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Volume 1, Issue 4, 2026

Journal of Undergraduate Health Research



UNIVERSITY OF
WATERLOO

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Dear Reader,

It is my pleasure to welcome you to the fourth issue of the University of Waterloo Journal of Undergraduate Health Research (JUHR).

This issue represents not only the continued growth of JUHR, but also the dedication of a team that has remained deeply committed to the journal throughout its development. Over the past year, we were fortunate to maintain a strong sense of continuity across our team, with many members returning to contribute their experience, ideas, and leadership. At the same time, a significant portion of our team approached the final stages of their undergraduate degrees. Balancing academic responsibilities, graduation preparations, employment, and other commitments made this publication cycle particularly demanding. Despite having much on their plates, our members continued to show up for one another and remained committed to bringing this issue to completion. Their perseverance reflects the collaborative spirit upon which JUHR continues to grow.

The articles featured in this issue demonstrate the interdisciplinary nature of health research across biological, social, cultural, and ethical perspectives. Khushleen Bawa explores how language barriers affect healthcare access for South Asian immigrant families and proposes a culturally responsive digital resource to improve communication. Fatima Zizi Fahlefi examines the growing use of preventative Botox among youth and raises questions about safety, autonomy, regulation, and the medicalization of aging. Sejal Bhagat discusses how epigenetic processes connect environmental influences with the development of neurological and psychiatric diseases. Maya Morton Ninomiya examines knowledge-mobilization initiatives related to food sovereignty and climate-change research in the Inuvialuit Settlement Region, emphasizing the importance of community-engaged and accessible knowledge sharing.

I would like to extend my sincere gratitude to every member of JUHR's Editorial, Creative, Administrative, and Executive Teams. The publication of this issue would not have been possible without the time, care, and dedication contributed at every stage of the process. From reviewing and refining manuscripts to coordinating operations, communicating with authors, and transforming each submission into a cohesive and visually engaging publication, every team played an essential role in bringing this issue to life.

It has been a privilege to work alongside a group who remained committed to the journal and to one another, even during an especially busy and transitional period. I am incredibly proud of what we have accomplished together and grateful for the lasting contributions each member has made to JUHR. I hope that this issue encourages you to engage with health research from new perspectives and serves as a reminder of the meaningful contributions undergraduate students can make to research, scholarship, and their communities.

Warm regards and happy reading,



Rajnandini Ganguli
Editor-in-Chief
University of Waterloo Journal of Undergraduate Health Research



Knowledge Translation Strategies for Healthcare Access in South Asian Immigrant Families

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LAY SUMMARY

Many South Asian immigrant families in Canada face challenges accessing healthcare due to language barriers. Often, children are asked to translate for their parents during medical appointments, which cause stress, misunderstandings, and even impacts the quality of care. This study explores how language barriers influence healthcare communication in these families and developed a solution to address the problem. A multilingual, user-friendly prototype website was created to support families in navigating the healthcare system. This website allows users to request professional interpreters, access health education in their preferred language, and share cultural preferences with healthcare providers. By reducing the burden on children as interpreters, the tool helps families communicate more accurately and comfortably, promotes culturally sensitive care, and creates trust in healthcare services. The findings highlight the importance of accessible language services in improving health outcomes and demonstrate the role of technology in bridging communication gaps, making healthcare more equitable for immigrant communities.

ABSTRACT

Language barriers limit equitable healthcare access for South Asian immigrant families in Canada. When professional interpreters are unavailable, children often act as informal translators, raising ethical concerns and causing communication errors. This Knowledge Translation (KT) study examined how these barriers affect healthcare experiences and guided the development of an intervention to improve communication. A literature review highlighted the negative impact of informal child interpretation and the benefits of professional interpreters in improving care quality and patient satisfaction. Guided by the Knowledge-to-Action Framework, a multilingual website was designed as a KT tool, offering real-time interpreter requests, culturally tailored care notes, and accessible health education resources. The website aims to reduce the reliance on children as interpreters, support patient-centered care, and enhance health literacy. Evaluation strategies include tracking website usage, conducting surveys to measure awareness and confidence, and engaging community stakeholders to assess impact and sustainability. This initiative demonstrates that technology-enabled KT strategies can improve healthcare access, support cultural competence among providers, and reduce inequities for immigrant families, providing a scalable model for other linguistically diverse populations.

KEYWORDS:

Language barriers, South Asian immigrants, healthcare access, medical interpretation, cultural competence, knowledge translation



INTRODUCTION

Effective communication is essential to deliver equitable healthcare, however many South Asian immigrant families in Canada are constrained by language barriers that limit their access and capacity to access quality health services.¹ These challenges often result in miscommunication, delayed diagnoses, missed vaccinations, and poorer health outcomes.² One common but problematic response is the reliance of children as informal translators during medical visits.³ This not only creates emotional stress for youth and increases the risk of misinformation but can cause discomfort for parents who do not wish to discuss sensitive health issues in front of their children.

This KT report investigates how language barriers impact the use of healthcare services by South Asian immigrant families and focuses particularly on childrens' roles as interpreters. This report presents a background review of current evidence, a focused PICO(ST)-framed research question, and a detailed application of the Knowledge-to-Action (KTA) Cycle to propose effective, evidence-informed knowledge translation (KT) strategies. In addition, the appendix includes a website designed as a KT tool to support immigrant families in navigating the healthcare system more effectively.

To explore the influence of language barriers on access to healthcare among South Asian immigrant families, systematic searches of scientific research were conducted. Boolean operators were useful for limiting and refining the search.⁴ The phrase "language barriers" AND "healthcare access" AND "South Asian families" was used to limit the search to those studies that reported on language barriers specific to this particular demographic. Additionally, "language barriers" OR "communication issues" helped to capture a broader range of studies related to healthcare communication, while "children" NOT "adults" narrowed the focus to research involving children as informal interpreters.⁴ Nesting was applied to group similar terms such as "language barriers" AND ("immigrants" OR "immigration") which restricted the search on immigrant populations. Truncation such as "*"immigrant"* was done to capture variations such as "immigrants" and "immigration".⁴ Quotation marks were used around phrases such as "language interpretation" ensured that only articles focused on this specific aspect of healthcare communication were retrieved.⁴ The search was conducted in sources such as PubMed and Google Scholar.

Literature reveals consistent evidence that language discordance between patients and healthcare providers strongly impacts care quality, patient satisfaction, and health outcomes.⁵ One of the most prominent findings in studies is the reliance of children as informal interpreters in health care when professional interpretation services are unavailable or underused. It was found that children will translate both medical terminology and sensitive health issues to parents, in the event that the physician and patient are not using the same language.⁶ This raises issues of miscommunication and inappropriate diagnosis, along with ethical and emotional challenges. Kaufert & Putsch (1997) also note that parents withhold information during consultations where children are present because of embarrassment or cultural taboos, which leads to gaps in clinical information and treatment delays.⁷ Children face emotional burdens, including feelings of responsibility for their parents' health and discomfort in translating sensitive topics.⁸ A study conducted by Gulati et al. (2012) explored the communication challenges faced by immigrant parents of children with cancer.¹ The findings highlighted that language difficulties influenced parents' roles in caregiving and their ability to comprehend complex medical terminology. The findings stressed that there was a barrier due to languages affecting parents' participation in care provision and the understanding of complex medical terminologies.

Literature relating to language barriers in health consists of qualitative and quantitative studies. Quantitative studies, such as national surveys, contribute to prevalence of language barriers but aggregate diverse South Asian populations, thus limiting cultural specificity. For example, in Gulati et al. (2012), data was aggregated across various ethnic groups, which is likely to overlook specific individual community issues.¹ While quantitative research provides broad information, it can lack the cultural richness captured

by qualitative research. Qualitative research, such as focus groups and interviews, provides a better understanding of the emotional and cultural lives of families. One research study, by Lauridsen et al. (2024), highlights the informal interpreters, particularly children, in medical settings. This study indicates children are likely to bear emotional burdens in acting as interpreters during sensitive situations, which may lead to incomplete or inaccurate information.⁹ Even though such qualitative studies are helpful in understanding the lived experience of immigrant families, they are based on small samples and are not generalizable.

Furthermore, many studies do not account for factors such as socioeconomic status or length of immigration, which can influence the reliance on children as interpreters. Although many reports demand trained interpreters and culturally appropriate care, there is insufficient exploration of how these interventions operate in South Asian populations. Few studies explore institutional barriers, such as financial constraints or administrative challenges, that prevent the use of professional interpreters. For instance, a study by Jacobs et al. (2004) discusses the lack of availability and cost of professional interpretation services, which are significant barriers for immigrant families in healthcare settings.¹⁰ Despite existing research, there is a need for more substantial, systematic research exploring language access interventions that are specific to South Asian populations. Future research will need to include more diverse and larger samples and examine how cultural sensitivity and policy in institutions can facilitate communication. Studies that include both patient and provider perspectives will be essential in developing comprehensive strategies to address language barriers in healthcare.

METHODS

This Knowledge Translation (KT) report aims to investigate the impact of language barriers on healthcare communication within South Asian immigrant families in Canada, particularly with a focus on the practice of children serving as informal interpreters for parents during medical encounters. The report aims to support healthcare providers by identifying and translating evidence-based strategies that minimize reliance on child interpretation and promote equitable, patient-centered care. The specific objectives include the following: (1) to assess the risk and impact of child interpretation in clinical settings; (2) to evaluate the effectiveness of professional interpreter services and culturally tailored communication tools; (3) to develop evidence-informed recommendations for healthcare providers to implement in linguistically diverse environments.

To guide this analysis, the report applies this PICO(ST) framework as follows: the Population (P) consists of South Asian immigrant families in Canada with limited English or French proficiency; the Intervention (I) focuses on the use of professional medical interpreters and culturally tailored communication approaches; the Comparison (C) group would use informal interpretation provided by children during healthcare visits; the Outcome (O) includes improvements in healthcare access; the Study Design (S) is qualitative research, which captures lived experiences and communication challenges in-depth; and the Timeframe (T) refers to the first five years after arrival in Canada, a critical period for health system navigation and adaptation.

The KT report is guided by the following research question: Among South Asian immigrant families in Canada, how does the use of professional medical interpreters and culturally tailored communication strategies, compared to the use of children as informal interpreters, impact healthcare access

during the first five years of resettlement?

