating these complex human emotions and motivations. On the other hand, cognitive empathy differs by focusing on the detection of individuals'



mental states through the representation of their circumstances and observable features in their expressions.<sup>8</sup> AI in its current state can only provide the latter due to its lack of biological instincts. This behavior, however, resembles that of psychopathic individuals who tend to excel in cognitive empathy, yet lack the emotional and motivational depth associated with human connection.<sup>8</sup> Thus, there is a risk of creating AI models that mimic a "psychopathic" lack of humanity.

The clinician's skill in resonating with a patient's perspective (i.e., emotional and motivational empathy) leads to more effective care for at least a few reasons. To begin with, a study by Suchman et al., that investigated 21 videotaped verbal exchanges showed that patients were hesitant to reveal information at first and instead gave emotional hints such as "my headache kept coming back" with great anxiety until they felt that their doctor understood the significance of this point in their narrative.' They were only willing to share additional information when this connection was perceived. Secondly, it is important to note that adhering to treatment plays a significant role in patient recovery. Patients are more likely to follow treatment suggestions when they get a sense that their doctor is worried and accompanying them empathetically, given that partnership and perceived affective empathy have the most significant impact on compliance and satisfaction.<sup>10</sup> Therefore, it is evident that with a proper comprehension of what "empathy" entails, abilities that are inherent in empathetic manifestations are beyond the reach of AI. Instead of attempting to replicate emotional understanding, AI can potentially focus on other areas such as minimizing clinicians' administrative burdens.

the development of research studies and innovative AI technologies, the lack of data sharing transparency poses a



significant risk of loss of public trust and even litigation against the implementation of AI in healthcare. The power imbalance between the government and tech companies fuels this issue even more given the latter's control over resources and data infrastructure.<sup>12</sup> Moreover, the lack of thorough AI legislation enables these companies to prioritize interests with few limitations. Although Canada is aiming to play a leading role in the Artificial Intelligence and Data Act global framework (planned to take effect in 2025), the deadline is still far away with AI currently advancing faster than the ability to regulate it.<sup>13</sup> Lastly, the issue of re-identification is another challenge of data security that needs to be tackled. It was discovered that an algorithm could be used to re-identify 85.6% of adults and 69.8% of children from a nutrition database with anonymous health information, indicating that current practices of de-identification might be insufficient.14 To address this issue, a potential solution involves the use of "generative models" which generate synthetic data that retains the statistical properties of the original patient without exposing any sensitive information.<sup>14</sup> The model learns statistical trends from a dataset and generates a new dataset that is similar statistically but with no actual patient records, thus preserving patient identity.

# Will patient data be secure when used with AI models?

Data privacy is crucial for the wellbeing of patients as it ensures trust and confidentiality in healthcare interactions. However, safe data has become a significant challenge, especially with advanced Al technologies falling into the hands of big tech corporations. Despite only 28.9% of 1841 surveyed American adults being open to sharing their data with these companies, hospitals continue to share patient information with such corporations, giving them valuable market insights for tool development. <sup>11,12</sup> This exchange can lead to potential privacy breaches, where sensitive patient data might be mishandled or improperly accessed, posing serious risks to individual privacy and autonomy. Hence, it is imperative to obtain consent from patients at different stages of data usage, providing them with the flexibility to revoke with changing circumstances. While there is, of course, a tradeoff between keeping data private and simultaneously accessible for

#### **Does AI provide biased suggestions?**

Considering the health and wellbeing of a diverse society, it is essential to tackle the risk of bias to ensure that treatments are personalized, adaptable, and free from discrimination. When training AI algorithms, there are 3 main sources of bias that the model can be affected by: data-driven, algorithmic, and human bias.<sup>16</sup> The algorithm learns from the data provided, and the higher the level of accuracy, diversity, and representativeness of the data, the more reliable and less

biased its clinical decisions are. One example of data-driven bias is the use of genome-wide association studies (GWAS) to evaluate an individual's genetic susceptibility to a disease. The drawback is that 81% of GWAS studies concentrate on people with European backgrounds, which affects the wider applicability of disease risk scores across diverse populations.<sup>13</sup> Algorithmic bias, on the other hand, can occur due to inadequate regulation during the design phase which does not represent the data from different groups equally.<sup>16</sup> For instance, the hurry to implement AI solutions during COVID-19 without thorough testing in diverse groups may have unintentionally worsened health disparities and diagnoses for these populations.<sup>18</sup> This is distinct from data-driven bias, which arises directly from the characteristics of the data itself, such as missing data from certain demographic groups. Algorithmic bias, however, stems from the decision-making process within the algorithm's design-choices about which data to emphasize, which models to use, and how to weigh different inputs.