Language barriers are a major obstacle to equitable healthcare for South Asian immigrant families in Canada with limited English proficiency. These barriers often lead to misunderstandings, delayed diagnoses, and poor treatment outcomes.¹¹ In many cases, children are relied upon to interpret during medical visits, which can compromise communication accuracy and place emotional strain on the child.⁹ Drawing on the Knowledge-to-Action (KTA) Framework, the problem has been clearly identified in the literature as a barrier to culturally safe, patient-centered care. Through knowledge inquiry, studies including Lauridsen et al. (2024), have demonstrated that reliance on informal interpreters, such as children, leads to clinically significant communication errors and poorer health outcomes.⁹ The next stage of knowledge creation is knowledge synthesis, which combines existing research into clear summaries. A large body of evidence supports the conclusion that professional interpretation services improve care quality, reduce disparities, and alleviate the psychological burden placed on young family members. These findings align with course concepts such as cultural humility and health equity, and have been consolidated into actionable best practices—such as integrating professional language services within care teams and providing staff with cultural competence training.⁹

Knowledge acquired from the inquiry and synthesis stages now forms a refined, context-sensitive knowledge tool: the recognition that system-level support for trained interpreters is a critical equity intervention. The KTA Cycle emphasizes that for this knowledge to be actionable, it must be tailored to local contexts (e.g., high South Asian immigrant populations) and made accessible to healthcare decision-makers, practitioners, and community advocates.¹² Therefore, this KT initiative seeks not only to identify a problem, but to support ongoing movement through the action cycle, toward implementation, evaluation, and sustainability of language support policies.

To ensure uptake and sustainability, information must be adapted to the South Asian immigrant community's social, cultural, and linguistic environment within Canada.¹² Professional interpretation is shown to augment communication and care quality¹⁰; however, without context, even strong evidence will fail to influence practice. This population of knowledge users, some of whom experience structural and cultural obstacles to health care, require KT materials that are linguistically appropriate, culturally secure, and logistically feasible.¹² Translated learning materials—such as interpreter-request systems in multiple South Asian languages and health care workers trained in cultural humility—can make knowledge more appropriate and useful. Translating knowledge in this way acknowledges not just the demand for language access but also the nuances of social dynamics, such as stigma, gender expectations, and intergenerational expectations, that shape South Asian family interaction with the health system. This tailor-made response facilitates actionable change and aligns with the KTA co-creation and local adaptability orientation.

RESULTS

One of the KT strategies to implement includes a user-friendly website, (refer to appendix), designed to help immigrant families navigate the Canadian health system. The website allows users to easily select the language of their preference, generating content available in real-time

translation. It includes an Interpreter Request Portal, where patients can request a professional interpreter before a medical appointment to avoid being reliant on children as interpreters. If an on-site interpreter is not available, virtual alternatives will be provided to ensure effective and respectful communication. In its efforts to support inclusive care, the website includes a Cultural Care Notes in which users can record cultural requests, such as a preference for same-gender providers, religious considerations, or traditional practices. These preferences can be shared with healthcare teams to help guide culturally sensitive care.

In addition, a Health Education Hub is integrated into the website, providing easy-to-understand materials and videos, in multiple languages and with audio options, regarding topics such as vaccinations, chronic disease management, prenatal care, and mental health. The Health System Navigation Guide component helps immigrants understand how to access different parts of the healthcare system, from walk-in clinics to emergency services, using visual guides and translated explanations. In the Ask Us tab, users are able to type in questions or concerns on the website using their own language, which will be translated to English for healthcare professionals, establishing a simple yet powerful communications bridge. Overall, this website aims to reduce language and cultural barriers while enhancing trust, comfort, and clarity during healthcare interactions.

To incorporate technology-enabled knowledge translation (TEKT) practices, the website developed is a practical, digital tool to reduce communication gaps and support evidence use among Canada's South Asian immigrant families in the healthcare sector. Digital TEKT approaches such as websites, online training, and tailored messaging can increase public health practitioners' knowledge and uptake of evidence.¹⁵ Additionally, the website is integrated with real-time translation and an Interpreter Request Portal (Figure 1) to facilitate more ethical and accurate communication, reducing reliance on children as interpreters. The Health Education Hub (Figure 2) features multilingual audio and video, making it accessible for low-literacy users. Also, the Cultural Care Notes section (Figure 3) Tab helps users communicate cultural needs, supporting providers in providing more patient-centered care. These practices align with KT best practices, emphasizing that tailoring knowledge to specific contexts and needs, especially through online channels, can bridge the research-practice gap and promote equal access to healthcare.

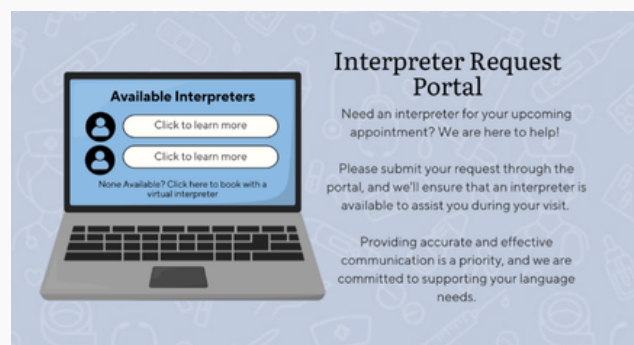


Figure 1. Interpreter Request Portal: This feature enables patients and families to request professional interpretation services in real time, reducing reliance on children as interpreters and promoting ethical, accurate communication between healthcare providers and South Asian immigrant families.

To address potential barriers, such as limited digital literacy or access to reliable internet and devices, the website could include offline features, simplified interfaces, and visual

navigation to support low-literacy users. Clinics could also provide on-site guidance or digital kiosks to ensure equitable access. Additionally, the website's real-time translation and Interpreter Request Portal would promote more ethical and accurate communication, reducing reliance on children as interpreters. The Health Education Hub's multilingual audio and video content ensures accessibility for low-literacy users, while the Cultural Care Notes Tab allows families to express cultural needs, helping providers offer more patient-centered care. Collectively, these features align with KT best practices, emphasizing that tailoring knowledge to specific contexts and needs, especially through accessible, inclusive online channels, can bridge the research-practice gap and promote equitable healthcare access.

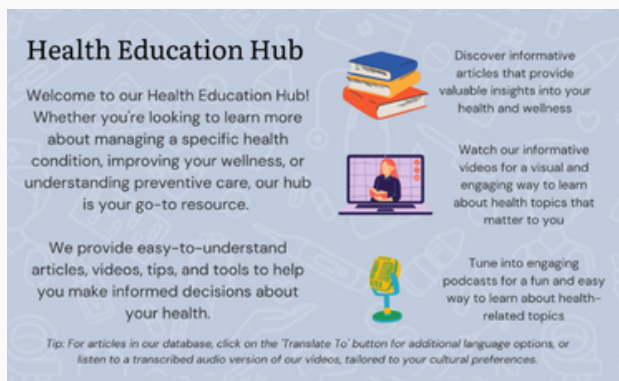


Figure 2 Health Education Tab: An interactive library featuring multilingual audio, video, and visual resources to enhance health literacy among users with varying literacy levels. The hub supports culturally relevant and accessible health education for South Asian communities.



Figure 3 Cultural Care Notes: A section allowing patients to share cultural practices, dietary preferences, and care considerations with healthcare providers. This tool facilitates patient-centered care by helping practitioners understand and respect individual cultural needs.

DISCUSSION

Several barriers impact effective knowledge use including help-seeking stigma, low awareness of interpretation services, and inadequate provider training on cultural competence.¹³ Even when interpretation services are available, some patients may feel uncomfortable or embarrassed sharing personal health information with someone they don't know, especially about sensitive issues. This emotional barrier can prevent full disclosure and lead to inaccurate medical assessments.⁹ Systemic issues, such as underfunding and insufficient staffing of qualified interpreters, also prevent best practices from being applied consistently.¹⁰

Key facilitators can improve KT strategies for South Asian immigrant families. Raising awareness within healthcare institutions about patient-centered care and health equity fosters an environment where inclusive policies thrive.¹⁴ Digital KT tools, like online interpreter request forms, culturally tailored infographics, and mobile apps, offer accessible options for families. Brown et al. (2020) noted that technology-enabled knowledge translation (TEKT) strategies are most effective when designed to meet users' cultural and practical needs.¹⁵ Partnerships with South Asian cultural organizations and community leaders are crucial for building trust, spreading awareness, and ensuring sustainable implementation.¹² These facilitators, aligned with evidence-based practices, can help bridge knowledge gaps and reduce health inequities faced by South Asian immigrant communities.

To evaluate how knowledge is being used, the assessment will focus on three levels: conceptual, instrumental, and strategic.¹⁴ Conceptual use will be measured through pre- and post-surveys, tracking changes in awareness and confidence regarding the healthcare system. Instrumental use will be assessed by tracking website usage, such as interpreter requests and educational content views. Strategic use will be explored through interviews with healthcare providers and community stakeholders to understand the tool's impact on broader discussions of culturally safe care. Evaluation will also occur at structural, process, and outcome levels.¹⁶

At the structural level, the focus will be on changes like improved access to professional interpreters and the integration of cultural preferences. Process-level assessment will involve surveys and website analytics, while outcome-level assessment will examine improvements in healthcare experiences, such as fewer missed appointments and increased trust. Administrative data may be used to look for reductions in health complications due to language barriers.¹⁷ The design includes an exploratory phase, where a pilot website will be tested with a small group to gather feedback on its relevance and usability. The pragmatic phase will involve ongoing data collection and adjustments to keep the tool effective. Sustainability is also a priority.¹⁶ To ensure long-term impact, community groups and healthcare providers will promote the website, and plans will be made to integrate it into routine healthcare intake processes. Securing funding for ongoing maintenance and interpreter services will be critical for scaling up the intervention.¹⁷

CONCLUSION

To conclude, language barriers pose a significant obstacle to equitable access to healthcare for South Asian immigrant families in Canada. The reliance on children as informal interpreters during medical visits compromises communication and places emotional and ethical burdens on parents and children. This report advocates for professional, culturally competent interpretation services through a knowledge translation intervention: an accessible, multilingual web site that is able to provide available tools for interpretation, health education, cultural preferences, and healthcare navigation. Through technology, community engagement, and cultural competence, the web site will allow for more respectful, informed, and inclusive care, while monitoring and evaluation will ensure responsiveness and scalability. Finally, the implementation of language-access tools for families will reduce child dependency, enhance trust in the health system, and improve health outcomes for South Asians in Canada.

ACKNOWLEDGEMENTS

I am deeply grateful to the many individuals who have contributed to the successful completion of this study. Firstly, I would like to express my sincere gratitude to Dr. Annalise Ferro for their invaluable guidance, expertise, and encouragement throughout this journey. Their insights and advice have been instrumental in shaping the direction and outcomes of this work. I also wish to extend my heartfelt thanks to the University of Waterloo for providing the immense support, without which this study would not have been possible. Special thanks to the Faculty of Health for their support throughout this journey as well. I am also deeply thankful to my family and friends, whose immense guidance and understanding gave me their strength to persevere. Lastly, I would like to acknowledge the inspiration and knowledge gained from UW JUHR, which served as a foundation for this study.

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Appendix

Link to Website (KT Tool): <https://saharahealth.my.canva.site/>

Pathologizing Aging: Risks and Concerns with Botox in Youth

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LAY SUMMARY

Botox was originally developed to treat medical conditions, but is also used now to prevent wrinkles, even for people in their late teens and early twenties. This paper argues that the growing popularity in preventative Botox amongst youth isn't just a cosmetic choice, it's part of a larger trend in society that treats visible aging as a medical issue. There are concerns regarding these trends that need to be tackled, especially regarding the lack of long-term research on Botox for younger people, how treatments are increasingly done outside of medical settings without proper supervision, and the ethical questions this popularity raises about autonomy.

ABSTRACT

The growth in preventative Botox for younger demographics as a treatment for wrinkles reflects a cultural shift where aging is no longer seen as a natural life process, but a medicalized condition that requires interventions. This paper argues that there are some serious concerns with this trend regarding safety, ethics, and autonomy which must be addressed. Using sociological perspectives along with medical considerations, this paper highlights how there is a need for better regulations of off-label procedures in informal settings, more long and short-term research into how Botox affects younger populations physically and psychologically, as well as a recognition that for the majority of individuals, outward signs of aging are not pathological.

Keywords: Botox, aging, medicalization, youth, risks, regulations

1. INTRODUCTION

Botulinum toxin, often referred to as Botox, is a neurotoxin that can relax targeted muscles by blocking acetylcholine release at the neuromuscular junction.¹ Originally developed in the 1970s as a treatment for strabismus—a condition causing misalignment of the eyes—it also gained popularity in the field of aesthetic medicine because of its ability to minimize dynamic wrinkles.² In a 2023 report by the International Society of Aesthetic Plastic Surgery, Botox comprised 46.3% of all non-surgical aesthetic procedures done globally.³ While it's most popular for adults aged 35–50, the usage as a “prejuvenation” or preventative treatment for younger adults aged 18–34 and even minors is gaining popularity.³ While in 2019, rhinoplasty was the most common procedure for minors, by 2023, Botox became the most common procedure for this age group.^{3,4}

This paper argues that the increase in popularity and normalization for youth reflects more than just an autonomous cosmetic trend but is part of a larger phenomenon: the growing medicalization of aging. Sociologist Irving Kenneth Zola has argued that medicalization can act as a strong form of social control.⁵ Experts are able to pathologize natural life processes such as aging by claiming neutrality and objectivity in their statements, and this perceived neutrality gives their authority more legitimacy in society.⁵ This allows them to redefine natural processes as medical issues that immediately require intervention. As a

result, visibly aging can be seen as a deviation from wellness and health, with youth oppositely seen as a marker of health. With the growing popularity of Botox throughout the years, access can be increasingly found not just at regulated medical settings but also informal settings like hotels and spas.⁶ There is a need to explore the lack of informed consent, safety concerns with the growing number of off-label procedures being offered in unqualified locations, as well as the clinical research gaps for younger age demographics.

2. AGING AS A PATHOLOGY

Zola describes medicalization as a process that allows for typical aspects of life or experiences to be labelled in medical terms.⁵ Using this definition, aging—which is an expected part of an individual's life—can become constructed as a pathology that requires intervention. Medicalization may not be inherently harmful, but it can become concerning when natural life experiences are pathologized in a way that fuels societal pressure. This perspective encourages preventative Botox as a treatment for the societally constructed problem that wrinkles are markers of a health decline that must be treated before they are visibly present. Aquino has described the concept of this phenomenon using the term “hybridization loop”.⁷ This loop describes how culturally constructed ideas of desirable features, for example smooth, youthful skin, become seen as an indication of health.⁷ At the same time, biological or medical statistical norms of physical features—for example nose shapes or facial symmetry—become treated as features

individuals need to upkeep to maintain ‘beauty’.⁷ Through this loop, cosmetic ideals become seen as clinical expectations, and in return these expectations further reinforce cultural beauty standards.⁷

This blurring of health and beauty is evident in the way dermatology clinics often market Botox using scientific or therapeutic-related terms. A study by Merianos et al. looks at the marketing materials in cosmetic clinics and finds a significant use of medical terms like “clinically proven,” “physician,” and “treatment” in brochures and websites of clinics.⁸ (p9) Procedures like Botox were described to be healthy, safe options to enhance the body, and the female body was often medicalized, portraying aging as a medical problem that can be fixed with treatment.⁸ This medical framing can cause Botox procedures to be seen as a necessity rather than an elective choice, even for youth.⁸ As clearly stated by The American Society of Dermatologic Society, there has been an increase by 50% from 2012-2016 of patients aged 30 years or younger using Botox.⁹ In addition, research shows that social media plays complex, intertwined roles in youths’ identity development and exploration.¹⁰ Since the concepts of image and identity are still developing among youth, as well as their ongoing growth in media literacy, advertisements using medical framing can have a stronger impact on their demographic.¹¹

3. RISKS AND AUTONOMY OF YOUTH

When it comes to the use of Botox for aesthetic purposes, only two indications have been formally approved by the FDA: 1) treatment of glabellar lines (wrinkles located between the eyebrows) and 2) treatment of lateral canthal lines (crow’s feet wrinkles).¹² Thus, other treatments are considered off-label, such as the treatment of eyebrow lifts, gummy smiles, and even the wide range of “prejuvenation” injections targeting youth.¹³ While off-label treatments can be safe, they are often supported primarily by smaller cohort studies and case series.¹³ There is still a big gap when it comes to larger, randomized, and long-term studies, especially for younger demographics.¹⁴ In one 2023 literature review by Michon, it was found that only 4 studies focused on a younger demographic, most of which being observational analyses. Existing studies are mostly focused on older adults, and as a result, questions about muscle atrophy, resistance to treatments, and dosing are still yet to be answered in depth for individuals considering preventative Botox treatments.^{14, 15} These gaps should not be ignored, especially considering that current patients are starting Botox treatments at significantly younger ages than previous generations.¹² In fact, a survey by Freeman et al. regarding individuals who have undergone Botox finds that for every 10 year gap in respondents’ ages, the age of first injection is an average of 8.8 years younger.¹² As the demographic of Botox patients shifts toward a younger audience, the focus of research must also evolve to study the specific long-term effects on this group.

Another concern with the growing popularity of Botox among youth is the growing extension of informal locations individuals get procedures done. While Botox is generally safe when performed at medical offices with licensed individuals, it is also possible to get procedures done outside of clinical environments.¹² The existence of Botox parties— occasions in which Botox injections are administered as part of a group setting, often in salons, spas, or even homes—serves as a prominent example.¹⁴ It’s important to place more importance regarding patient safety and oversight in these settings, especially when adverse reactions occur without medical oversight to mitigate them.¹⁶ In April 2024 alone, there were 22 cases of iatrogenic botulism linked to Botox in the United

States.¹⁶ Iatrogenic botulism is a form of botulism resulting from medical treatment, in this case Botox, and 20 of the 22 cases occurred outside of a formal healthcare setting.¹⁶ This is concerning especially given the growing popularity of such procedures in younger groups who may be influenced further by agents like media and peers.¹⁷

Furthermore, many frame Botox as an act of personal autonomy and even empowerment. While there can be genuine psychological benefits, such as an increase in self-esteem, body image, and social opportunities, it is important to ask what “autonomous” means in this context.¹⁸ After all, how autonomous can this decision be when the idea of youth is deeply intertwined with health?



4. CONCLUSION

Overall, it’s important see preventative Botox as not just an autonomous cosmetic procedure individuals partake in, but as a key example of how the lines between aging and health are being blurred in today’s age. As youthful skin becomes viewed with the lens of wellness, and individuals feel compelled to self-manage youth in the name of health, Botox can be increasingly framed as more than an elective cosmetic procedure.⁸ This pathological framing can narrow the space that visible aging can be considered acceptable societally. When aging is intertwined with health and portrayed as something to delay and manage, framing preventative Botox as just a cosmetic trend ignores how deeply medicalization plays a role in society’s perception of aging.

Furthermore, while Botox can be safe when administered by qualified professionals in professional settings, the increasing use outside such settings raises some ethical questions and concerns.¹⁶ To address the concerns raised in this paper, three objectives must be pursued. First, conducting more robust research on the effects of repeated Botox use in youth. Second, strengthening regulatory oversight of its off-label applications, particularly in informal settings. Finally, it’s important that younger demographics interested in Botox are educated on risks of having procedures done in such settings, and the importance in finding reputable areas to get procedures done at.

In the end, what we should reflect on is not about whether youth can choose preventative Botox, but about whether the growing popularity reflects the increasing view of aging as a medicalized issue. If this is the case, then we should consider the potential implications, as well as recognize that as a whole, there should be a better cultural representation of aging in society. After all, automatically linking youth with

wellness oversimplifies a very complex experience, and being able to challenge this can help us move towards a more balanced, understanding view of aging in society.

Acknowledgements

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How Epigenetics Shapes Brain Diseases: Same Mechanisms, Different Outcomes

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LAY SUMMARY

Neurodegenerative diseases are conditions where nerve cells in the brain and the peripheral nervous system lose function over time, causing a decline in nervous system's physiological functions.

Epigenetics, alongside ageing and genetics (family history & mutations), have been recently found to have an important role in the cause of neurodegenerative diseases. Epigenetics are heritable changes in our gene expression that occur without altering the DNA sequence itself and dictate genes that will be turned on/off, ultimately impacting cellular processes that lead to these neurodegenerative diseases.

Fortunately, epigenetic changes are often times reversible, hence current researchers are urged to look for ways to target these epigenetic changes with drugs called epigenetic modulators, that can reverse destructive epigenetic marks and/or promote beneficial markers

This literature review focuses on how epigenetic mechanisms such as changes in DNA methylation, histone modification, and non-coding RNAs contribute to the onset and progression of Alzheimer's Disease, Parkinson's Disease, and Huntington's Disease. It also highlights how emerging epigenetic therapies may offer new hope for treatment by restoring healthy gene expression patterns and could lead to new diagnostic tools (biomarkers) and more effective treatments for these debilitating diseases.

ABSTRACT

This report investigates the role of epigenetic mechanisms, like DNA methylation, histone methylation/acetylation, non-coding RNA changes, and microglial priming, in the pathogenesis of neurodegenerative diseases, specifically Alzheimer's Disease (AD), Parkinson's Disease (PD), and Huntington's Disease (HD) 2. This report synthesizes findings from multiple primary research articles to analyze how these mechanisms influence gene expression across different diseases. Relevant primary research published between 2018 and 2024 was identified through searches on PubMed, ScienceDirect, and Google Scholar using predefined inclusion and exclusion criteria for studies examining epigenetic mechanisms in Alzheimer's, Parkinson's, and Huntington's diseases. Consistent patterns of hypermethylation were observed to silence genes critical for mitochondrial function, synaptic integrity, and neuroprotection. Histone modifications further contributed to inflammation and transcriptional dysregulation.¹ Notably, one counter-study revealed that hypomethylation and gene overexpression of synaptic transport genes in PD led to excitotoxicity, suggesting that epigenetic changes are not uniformly detrimental or beneficial.³ The direction and impact of such alterations are gene- and region-specific.⁸ These findings emphasize the complex, context-dependent nature of epigenetic dysregulation in neurodegeneration and highlight potential avenues for targeted therapeutic strategies.