Lastly, human biases in AI can be among the most difficult to identify because they stem from ingrained societal prejudices that are often subtle but magnified by AI and big datasets16. However, there are many things that can be done to mitigate these effects in the long term. Standardizing data to make it compatible with different algorithms could assist in accessible data that captures diverse population information<sup>19</sup>. For example, if healthcare data from different hospitals use varying terms for the same medical conditions, standardizing this data would involve mapping these disparate terms to a single, consistent vocabulary. This would allow algorithms to analyze the data uniformly, improving accessibility and inclusiveness. Therefore, standardizing data is crucial for creating accessible datasets that accurately reflect diverse population information, ultimately mitigating long-term effects in data-driven fields. Sharing inclusive AI models can also promote transparency and collaboration by ensuring that code is tested across the globe, with different populations and developers to validate and ensure its efficiency across various clinical settings.<sup>20</sup> Additionally, including communities in the design process can not only mitigate biases but also fulfill the health needs of these communities directly through the input of their personalized experiences and ideas, which are especially important in the current era of precision health care. A notable example is the OpenAPS initiative which is a system that pumps insulin through a device at home based on the patients' self-collected glucose levels, providing safe and personalized diabetes care.<sup>21</sup>

#### Limitations

This paper intends to provide readers with a brief overview of the ethical challenges and solutions regarding empathy, bias, and data privacy in healthcare. It does not focus on areas such as transparency, accountability, and governance which can give the reader a multi-dimensional analysis of Al's impact on healthcare. Additionally, the solutions are meant to be introductory in nature and do not discuss details of the specific steps that need to be taken. Future research can explore the complexities of achieving this in practice. This includes how Al can enhance rather than replace patientclinician relationships, along with specific data collection and design strategies and regulations that can ensure ethical practices.

## CONCLUSION

To sum up, AI has enormous potential to shape the healthcare industry. It is important that its integration into the healthcare system is done so responsibly and in a way that does not impair the well-being of society along the journey. Being aware of AI's limitations, training caregivers to collaborate with it, ensuring strict legislation on designing unbiased models, and establishing security safeguards to protect patient data are all necessary steps to be taken to foster safe AIdriven healthcare. Given that the AI technologies we use today are capable of rapid advancement, we run the risk of falling behind very quickly.

Acknowledgements: I would like to express our special thanks to the scientists who have provided knowledge in their research. I declare that I have no conflict of interest.





Table 1: Summary of sources selected in the review

Author	Origin	Ethical Concer ns	Purpose	Type of Source	Research Design	Target Population	Framework Proposed	Major Themes
Montemayo r et al. (2022)9	USA	Empat hy	Assess AI's limits in empathetic roles in healthcare	Discuss ion	N/A	Public healthcare patients	No	Limitations of AI in empathetic healthcare, moral and ethical implications
Suchman et al. (1997)14	USA	Empat hy	Formulate a model of empathic communication in medical interviews	Resear ch	Descriptive, qualitative	Public healthcare patients	Model of empathetic communicati on	Empathic communication, emotional expression, physician-patient interaction
Kim et al. (2004)6	USA	Empat hy	Develop scales for empathy-related constructs and test their effect on patient satisfaction and compliance	Resear ch	Survey and modeling	University hospital outpatients	Empathy- satisfaction- compliance relationship	Physician empathy, patient satisfaction, patient compliance, communication skills
Trinidad et al. (2020)15	USA	Data Privacy	Assess public comfort with sharing health data with third-party companies for different purposes	Resear ch	Survey and regression analysis	General U.S. public	No	Public comfort with data sharing, demographic factors, privacy concerns, healthcare data usage
Winkler et al. (2023)17	German y	Data Privacy	Discuss the ethical considerations of sharing patient data from public healthcare with for- profit companies for research	Resear ch	Conceptual analysis	Public healthcare patients	Ethical conditions for data reuse	Ethics of data sharing, patient rights, public health benefits
Gurevich et al. (2023)4	Canada	Data Privacy	Explore the interplay between health equity and Al, and how Al can either support or undermine health equity	Resear ch	Conceptual analysis	Healthcare systems and patients	guidelines for ethically sharing patient data with for- profit companies	Health equity, AI in healthcare, ethical considerations, data sharing
Na et al.10	USA	Data Privacy	Evaluate the possibility of reidentifying individuals from deidentified physical activity data using machine learning	Resear ch	Cross- sectional study	U.S. population	No	Data privacy, reidentification, machine learning, physical activity data