Keywords: alzheimer's disease, parkinson's disease, huntington's disease, DNA methylation, histone modifications, chromatin remodeling

INTRODUCTION

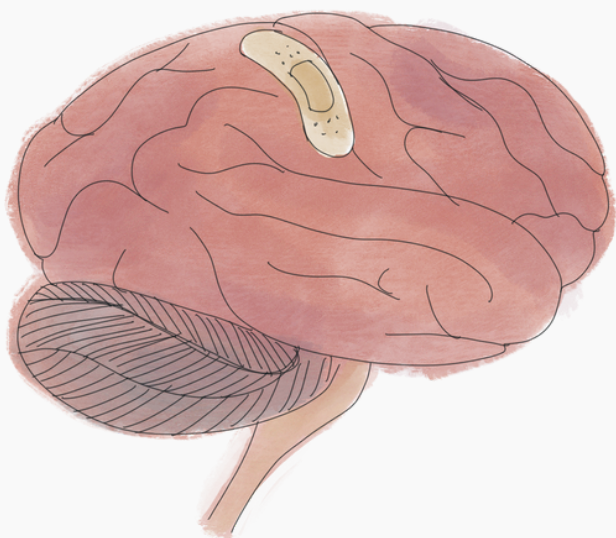
Neurodegenerative diseases are a major global health issue given their progressive neuronal loss and lack of curative treatments.⁹ Aging is the strongest risk factor for neurodegenerative disease, in part because it leads to cumulative dysregulation in gene expression.(Fan et al, 2024) This dysregulation in gene expression happens due to epigenetic modifications, such as **DNA methylation, histone modifications, and non-coding RNAs** (e.g., microRNAs, long noncoding RNAs).⁸ Unfavourable changes in gene expression due to harmful epigenetic modifications are closely linked to

be the primary causes of disease onset and heterogeneity and can be influenced by age, environmental exposures, and lifestyle.¹ Unlike permanent genetic mutations, epigenetic changes are reversible, offering potential targets for novel therapeutic interventions.⁵

Early studies have identified disease-specific epigenetic alterations: aberrant DNA methylation in APP and BACE1 promoters in Alzheimer's Disease (AD)², histone deacetylation changes linked to dopaminergic neuron vulnerability in Parkinson's Disease (PD)¹⁰, and altered histone methylation patterns in Huntington's Disease (HD) models.¹ Even more

compelling, non-coding RNAs such as microRNA-205 have emerged as potential modulators of disease-related gene expression (e.g., *LRRK2* in PD)¹². Yet, while extensive research exists individually for each mechanism or disease, an integrative review across these epigenetic layers and conditions is lacking.

This narrative literature review combines current research on how epigenetic modifications like **DNA methylation**, **histone modifications**, and **non-coding RNAs** contribute to AD, PD, and HD. By comparing these mechanisms across diseases, we aim to highlight shared and disease-specific epigenetic signatures and assess their potential as biomarkers or therapeutic targets.



METHODS

To answer the proposed research topic, I used a narrative analysis of existing primary research studies on the role of epigenetic mechanisms like DNA methylation, histone methylation/acetylation, and non-coding RNAs in the development of neurodegenerative diseases like AD, PD, and HD².

SEARCH STRATEGY:

Keywords: like alzheimer's disease, parkinson's disease, huntington's disease, DNA methylation, histone modifications, chromatin remodeling

Keywords were searched on platforms like Google Scholar, PubMed, and Science Direct to conduct a comprehensive research analysis.

Inclusion criteria for the article were:

- The article's content must focus on epigenetic mechanisms of Alzheimer's, Parkinson's or Huntington's Disease.
- Original peer-reviewed primary research, involving human, animal or in vitro models
- Article must have been published recently—within the years of 2018 and onwards

Exclusion criteria included:

- Review articles
- Papers that did not report original experimental data
- Studies focused exclusively on developmental disorders or cancer

Bias check and the quality of evidence

To reduce potential bias from research, studies chosen were

highly cited and influential academic publications. Since the analysis is a narrative review and not a systematic review, rigid protocols like PRISMA were not used, which could potentially skew the results as only studies with "significant findings" are more likely to be published, whereas those with "null" views are more likely not to be published. Hence, to address this, I used a critical appraisal approach to mitigate selection and interpretation bias⁷:

- Articles with clearly described methods, validated assays (e.g., ChIP-seq, qPCR), and statistically significant results ($p < 0.05$) were chosen⁷
- Reproducibility of results when cross-referencing from different studies to identify similar/different findings.⁷
- Recognized potential publication bias (i.e., favouring studies that report positive findings) and tried to include studies that acknowledge null or contradictory results.⁷

Furthermore, to strengthen the results from this narrative analysis, I included a **counterpoint study** that questions the **causality vs consequence** of histone modifications in PD, in order to showcase whether epigenetic changes are the disease drivers or the byproducts of the disease.

RESULTS

With the inclusion and exclusion criteria and specific keyword search, the following articles were chosen: see Table 1.

1. The role of histone methylation and heterochromatin remodelling in Neurodegeneration

According to Basavarajappa et al (2021) in the International Journal of Molecular Sciences, there was an imbalance in histone methyltransferases (HMTs) and histone demethylases (HDMs), which led to abnormal expression of genes governing synaptic plasticity and neuronal survival, in mouse models with Alzheimer's and Parkinson's Disease. Specifically, there was an increased expression of the gene **H3K9me2**—a repressive marker—in the hippocampus neurons.¹ This led to downregulation of memory-related genes in Alzheimer's disease.¹ Furthermore, in mouse models with Huntington's disease, overexpression of **SETDB1**, an H3K9 methyltransferase, led to heterochromatin loosening and silencing of transcription of genes involved in motor control¹ Furthermore, post-translational modifications in mouse models with Parkinson's led to heterochromatin disability as researchers found decreased H3K27me3, which is a trimethylation of lysine 27 on histone H3 (histone modification)¹, which is a repressive gene marker found at the promoter region of SNCA, potentially leading to disease pathogenesis.¹ Additionally, increased expression of H3K9ac was found, associated with increased neuroinflammation.¹ This was found through a ChIP-seq analysis in neuron chromatin obtained from brain tissue of mouse models with Huntington's Disease postmortem pre-frontal cortex and non-neurologic control systems.¹

[Figure 1¹] provides an illustration of histone methylation-specific epigenetic defects in neurodegenerative diseases.¹

2. DNA methylation and disease-specific gene silencing

Researchers, after analyzing DNA methylation patterns in the brain tissue of post-mortem humans, found huge amounts of methylation in the promoters of genes used for mitochondrial and synaptic functions, like PINK1, PRKN, and NDUFA2.⁸ The silencing of these genes is found to be associated with increased oxidative stress and loss of neurons related to dopamine.⁸

TABLE 1: SUMMARY OF PRIMARY RESEARCH ARTICLES INCLUDED IN THE NARRATIVE REVIEW EXAMINING EPIGENETIC MECHANISMS IN NEURODEGENERATIVE DISEASES

Author (Year)	Article Title (Shortened)	Disease Focus	Model System	Study Method	Country
Desplats et al. (2019)	Microglial memory of early-life stress	General (neurodegeneration risk)	Rat model	LPS exposure + ChIP-seq analysis	Argentina
Basavarajappa & Subbanna (2021)	Histone methylation, regulation pathways in neurodegenerative diseases	AD, PD, HD	Mouse model	HMT/HDM assays + gene expression	USA
Klokkaris & Migdalska-Richards (2024)	Epigenetic changes in PD brain	Parkinson's disease	Human post-mortem tissue	DNA methylation profiling	UK
Fisher & Torrente (2024)	Histone PTMs & heterochromatin remodeling	AD, PD	Human + cell culture	Histone modification mapping + immunoblot	USA

(LPS = LIPOPOLYSACCHARIDE; PTMS = POST-TRANSLATIONAL MODIFICATIONS; HMT = HISTONE METHYLTRANSFERASE; HDM = HISTONE DEMETHYLASE)

Similarly, previous studies showed that methylation of BACE1 (an enzyme important in the formation of myelin sheaths in peripheral nerve cells) and APP promoters in Alzheimer's models reduces their gene expression initially, but fluctuates with disease progression.²

3. Microglial memory and epigenetic priming via early-life stress

Early-life stress induces long-lasting epigenetic changes in microglial cells due to a concept called microglial memory, as rat models in the experiment showed that early exposure to lipopolysaccharide (LPS) led to upregulation of inflammatory genes (e.g., interleukin-1 beta, tumor necrosis factor alpha) upon secondary stimulation, even months later.³ This was associated with stable changes in histone marks (H3K4me3, H3K27ac) in gene promoter regions, priming microglia for a hyper-responsive state in adulthood.³ Genes exposed to stress early on in one's life led to microglial memory, which made them hypersensitive to stress later on in adulthood, which made the brain more prone to neurodegeneration.³

4. Non-coding RNAs in disease-specific gene regulation

MicroRNAs (miRNAs) also play an important role in regulating Parkinson's Disease-associated genes, as downregulation of a short RNA molecule, miR-205 leads to failure in suppressing LRRK2, a gene mutated found in PD patients.⁸ Additionally, downregulation of miR-124 has been shown to impair neuronal differentiation and reduce synaptic plasticity by decreasing the expression of neurogenic transcription factors

such as REST and CREB, leading to disrupted axonal growth and altered synapse formation.⁸ These changes in miRNA levels were directly linked to neurodegenerative phenotypes in PD cell models, suggesting non-coding RNAs act as post-transcriptional regulators in neurodegeneration.⁵ This mechanism is critical for fine-tuning the expression of genes such as LRRK2 and other PD-related targets, and its disruption contributes to abnormal protein accumulation and neuronal vulnerability.⁴ While Desplats et al. emphasised neuroinflammation as a driving factor, the study also proved that the inflammatory state arises from epigenetic priming.³ While Desplats et al. emphasised neuroinflammation as a driving factor, the study also proved that the inflammatory state arises from epigenetic priming.³ [Figure 2] illustrates how a miRNA binds to the 3'UTR of a target mRNA.

Discussion – implications, comparisons, limitations, future research

This narrative literature analysis conducted a thorough investigation of various primary research articles to analyze how epigenetic mechanisms, such as DNA methylation, histone modifications, and non-coding RNAs, contribute to the development and progression of AD, PD, and HD. A common trend existed among all studies: epigenetic dysregulation leads to altered expression of genes that code for synaptic plasticity, neuroinflammation, and mitochondrial function—all markers of neurodegeneration^{1,3,5,8}

TABLE 2. SUMMARY OF EPIGENETIC FACTORS AND THEIR EFFECTS ON ENZYME ACTIVITY, GENE EXPRESSION, AND BRAIN REGIONS ACROSS NEURODEGENERATIVE DISEASE MODELS.

Disease	Epigenetic factor	Enzyme / mRNA affected	Gene(s) affected	Model System	Brain Region Affect	Effect
AD	Histone methylation	G9a/GLP1	Gria2, Grin2b, Shank21	FAD mice1	Pre-frontal cortex, hippocampus1	↑ H3K9me2 → Gene repression1
AD	Histone methylation	KMT2A-D1	Ankyrin 11	Post-mortem human1	Pre-frontal cortex- Nucleus 1	↑ H3K4me3 → Gene activation1
AD	Histone methylation	-	-	CK-p25 Alzheimer's transgenic mouse model1	IncRNA targets1	↑ H3K4me3, ↓ H3K27me31
PD	Histone Modification	-	Immune-response genes 5	Human PD cortex5	Substantia Nigra / general5	↑ H3K9ac → Inflammation 5
PD	Histone Modification	-	LRRK25	Human PD tissue / in vitro 5	-	↓ H3K27me3 → Genomic instability 5
PD	Non-coding RNA	miR-2055	LRRK25	Human PD / in vitro 5	-	↓ miR-205 → ↑ LRRK2 5
PD	Non-coding RNA	miR-1245	Neuronal genes5	PD cell models5	-	Dysregulated expression5
PD	DNA Methylation	-	PINK1, PRKN, ATP13A2, NDUFA28	Human PD brains 8	Substantia nigra pars compacta8	↑ Methylation → ↓ expression8
General	Histone Acetylation	-	IL-1β, TNF-α3	LPS-exposed rats3	Microglia 3	↑ H3K4me3, H3K27ac → Inflammatory priming 3

Abbreviations:

↑ = increased; ↓ = decreased; → = leads to; - = not specified, AD: Alzheimer's Disease , ATP13A2: ATPase cation transporting 13A2, FAD: Familial Alzheimer's Disease mouse model , Gria2/ Grin2b: Glutamate ionotropic receptor AMPA type subunit 2/2B, G9a/GLP: Euchromatic histone lysine methyltransferases , H3K4me3: Histone 3 lysine 4 trimethylation , H3K9me2/3: Histone 3 lysine 9 di/trimethylation , H3K27me3: Histone 3 lysine 27 trimethylation , LPS: Lipopolysaccharide (inflammation inducer), LRRK2: Leucine-rich repeat kinase 2, miR-205, miR-124: microRNAs , NDUFA2: NADH:Ubiquinone Oxidoreductase Subunit A2 (a protein coding gene), PINK1: PTEN-induced kinase 1, PRKN: parkin, PD: Parkinson's Disease , Shank2: SH3 and multiple ankyrin repeat domains 2, SNCA: α-synuclein.

Across all the studies, histone methylation was found to be important for controlling gene expression of genes for major neuronal function ^{1,3,5,8}. The study found that elevated H3K9me2 and reduced H3K27me3 in Alzheimer's and Parkinson's models, correlated with suppression of synaptic plasticity-related genes and inflammatory signalling.⁵ Furthermore, Table 1 depicts how overexpression of SETDB1, and other histone methyltransferases resulted in chromatin compaction and motor gene transcriptional repression in Huntington's Disease, which underlies motor dysregulation seen in HD models.¹ These findings suggest that histone marks disrupt transcriptional homeostasis and trigger disease phenotypes. Correspondingly, post-mortem PD brain DNA methylation profiles suggested hypermethylation of protective genes like PINK1 and PRKN, which in turn hinted at gene silencing in mitochondrial pathology and degeneration of dopaminergic neurons.¹

Non-coding RNAs were also shown to be critical epigenetic regulators. Downregulation of the miR-205 that suppresses LRRK2 and dysregulation of miR-124, a neuronal differentiation regulator, were shown to exacerbate PD pathology.⁵ This supports the claim that epigenetic changes are not just consequences of disease but may also act as initiating factors—highlighting the need to interpret inflammation in the context of upstream regulatory changes. Microglial priming by early-life stress also illustrates how lasting histone acetylation marks like H3K4me3 can lead to increased neuroinflammation in later life, providing evidence for the hypothesis that epigenetic memory plays a role in long-term brain health.³ These findings suggest that early environmental exposures can prime the brain for future neurodegeneration via long-term epigenetic reprogramming.³

TABLE 2. SUMMARY OF EPIGENETIC FACTORS AND THEIR EFFECTS ON ENZYME ACTIVITY, GENE EXPRESSION, AND BRAIN REGIONS ACROSS NEURODEGENERATIVE DISEASE MODELS.

Epigenetic Mechanism	Disease	Key Findings
Histone methylation	AD, HD, PD	Alters synaptic genes, promotes inflammation, disrupts chromatin structure
DNA methylation	AD, PD	Silences mitochondrial, synaptic, and neuroprotective genes
Histone acetylation	PD	Deregulates immune-related transcription
Non-coding RNAs (miRNAs)	PD	Loss of gene repression (e.g., LRRK2) contributing to proteinopathy
Microglial priming	General Findings	Epigenetic marks from early-life stress predispose to exaggerated inflammation

Abbreviations

AD: Alzheimer’s Disease , HD: Huntington’s Disease, LRRK2: Leucine-rich repeat kinase 2 , miRNA: microRNA, PD: Parkinson’s Disease

COUNTER-STUDY

However, one of the studies by Klokkaris and Migdalska-Richards (2024) offered a critical counterpoint to the dominant epigenetic narrative observed in other studies by emphasizing disease- and gene-specific variability in DNA methylation patterns.⁸ While other studies emphasize how epigenetic DNA hypermethylation is a primary mechanism of silencing genes involved in neuroprotection, metabolism, and synaptic maintenance, Klokkaris and Migdalska-Richards’ analysis of postmortem substantia nigra samples from Parkinson’s Disease (PD) patients revealed a completely different trend⁸. They found that genes involved in synaptic vesicle cycling and glutamatergic neurotransmission were hypomethylated and subsequently overexpressed.⁸ This resulted in increased excitatory signalling and a heightened risk for glutamate-induced excitotoxicity, which is a common contributor to neuronal death in PD8.

This insight complicates the most common assumption that methylation acts solely as a silencing force in neurodegenerative disorders. This insight rather showcases the idea that the epigenetic change will have context-dependent functional changes, determined by both the biological role of the gene affected and the neural circuit in which it is expressed. For instance, while hypermethylation of mitochondrial or antioxidant genes may impair neuronal resilience, hypomethylation of genes that drive excitatory neurotransmission may intensify neurotoxicity. Therefore, a deeper analysis on the counter study shows that inflammation happens due to epigenetics. This showcases that epigenetic mechanisms increase disease onset and factors that in a positive feedback way, also increase disease progression.

A summary of epigenetic mechanisms that lead to the onset & progression of PD have been summarized in Figure 3.⁸

Significance to the research field:

These findings showcase the central role of epigenetic modifications in both initiating and perpetuating neurodegenerative processes. Unlike genetic mutations, epigenetic changes are reversible, making them attractive targets for therapeutic intervention.¹¹ For instance, histone deacetylase inhibitors or DNA methyltransferase inhibitors could restore normal gene expression patterns.⁴ Moreover, miRNAs may serve as diagnostic biomarkers and therapeutic agents by modulating disease-related genes.⁸ This review adds value by comparing multiple epigenetic layers across three neurodegenerative diseases, highlighting both shared and disease-specific regulatory mechanisms. Such integrative insights are crucial for developing precision epigenetic therapies and early detection biomarkers.

Limitations:

As a narrative review, this study is limited by selection and interpretation bias. Only articles published after 2018 and with significant findings were included, which may exclude important null results. The absence of PRISMA guidelines means the methodology lacks the rigour of a systematic review. Additionally, most studies analyzed were conducted in animal models or cell lines, which may not fully recapitulate human neurodegeneration. Furthermore, the functional significance of some gene expression changes remains unclear—especially in cases where gene function was not specified, or where it was not evident whether increased or decreased expression was beneficial or detrimental for the disease.

Summary of Discussion

Table 2 offers a useful summary of the directionality of gene expression changes in response to DNA methylation across neurodegenerative diseases. Notably, it shows that Parkinson’s Disease exhibited the most balanced profile, with an almost equal number of hypomethylated/overexpressed

and hypermethylated/underexpressed genes, suggesting complex and competing epigenetic forces at play. In contrast, AD had a larger proportion of hypermethylation-linked downregulation, particularly in genes related to synaptic plasticity and glucose metabolism. These observations support the hypothesis that while epigenetic dysregulation is a shared feature across neurodegenerative disorders, the exact methylation patterns and their consequences on gene expression differ depending on the disease type, brain region, and molecular pathway involved.

Conclusion

This review addressed the role of epigenetic regulation in neurodegenerative diseases like Alzheimer's, Parkinson's, and Huntington's. The aim was to have an understanding of the role of gene expression alteration in disease pathogenesis. Four principal articles between 2018–2024 were selected via ScienceDirect, MDPI, and Frontiers^{1,3,5,8}. Studies included focused on gene-level epigenetic changes in human brain tissue or disease models. Data was analyzed for patterns of DNA methylation, histone modifications, and non-coding RNA expression^{1,3,5,8}. Hyper-methylation of neuroprotective genes and disrupted histone marks between studies were linked to inflammation, mitochondrial dysfunction, and protein misfolding². For example, miRNA dysregulation (e.g., miR-7, miR-153) was observed to influence PD-related protein aggregation⁵. Gene expression patterns inevitably showed inflammatory markers overexpression and protective mechanism suppression⁵. However, a counter-study showed that hypomethylation of excitatory genes in PD can also lead to harmful consequences, unveiling the complex, context-specific nature of epigenetic modification⁸.

Acknowledgements

Special thanks to the authors of the primary research studies referenced, whose work provided critical insight into the epigenetic mechanisms underlying neurodegenerative diseases.