Author	Origin	Ethical Concern s	Purpose	Type of Source	Research Design	Target Population	Framework Proposed	Major Themes
Baowaly et al. (2019)1	Taiwan	Data Privacy	Develop and test advanced generative adversarial network models for creating synthetic electronic health records that are more realistic and efficient	Research	Experimental study using databases	Medical researchers	Improved data synthesis models	Syntheti c data, model compari son
Norori et al. (2021)11	Switzerla nd	Bias/	Address algorithmic bias in Al for healthcare by promoting open science practices.	Research	Theoretical analysis	Healthcare professionals and Al researchers	Open science framework to mitigate Al bias	AI bias, data represen tation, open science approac hes
Popejoy and Fullerton (2016)13	USA	Bias	Evaluate diversity in genomic studies and its implications for precision medicine.	Research	Analysis	Global population	Framework for inclusive genomic research	Genetic diversity , precisio n medicin e, underre presenta tion
Leslie et al. (2021)7	UK	Bias	Assess Al's impact on health inequities during the COVID-19 pandemic	Discussi on	Conceptual analysis	Global healthcare systems and vulnerable populations	Recommendati ons for equitable Al use	Al and health equity, COVID- 19, algorith mic bias
Kelly et al. (2019)5	USA	Bias	Explore the challenges and necessary steps for integrating Al into clinical healthcare practice	Discussi on	N/A	Healthcare professionals and patients	Al integration in healthcare	AI in healthca re, clinical integrati on, machine learning challeng es, regulato ry consider ations



Author	Origin	Ethical Concern s	Purpose	Type of Source	Research Design	Target Population	Framework Proposed	Major Themes
Tzovaras et al. (2019)3	USA	Bias	Explore challenges of integrating and sharing personal data for research via Open Humans platform	Research	Platform- based participatory research	Digital platform users	Open Humans platform	Personal data integrati on, ethical consider ations, privacy, commun ity- centric data sharing
Lewis et al. (2016)8	USA	Bias	Explore the real-world use and implications of open-source artificial pancreas systems by the diabetes community	Research	Descriptive analysis	Diabetes patients using open-source systems	No	Commu nity- driven innovati on, safety, user autono my

## REFERENCES

1. Bercean BA, Birhala A, Ardelean PG, et al. Evidence of a cognitive bias in the

8. Suchman AL, Markakis K, Beckman HB, Frankel R. A model of empathic communication in the medical interview. JAMA. 1997;277(8):678-682.

9. Kim SS, Kaplowitz S, Johnston MV. The effects of physician empathy on

patient satisfaction and compliance. Eval Health Prof. 2004;27(3):237-251. doi:10.1177/0163278704267037.

quantification of COVID-19 with CT: an artificial intelligence randomised clinical trial. Sci Rep. 2023;13(1):4887. doi:10.1038/s41598-023-31910-3