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Figures/Illustrations

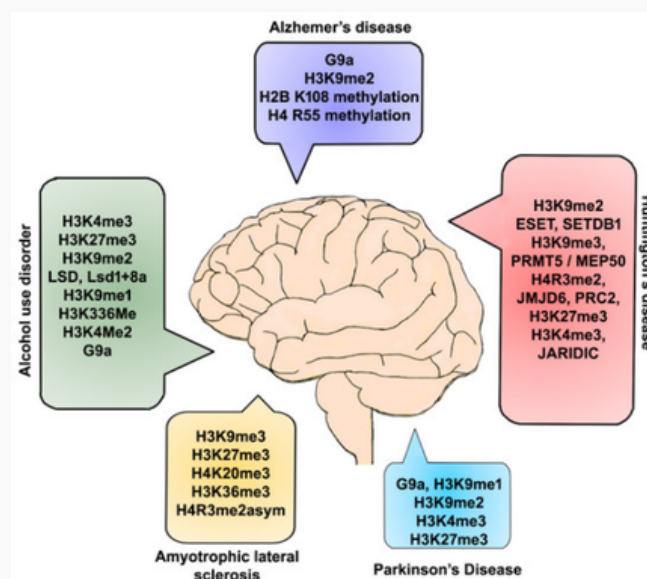


Figure 1²: Neurodiverse-inducing conditions have been shown to affect DNA-associated histone methylation via specific Lysine Methyltransferases and KDMs Lysine Demethylases, followed by several changes in gene and protein expression that are important for cognitive and other ND-related brain pathologies.²

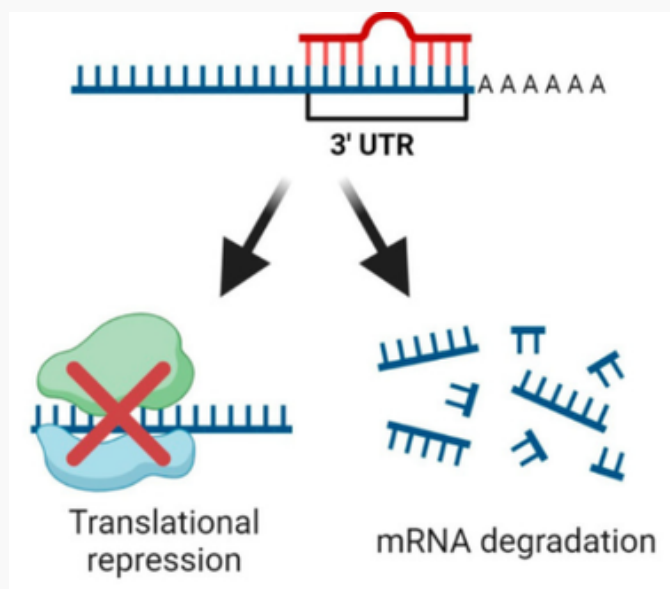


Figure 2³: Illustration showing how a miRNA binds to the 3'UTR of a target mRNA, which results in gene silencing either by translational repression or mRNA degradation.³

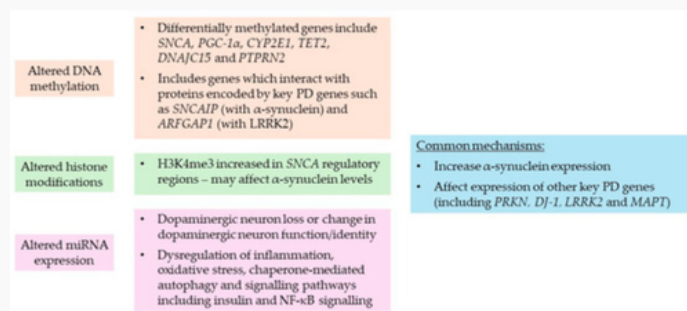


Figure 3³: Studies related all three epigenetic mechanisms to an increase in α -synuclein expression and changes in multiple PD risk gene expression levels.

Examining the process, outcomes and impacts of knowledge mobilization (KMb) initiatives from food sovereignty and climate change research in the Inuvialuit Settlement Region, Northwest Territories, Canada

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This study was approved by the University of Waterloo Research Ethics Board (ORE#45847) on January 29, 2024.

LAY SUMMARY

Knowledge mobilization (KMb) is the process of bringing information back to the individuals or communities who will be most significantly impacted by it. In the North American Arctic, KMb has already been done in the North American Arctic taking the form of things like storytelling workshops, radio broadcasts, and image-based surveys in schools. Conducting KMb in northern communities is critical, but it comes with a lot of challenges such as lack of funding to support longstanding relationships between researchers and community, data accessibility/ownership concerns, and the ongoing impacts of colonization. Our study focuses on KMb context of the Inuvialuit Settlement Region (ISR), Northwest Territories. By interviewing key rightsholders including researchers, co-developers, and community members, we describe what KMb looks like, identify challenges, and make recommendations on how to improve future KMb in the ISR. Why does this research matter: Food insecurity impacts almost half of the households in the ISR. Climate change is making it harder to access country foods in most Arctic communities. Through this research we aim to improve KMb strategies that increase access to country foods and climate resiliency for those living in the ISR and in Arctic communities across the global north.

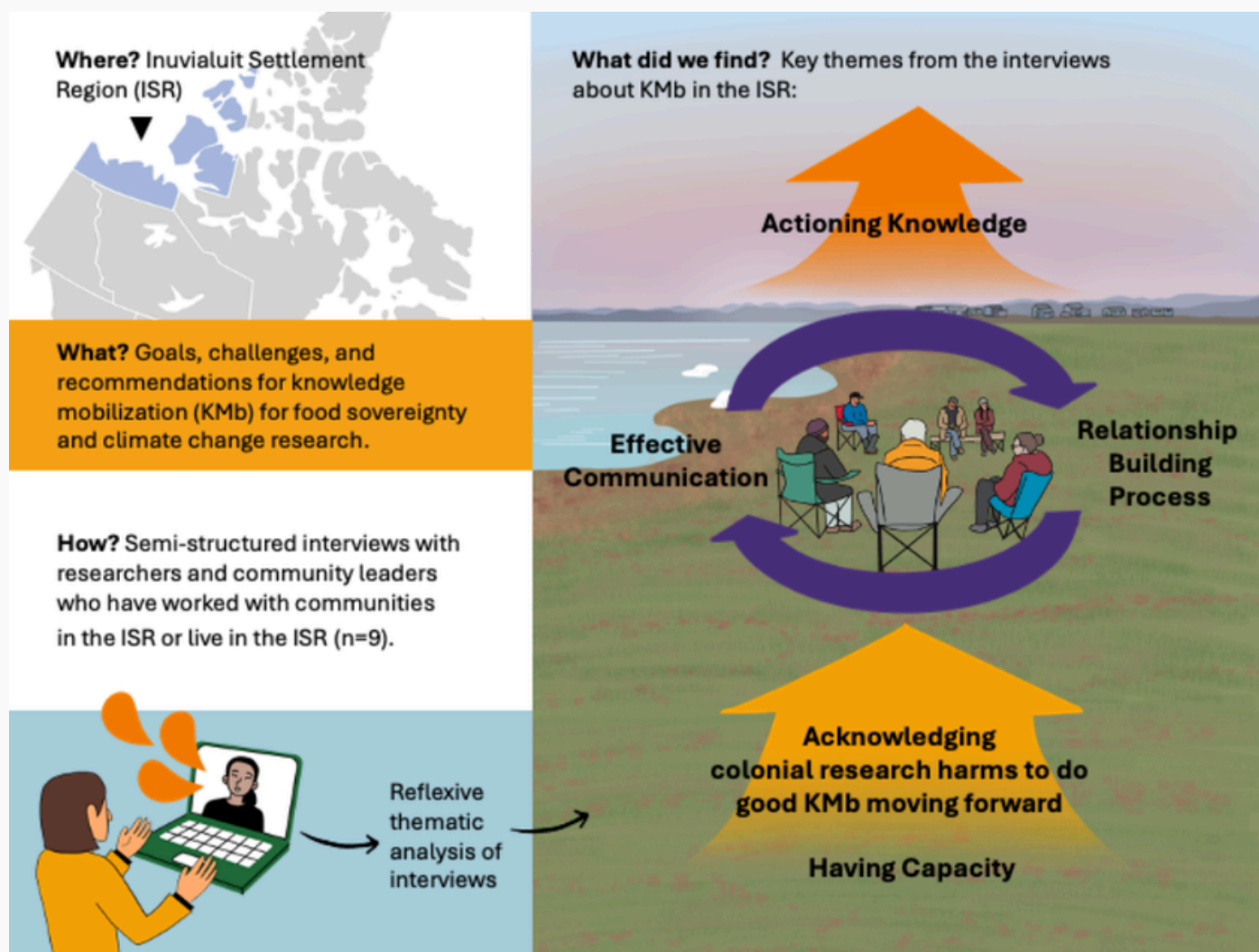
ABSTRACT

Food insecurity impacts almost half of the households in the Inuvialuit Settlement Region (ISR), Northwest Territories. Climate change is making it harder to access country foods in most Arctic communities. Knowledge Mobilization (KMb) refers to the process of translating or exchanging knowledge between researchers and knowledge users. Conducting KMb in northern communities is critical to respond to these issues, but it comes with many challenges such as lack of funding, data accessibility and ownership, and the ongoing impacts of colonization. Semi-structured interviews were conducted with nine key rightsholders including researchers and community leaders to investigate the current goals, challenges and recommendations for KMb in the ISR. The transcripts were analysed for key themes in NVivo using a reflexive thematic analysis approach. This study shows that KMb in the ISR is fundamentally relationship-based and relies on strong communication and collaboration. This study provided a focused insight into what KMb looks like in the ISR, and what tools are being used to achieve effective KMb. Future considerations for KMb in the ISR include: continuing to build community research capacity, uplifting the voices of those with lived experience, being mindful of community and research team capacity, and preemptively engaging policy decision makers.

KEYWORDS

climate change, country foods, food sovereignty, Inuvialuit Settlement Region, knowledge mobilization, Northwest Territories

1. SUMMARY OF RESEARCH STUDY DESIGN AND RESULTS



INTRODUCTION

The Inuvialuit Settlement Region (ISR) is one of the four Inuit homelands in Canada, located in the northern part of the Yukon and Northwest Territories. The ISR is made up of six communities; Aklavik, Inuvik, Paulatuk, Sachs Harbour, Tuktoyaktuk, and Ulukhaktok ranging in population from just over 100 to 3300. 1,2 In the ISR, as of 2022, 78% of the population is Indigenous.³

The ISR is governed by the Inuvialuit Regional Corporation (IRC), established in 1984, which manages the land as per the Inuvialuit Final Agreement.⁴ The IRC is co-managed by Inuvialuit organizations including the Hunter and Trapper Committees (HTCs), the Inuvialuit Game Council (IGC), territorial government agencies within the Yukon and Northwest Territories (NWT), and the Canadian federal government.⁵

Colonial policies involving Inuit relocation, resettlement, and residential schools have had a detrimental effect on Inuit food systems and the transmission of traditional knowledges.^{6,7} Furthermore, climate change is increasingly compromising Inuit food security by impacting the availability, accessibility, and quality of country foods, which forces Inuit communities to rely more heavily on store bought foods.^{8,9} Inuit residing in Inuit Nunangat now experience the highest prevalence of food insecurity among all Indigenous peoples living in developed countries.⁶ Almost half (43%) of the households in the ISR experience food insecurity.¹⁰

Country foods are essential to Inuit food sovereignty, and overall health and wellbeing, including physical, emotional, spiritual, and mental health.^{6,8} Inuit food sovereignty is “the right of all Inuit to define their own hunting, gathering, fishing, land, and water policies; the right to define what is sustainably, socially, economically, and culturally appropriate for the distribution of food and to maintain ecological health; and the right to obtain and maintain practices that ensure access to tools needed to obtain, process, store, and consume country foods.”¹¹ Inuit self-determination and cultural resurgence through the intergenerational sharing and practice of knowledge and skills that sustain relationships to the land, community, and country foods has been emerging through a movement toward Inuit food sovereignty.¹² *Inuit Qaujimajatuqangit (IQ)* encompasses the Inuit worldview, including Inuit culture, epistemology, and knowledge.⁷ IQ relies on *iqqaqqaukkaringniq* which is described by Tagalik, as “the dynamic process of knowing, applying, experiencing, evaluating and creating new knowledge grounded in a continuum of knowing and continually improving”.⁷

Research on knowledge mobilization (KMb) has occurred in the fields of health, environment, Indigenous studies, going by many names, including: ‘knowledge mobilization’, ‘dissemination’, ‘translation’, ‘exchange’ or ‘knowledge to practice’¹²⁻¹⁴. The concept of KMb has been described as “the reciprocal and complementary flow and uptake of research knowledge between researchers, knowledge brokers and knowledge users—both within and beyond academia—in such a way that may benefit users and create positive impacts...”¹³

Over-researching by colonial, Euro-Western research and exclusion of Indigenous peoples from the research process has disrupted Indigenous health and healing.¹⁴ Dominant methods of knowledge transfer in research have reinforced this pattern of treating researchers as expert knowledge holders and communities as passive users.¹⁵ In this study, we view KMb as a method that focuses on developing, synthesizing and disseminating knowledge in a culturally relevant and useful manner *within* Indigenous communities.^{14,16} KMb is an important tool for food sovereignty and climate change research in the north because, when done well, it can align with the goals of community-led, participatory research, that centers around a collaborative, respectful, interactive approach involving all rightsholders.^{17,18} In the context of the North American Arctic, the key rightsholders can include but are not limited to: Indigenous and non-Indigenous community members, researchers, principal investigators, KMb co-developers, Elders, organization leaders, community leaders, and research licensing agencies.

Current common KMb practices in community-based and -engaged climate change research in the North American Arctic include open houses, plain language summaries, image-based surveys, visual posters, photo books, and storytelling workshops.¹⁹ KMb has also taken the form of more unidirectional communication such as radio stations, posters, physical copies of short data summaries, or newsletters.^{19,20} An important area of opportunity, is using social media (Facebook, YouTube) as a KMb tool, as social media is commonly and intergenerationally used by northern community members.^{19,21}

Indigenous Arctic communities present a unique context and therefore distinct challenges for KMb.¹⁹ It is hypothesized that KMb in the ISR reflects many of these challenges. Previously identified challenges include a limited understanding of local community protocols, insufficient infrastructure and inadequate funding and/or time necessary for developing a strong, reciprocal relationships with community members.¹⁹ Another barrier is that academic institutions and funding agencies often prioritize 'scientific' and 'intellectual' outcomes over meaningful community outcomes.^{19,22} Additional challenges involve determining how to respectfully integrate Indigenous knowledges (IK) into Euro-Western Arctic research that highlight their value without 'othering' or 'orientalizing' them^{19,23} and translating Indigenous concepts and words into English (and vice versa) without losing or distorting the meaning.^{19,24-26} Researchers may also lack the soft skills necessary for effective KMb,¹⁹ and Indigenous KMb effort are rarely evaluated.^{19,27} Other barriers include community research fatigue;¹⁹ limited Internet bandwidth, and inequitable access to research databases;^{28,29} high turnover of government and health care staff at the community, regional, federal level,^{18,19,24} and the ongoing impacts and experiences of colonization in Indigenous northern communities.^{20,30} This study hopes to identify which of these challenges pose the greatest barriers and to synthesize recommendations from rightsholders on how to address them.

Studies have summarized KMb strategies and lessons learned in environmental research globally.^{31,32} A previous study on key principles of KMb in the context of the North American Arctic was published in 2020.¹⁹ The study population included Alaska and populations living within Inuit Nunangat, including the ISR, Nunavut, Nunavik, and Nuniastivut. Their study identified the three key principles of KMb as respect, mutual understanding, and researcher responsibility, supported by the underlying considerations of trust and relationship

building.¹⁹ Presently, there have not been any studies that focus on the specific KMb context of the ISR, hence the need for this study. The goal of this study is to describe what KMb tools are being used in the ISR and summarize the successes, challenges, and opportunities of KMb in the ISR that could be addressed.



METHODS

Positionality and Epistemological Approach

KS is a non-Indigenous settler researcher who has been working with ISR communities for several years on projects related to northern food systems. KS has been engaged in community-based research within the provincial north of Canada and since 2002 and with territories since 2015 and she has established strong relationships with ISR community members and organizations. MMN is a non-Indigenous researcher of mixed Canadian and Japanese descent, who brings experience in KMb in the context of health research.

This study utilizes a constructivist approach³³ that sees knowledge as a social, political, and moral construct and therefore that we, as researchers, come to understand the world through the systems and discourses that we reside within. This analysis will be done using the reflexive thematic analysis approach,³⁴ which focused on researcher positionality and its impacts on the data analysis process.

METHODOLOGY

Participants were recruited using purposive sampling, based on preexisting relationships with KS and suggestions from her colleagues. Researchers, KMb co-developers, and community members who have been involved in previous projects regarding food sovereignty and climate change in the ISR were invited to be participants in a semi-structured interview. The interview guides were adapted based on some of the questions developed by Flynn and Ford.¹⁹ The guides were tailored into three versions for each of the participant categories, (researchers, co-developers, and community members) but primarily only the researcher-specific questions were asked, as the majority of participants were researchers, or had significant research experience. (Refer to the Researcher Interview Guide in Table 1 below). The interview guides were reviewed by KS and CT. Interviews ranged from 30-60 minutes and were either conducted online or over the phone. The interview questions were open-ended, and probes

were used to illicit further information as needed. The questions mainly focused on what methods are currently being used to conduct KMb in the ISR, what KMb challenges have been experienced, and recommendations for future KMb.

Part of the research process included asking participants to share examples of effective KMb products. The purpose of this was to provide the researchers with more community and project context to understand what aspects of KMb are effective to translate the recommendations and learnings in a way that is more reflective of the experience of the participants. These products were reviewed by MMN and were cross referenced throughout the coding process to provide more context to the examples of KMb given by participants.

The qualitative interviews with key informants were conducted by MMN and transcribed by a confidential transcription service. The transcripts were all reviewed once by MMN to familiarize with the data and correct any errors in the transcript. The transcripts were then coded by MMN in NVivo® version ¹⁴ qualitative analysis software using Braun and Clarke's reflexive thematic analysis approach. ³⁵ MMN coded inductively for the first round. The initial codes were then searched for broader level themes. These themes were reviewed by MMN at the level of the coded data extracts and at the level of the entire data set. Through this process, the codes were refined into core themes and sub themes, which were reviewed by KS. The interviews were then coded in a second round based on the framework of core themes and subthemes, which were further refined and reviewed once more by KS.

The final themes and their relationships were summarized into a Figure 2. Figure 2 was based on a synthesis of the core themes and how they interacted with one another based on a thematic map created in the process of refining the codes.

RESULTS

Semi-structured interviews were conducted with key rightsholders (n=9) who have been involved in previous projects regarding food sovereignty and climate change in the ISR, most notably the CIHR-funded team grant project called C4FS: Community Capacity for Climate Change and Food Security Action in the NWT. ³⁶ There were eight interviews, as one was a group interview and included two participants working together on a project. The key rightsholders included seven researchers, one territorial nutritionist, and one community leader who is also a researcher. The participants either worked for, with, or in communities in the ISR. At the time of the interviews, several participants (n=4) lived in communities in the ISR including Inuvik, Paulatuk, or other communities in the NWT. The other participants (n=5) do not live in the ISR but have worked with communities in the ISR for over five years. The participants were primarily non-Indigenous, but we did not ask participants about their identities. The participants specialized in a variety of different areas related to food sovereignty and climate change including: food and water security, community climate change adaptation, nutrition, environmental monitoring, aquatic biology, biomonitoring, community food programming, and school programming.

The participants described the core of KMb in the ISR as the process of relationship building and effective communication, with one supporting the other, and vice versa. Supporting this core of KMb was having community and research team

capacity and an understanding of historical and ongoing harmful research informed by colonial practices. Emerging from these supports and core elements, was the uplifting of community voices and actioning of knowledge to improve programming and policy. These five final themes and their relationships are shown in Figure 2. It became evident through this process that two of the core themes were strongly co-related and the other core themes were an essential foundation for the final core theme.

Effective Communication

Several participants described the open, transparent, reciprocal, ongoing dialogue as integral to effective KMb. There were several key rightsholders with whom effective communication is fundamental for KMb. This included communication within and between communities, and within and between research teams. Key rightsholder communication also included regional governing bodies such as the IRC, HTC's, policy decision makers, and the federal government.

Participants described frequent feedback and engagement from the community as a sign of doing KMb well. Effective KMb is conducted in a space of open communication and is founded upon strong relationships and trust between the community and researchers built prior to the start of the research project. Among participants, constant iterative feedback from community and community partners was built into the research process itself as a general norm or expectation.

“From my experience just working closely with the community and working with community partners all throughout the research, it's just embedded in the process. So... in that way... there weren't really any challenges or big changes that needed to be made, just because we were working closely throughout the process from start to finish.”
(Participant 3)

Academic deliverables such as peer-reviewed publications were one aspect of how information from co-designed research projects was translated to community. Drawbacks to communicating community research findings through peer-review publications were that they are not engaging and it takes a long time for the results to be returned and acted upon. Researchers are moving away from academic deliverables towards more creative, engaging, succinct KMb outputs such as one-page infographics, videos, podcasts, graphic illustrations, presentations to community, plain language summaries, and accessible academic writing for general audiences. For example, one participant shared a video they made that was shared at a community night that included drone footage of belugas and documented the research process. Another participant shared a diagram that visually describes the Mukluk Logical Model behind a cooking circle program in the ISR. ³⁷

Participants emphasized the importance of culturally appropriate deliverables that have been co-produced and are meaningful and useful to the community. Participants expressed their desire to not only make knowledge accessible, but to use research deliverables to continue foregrounding traditional knowledges and Inuvialuktun terminology and culture. Several participants described how their most valuable and meaningful KMb outputs were solely for the benefit of the community with no academic components whatsoever.

“Or some things that I’ve discussed with other academics or researchers, which is how to foreground Inuvialuktun terminology in various products... like our maps should be probably in Inuvialuktun, which is the major language spoken in ISR. And it’s a conversation that we want to have with our partners in terms of , ‘Do you prefer those terms? Do you prefer the English terms? Which one should come first? How do we bring in more of the ontological elements of Inuvialuit culture into this work and how do we represent that in our knowledge products.’” (Participant 4)

Several participants talked about the importance of having strong communication within the research team and across research teams to avoid duplication of work and ensure all the work is getting done.

Some barriers to effective communication were the high rates of turnover in regional and federal government positions or in elected community boards. Several participants discussed the gap in communication between the community and policy decision makers in the NWT and federal government. Raw data has been collected by the community on food insecurity and food costing in the ISR, but the federal government has not been using this information to make changes to policy that could improve food security in the ISR. This is a barrier that needs to be addressed in order to properly action knowledge.