- Petersen S, Houston S, Qin H, Tague C, Studley J. The Utilization of Robotic Pets in Dementia Care. J Alzheimers Dis. 2017;55(2):569-574. doi:10.3233/JAD-160703
- Wallace MB, Sharma P, Bhandari P, et al. Impact of Artificial Intelligence on Miss Rate of Colorectal Neoplasia. Gastroenterology. 2022;163(1):295-304.e5. doi:10.1053/j.gastro.2022.03.007
- Esteva A, Kuprel B, Novoa RA, Ko J, Swetter SM, Blau HM, Thrun S. Dermatologist-level classification of skin cancer with deep neural networks. Nature. 2017;542(7639):115-118. doi:10.1038/nature21056
- Dodington DW, et al. Analysis of tumor nuclear features using artificial intelligence to predict response to neoadjuvant chemotherapy in high-risk breast cancer patients. Breast Cancer Res Treat. 2021;186(2):379-389. doi:10.1007/s10549-020-06093-4
- Khawaja, Z., & Bélisle-Pipon, J. C. (2023). Your robot therapist is not your therapist: understanding the role of AI-powered mental health chatbots. Frontiers in digital health, 5, 1278186. <u>https://doi.org/10.3389/fdgth.2023.1278186</u>
- 7. Seh, A. H., Zarour, M., Alenezi, M., Sarkar, A. K., Agrawal, A., Kumar, R., & Khan, R. A. (2020). Healthcare Data Breaches: Insights and Implications. Healthcare (Basel, Switzerland), 8(2), 133. <a href="https://doi.org/10.3390/healthcare8020133">https://doi.org/10.3390/healthcare8020133</a>
- Montemayor C, Halpern J, Fairweather A. In principle obstacles for empathic
   Al: why we can't replace human empathy in healthcare. Al Soc.
   2022;37(4):1353-1359. doi:10.1007/s00146-021-01230-z

10. Trinidad MG, Platt J, Kardia SLR. The public's comfort with sharing health data with third-party commercial companies. Humanities Soc Sci Communications. 2020;7(1):149. doi:10.1057/s41599-020-00641-5

11. Winkler EC, Jungkunz M, Thorogood A, Lotz V, Schickhardt C. Patient data for commercial companies? An ethical framework for sharing patients' data with for-profit companies for research. J Med Ethics. Published online 2023. doi:10.1136/jme-2022-108781

12. Gurevich E, El Hassan B, El Morr C. Equity within Al systems: What can health leaders expect? Healthc Manage Forum. 2023;36(2):119-124. doi:10.1177/08404704221125368

13. Na L, Yang C, Lo CC, et al. Feasibility of Reidentifying Individuals in Large National Physical Activity Data Sets From Which Protected Health Information Has Been Removed With Use of Machine Learning. JAMA Netw Open. 2018;1(8):e186040. doi:10.1001/jamanetworkopen.2018.6040

14. Baowaly MK, Lin CC, Liu CL, Chen KT. Synthesizing electronic health records using improved generative adversarial networks. J Am Med Inform Assoc. 2019;26(3):228-241. doi:10.1093/jamia/ocy142

15. Norori N, Hu Q, Aellen FM, Faraci FD, Tzovara A. Addressing bias in big data and AI for health care: A call for open science. Patterns. 2021;2(10):100347. doi:10.1016/j.patter.2021.100347

16. Popejoy AB, Fullerton SM. Genomics is failing on diversity. Nature. 2016;538(7624):161-164. doi:10.1038/538161a

17. Leslie D, Mazumder A, Peppin A, Wolters MK, Hagerty A. Does "Al" stand for augmenting inequality in the era of covid-19 healthcare? BMJ. 2021;372:n304. doi:10.1136/bmj.n304



18. Kelly CJ, Karthikesalingam A, Suleyman M, Corrado G, King D. Key challenges for delivering clinical impact with artificial intelligence. BMC Med. 2019;17(1):195. doi:10.1186/s12916-019-1426-2

19. Greshake Tzovaras B, Angrist M, Arvai K, et al. Open Humans: A platform for participant-centered research and personal data exploration. GigaScience.
2019;8(6):giz076. doi:10.1093/gigascience/giz076

20. Lewis D, Leibrand S, #OpenAPS Community. Real-World Use of Open Source Artificial Pancreas Systems. J Diabetes Sci Technol. 2016;10(6):1411. doi:10.1177/1932296816665635

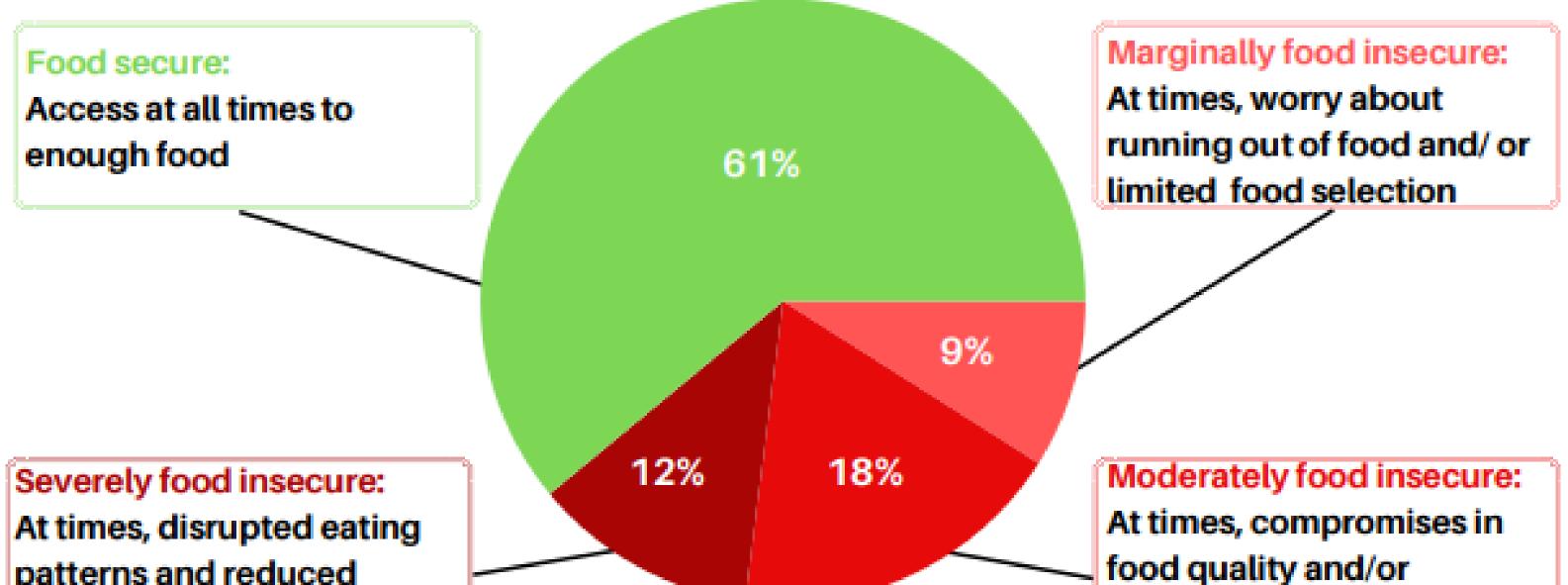
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# A snapshot of food insecurity and health among University of Waterloo undergraduate students

## Food insecurity at the University of Waterloo

- Household food insecurity refers to compromised food access due to financial constraints.
- A 2019 study of 256 undergraduate students found that four in ten (39%) lived in households that experienced some level of food insecurity in the past 12 months.<sup>1</sup>



#### patterns and reduced food intake

quantity

Given disruptions associated with the pandemic and increases in food and housing costs, the prevalence of food insecurity among undergraduate students may now be higher.

# Food insecurity and self-reported indicators of health

The odds of poor health were significantly higher among students who had experienced any level of food insecurity over the past 12 months versus those who had not.



2.2x1 Likely to report poor or fair mental heath

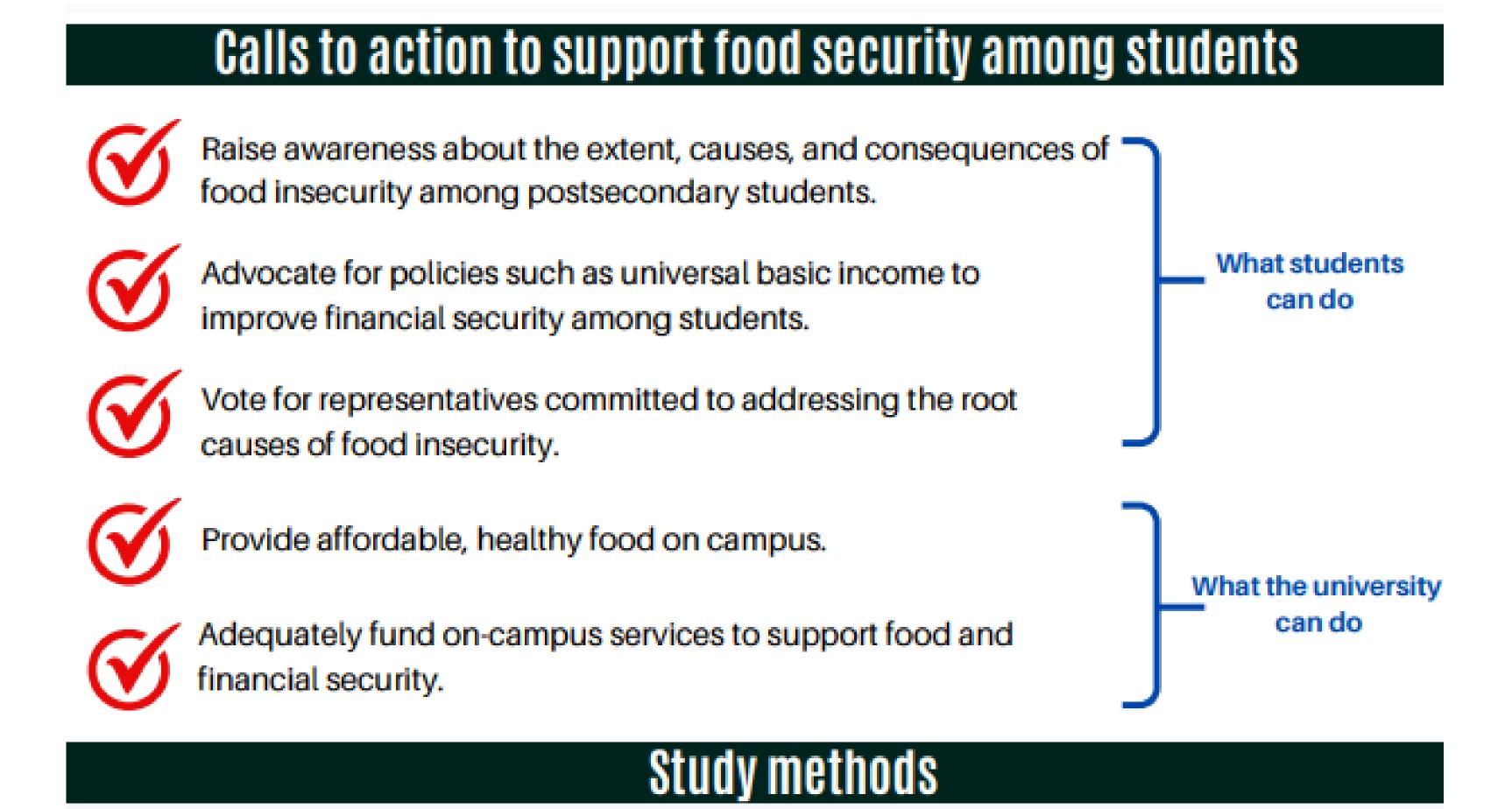




Odds ratios were adjusted for gender identity, financial insufficiency, racial/ethnic identity, residency status, co-op enrollment, and year of study.<sup>1,2</sup>



1



- Students were recruited using on-campus posters, the LEARN online learning platform, internal student Facebook pages, Reddit, and announcements during lectures.
- A web-based survey collected information on household food insecurity using the Household Food Security Survey Module, which captures inability to access adequate food due to limited financial resources.<sup>3</sup> The survey included self-reported indicators of stress, mental health, and physical health status.
- · Students also provided sociodemographic information, such as gender identity and financial sufficiency.
- Although the study drew upon a convenience sample that may not be fully generalizable to all undergraduate students at the University, students from all six Faculties were included: Art (20%), Health (19%), Science (19%), Engineering (18%), Math (15%), and Environment (9%).
- · Seven in ten participants identified as women and three in ten identified as men.
- Nine in ten participants were domestic students.

Data collection was conducted as part of Mona Qutub's undergraduate thesis. Analyses were conducted by Alexandra Pepetone, and the infographic was compiled by Lesley Andrade, Sanaa Hussain, Alexandra Pepetone, Mona Qutub, and Sharon Kirkpatrick of the School of Public Health Sciences at the University of Waterloo. We are grateful to the study participants and to Kirsten Lee, Carolyn Minnick, and Amanda Raffoul for their involvement in the study. The study was funded by an Ontario Ministry of Research and Innovation Early Researcher Award held by Sharon Kirkpatrick. All images are part of Canva's free licensing agreement. **Contact**: sharon.kirkpatrick@uwaterloo.ca

#### References

1. Pepetone A, Qutub M, Andrade L, Wallace MP, Kirkpatrick SI. Food security status in relation to co-operative enrolment among University of Waterloo undergraduate students: A cross-sectional analysis. Can J Diet Pract Res. 2023;84(4):211-17.

 Jessiman-Perreault G, McIntyre L. The household food insecurity gradient and potential reductions in adverse population mental health outcomes in Canadian adults. SSM - Popul Heal, 2017;3:464–72.

3. Government of Canada. The Household Food Security Survey Module (HFSSM) [Internet]. 2012 [cited 2023 Apr 27]. Available from: https://www.canada.ca/en/healthcanada/services/food-nutrition/food-nutrition-surveillance/health-nutrition-surveys/canadian-community-health-survey-cchs/household-food-insecurity-canadaoverview/household-food-security-survey-module-hfssm-health-nutrition-surveys-health-canada.html

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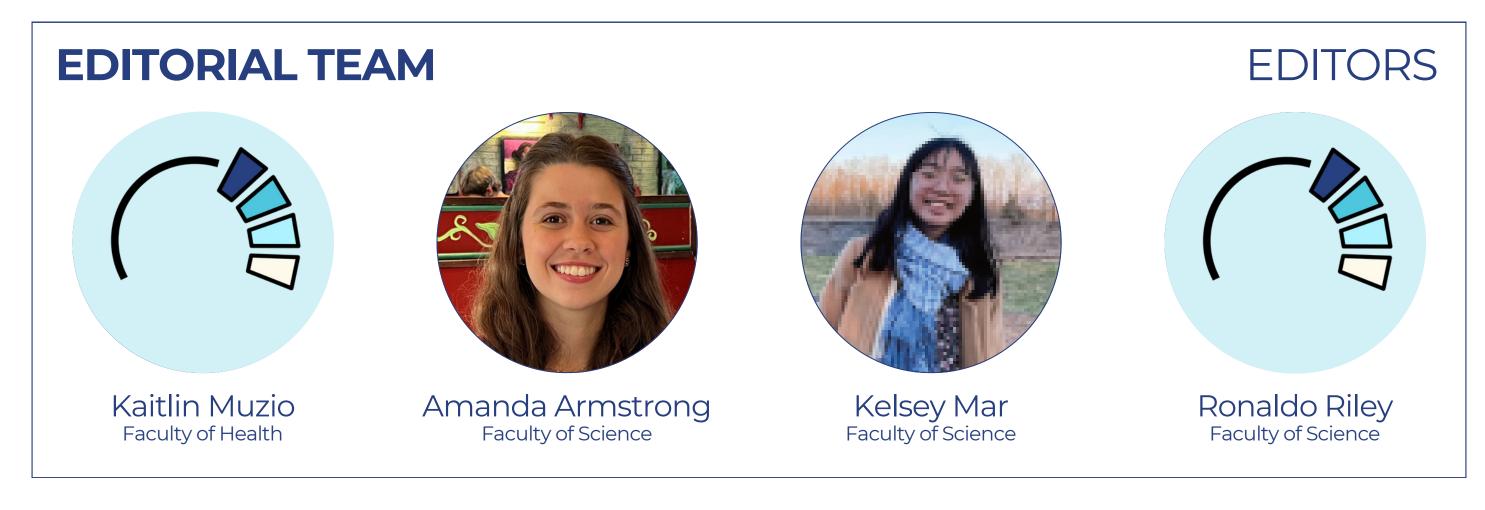


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T he University of Waterloo (UW) Journal of Undergraduate Health Research was founded in 2021 by Tara Behroozian and Shayanne Thomas, both undergraduate students in Hon. Health Studies.

The UW Journal of Undergraduate Health Research hopes to bring together undergraduate students'. Research works related to health from all faculties at the University of Waterloo. This will act as a platform to bring current undergraduate research work to light while allowing students to make contributions to the field of health research.

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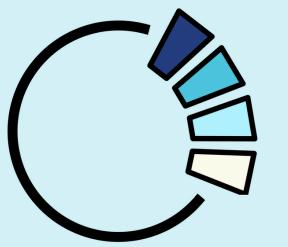


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