“I think the other issue is that there’s high turnover in a lot of government positions, especially in the north. And by the time you’ve built to this great... positive flow of information between communities and researchers and decision-makers and knowledge users... often the people in those government positions... they’ve transitioned to a different department or region or role. And that is difficult, very, very difficult. And I see that happen at all levels from federal to regional governance” (Participant 9)

Relationship Building Process

Several participants discussed the goal of KMB as the process of relationship building. While KMB has previously been described as a product or a tool, the participants in this study described it more as a process of having a discussion in which everyone feels comfortable providing honest feedback and through this process, the most pertinent questions and issues will emerge. This discussion needs to occur with all of the key rightsholders in the same room, most importantly, community members and leaders with lived experience of fighting for food security.

“...I think effective knowledge mobilization is a process. It is that dialogue and that bidirectional flow of information from people that have lived experience of the issues towards researchers, towards policymakers and I think when that information is flowing freely and the questions can emerge organically from that process. Yes, I wouldn’t see it as a final endpoint. I think it’s more so when there’s those relationships of trust that are established and that together we can work to generate information that serves as the betterment of the living conditions in the communities.” (Participant 9)

The participants described how the community is living reality of what it means to adapt to climate change and to food insecurity. Therefore, members of the community have traditional knowledge that will determine the highest quality questions, from which the most valuable solutions will come from. Hence, it is through relationship building and dialogue between community members, leaders, researchers, and policy makers that the most relevant research questions will emerge that can then be addressed.

“For knowledge mobilization for climate change and food security is just proper raw data collecting, because you can’t get any better quality answers out of what you’re looking for... I believe we build a really good foundation for any group to work off of, because we know the problems, we are trying to find solutions. And this is all data collected from the public. And they’re living reality... they adapt, then they’re very resilient people. But this is – and this is where we get the traditional knowledge that comes in to help with data knowledge mobilization.” (Participant 2)

Recognizing Colonial and Research Harms to do Good KMB Moving Forward

Participants acknowledged the harms that Western research has had on Indigenous communities, and some provided specific examples of how this has happened in the ISR specifically.

“Historically Western science and “research” has been often single disciplinary, Western science-oriented, hegemonic, not involving other ways of knowing. And really looking at knowledge production as a process of the researcher going somewhere and taking that information and taking it back for their own purposes.” (Participant 4)

Several participants described themselves as outsiders to community who do not have a full understanding of cultural norms and procedures. Some participants acknowledged how research is still benefitting them as Western researchers to this day, and to be mindful that communities in the ISR need to benefit at least equally, if not more, from the research being done in the ISR.

“...we’re really in a privileged position and I think we have to constantly remind ourselves of that and recognize that we’re outsiders coming in and we don’t fully, can’t fully understand the context, the world view, all of the different pieces of the puzzle I guess. Or potential triggers that in our research might be triggering somebody because of a past experience or ... or for some other reason... we have to remember our role and... recognize when we need to pull out or pull back or get out of the way.” (Participant 8)

Several participants described the goal of KMB as privileging the voices of people with lived experience. Participants emphasized that initial engagement, co-production, and participatory research is essential because it ensures that community questions and issues are being answered and addressed. Effective communication and relationship building are essential to actively ensuring that future harms to

communities in the ISR are not committed in the process of doing research, and that KMb done by and with communities in the ISR can continue to be done in a good way.

“When you listen to the people and use their knowledge, then you get a better accurate way of finding solutions to what they need, instead of doing research, and then...I don’t know if you call it manifesting an outcome. But if you just say, “OK, I’m going to do it this way no matter what the people say, and this is my solution to your problem,” it’s not going to work. You need to use the information from the public to get something that will work for them.” (Participant 2)

Actioning Knowledge

Participants discussed several ways in which traditional knowledge from the community on climate change and food sovereignty has and should continue to be mobilized. First and foremost, the knowledge generated through co-production and participatory research needs to be given back to the community. Several participants discussed the importance of using the knowledge to improve programming and services in the community, by combining research knowledge with traditional knowledge. For example, finding ways to utilize country foods more in programming. Effective KMb came back to strong communication between partners and community that ensures knowledge is getting fully implemented as partners with the appropriate resources and tools come together.

Several participants emphasized the importance of using KMb to inform territorial and federal government policy. Participants discussed how data collected by community for community is very policy relevant and that there are areas in which relatively simple changes to government policy could make a big difference in food security in the ISR. Proactively involving policy decision makers into the conversation earlier and throughout the research process may be a way of actioning knowledge more effectively in the future. Additionally, continuing to provide evidence of the cost of not addressing these issues that are remediable by policy changes is also a future area of focus.

Having Capacity

There are many community priorities that come before research. Recognizing the pre-existing commitments of the community members, researchers, and partners is important to maintaining a sustainable KMb process. Participants described how when unforeseen circumstances have arisen, being flexible and adaptable was a critical skill for doing proper KMb. Communicating within the team and recognizing when people are at their capacity with projects is very important. Participants again recognized the need for constant, transparent, ongoing communication to avoid fatiguing local partners.

Participants frequently discussed how conducting quality KMb with a good process and quality deliverables is very costly and time consuming. Co-presenting and traveling to all communities for dissemination, while essential, takes time and requires significant funding. Building time into the research ethics and funding process is critical for successful KMb. For masters and PhD students, time and resources was a significant challenge as academic timelines do not always align with community timelines. Scoping the project beforehand is critical to determine what a realistic and

sustainable project would be. For researchers in longer term positions, developing strong project management skills and effectively mobilizing a team were very important to conducting quality KMb.

“...there is a significant amount of work that’s expected of you in terms of – especially working in a remote northern and Indigenous community and so finding the balance of getting the outputs that you need for your project, to get your degree. And then also being able to give that information back in a way that’s a nice package with all the information is sometimes a challenge when you know you’re only expected to do one thing... I think a lot more work goes into good research that happens in the north.” (Participant 1)

Finally, having a transdisciplinary team with a diverse skill set that includes those who have a strong relationship with community and experience with co-production was another factor that enabled strong KMb.

Overall, there was a sense that the KMb process and deliverables in the ISR have changed over time. Importantly community outputs are now becoming equally, if not more valued, than academic outputs. The deliverables themselves have changed from more traditional project reports and peer-reviewed publications to more easily digestible, creative, and engaging outputs. More time and funding is being built into the research and ethics process to do KMb. Policy is starting to reflect the data being collected, analyzed, and disseminated by community. Despite these positive changes, there is a desire to continue building up KMb. There was a general consensus that KMb is moving in a good direction. However, it is important to remember that this is coming from researchers and community leaders that have been working in the ISR, but many of whom are not living in the ISR and do not have lived experience of food insecurity.

DISCUSSION

This study aimed to describe KMb goals, tools, successes, challenges, and recommendations in the ISR according to key rightsholders. The key goals of KMb in the ISR include building relationship and trust between community and researchers, addressing community questions, and improving community food sovereignty through programming and policy that incorporates country foods and knowledges. Building strong relationships and maintaining open communication were both foundational goals and essential tools for KMb. Strong relationships, engagement, and feedback from the community was described not as a success, but rather as sign of doing effective KMb; an indication that the chosen research questions were relevant to the community. Challenges to KMb included academic deliverables and timelines not aligning with community deliverables and timelines that limited the ability of time and funding available for meaningful collaboration. Challenges or considerations for Western researchers also included being outsiders lacking complete understanding of community protocol and/or social and cultural norms and historical and ongoing Western research practices that have harmed communities. Recommendations for future KMb included involving policymakers earlier, using social media more effectively, communicating intentionally about research team capacity, and considering how to incorporate more Inuvialuktun language and culture into KMb. Building strong relationships was a key finding and consistent with the literature. The study by Flynn and Ford (2020) on KMb

in the Arctic, also identified strong relationships as key to effective KMb. ¹⁹ This finding aligns strongly with previous international systematic reviews on the principles of KMb and health evaluation in Indigenous contexts that identify building collaborative relationships and trust between researchers and community as simultaneously a goal, tool, challenge, and recommendation, integral to effective KMb. ^{18,27,38,39}

One of the most significant challenges identified in our study was managing the time and funding required to develop strong relationships with community members. Graduate students found it challenging to scope projects given limited time to create meaningful community deliverables. Participants who were in project-lead roles, were challenged by effective time management, and team management, skills they had never officially been trained for in academia, but that were an essential part of their KMb work.

Being mindful of community capacity was discussed but community research fatigue did not seem to be an immediate concern in the ISR. Participants in our study discussed how a uniquely large number of research teams do work across the six communities of the ISR. While the ISR is relatively small in terms of population, a cohesive team may also be what allows researchers and communities to communicate more effectively about their collective capacities and adjust accordingly.

High turnover of government and community board positions at the community, regional, and federal levels was also discussed as a significant challenge in KMb in the ISR. Participants described working closely with local community partners on language and communication throughout the research process which meant that mistranslation was not as much seen as a challenge but as a reality. Navigating whether, when, and how to integrate IK into Euro-Western Arctic research in a way that highlights the value of IK, but that does not 'other' or 'orientalize' IK seemed to also be something that participants were actively wrestling with and were incorporating part of the continuous dialogue process. Limited internet bandwidth in Arctic communities, ¹⁹ and inequity in research database access due to limited computer literacy or availability in communities ^{28,29} were not discussed by our study participants. This may be because access to internet in the ISR has been improving with many community members and researchers now having access to Starlink which provides internet to remote communities using satellite connection.

Our study combined some of the concepts around colonial research harms and the implications for KMb that were discussed separately in the Flynn and Ford study. ¹⁹ For example, in the Flynn and Ford study, the 'Including different knowledge systems' section discussed holistic methods of inclusive knowing and continuous consultation with community participants that centred community priorities and challenged the ongoing dichotomies in Western scientific research that place Western knowledge above Indigenous ways of knowing and doing. ¹⁹ The 'Reconcile research' section discussed power imbalances in academic research as a result of the colonial history, and that non-Indigenous researchers need to recognize when to take a step back. ¹⁹ The 'Acknowledging the value of KMb' section discussed the challenge of academic research institutions and funding agencies in the arctic research context not placing enough value in KMb or broader community impact, but rather the 'scientific' or 'intellectual merit'. ¹⁹

Similar topics arose within this study, however, they were

more often contextualized back to their colonial Euro-Western science-oriented origins and were all seen as different manifestations of the same issue. Several participants identified how historical and ongoing impacts of colonial research practices led to them benefitting from research as non-Indigenous researchers living outside the community. Participants then acknowledged the challenge of academic institutions not placing equal value in meaningful community products and academic outputs, which occurs as a result of contemporary research being dominated by Euro-Western values, and evidence hierarchies. ⁴⁰ Participants then not only recognized these colonial harms, but their resulting obligation as researchers to advocate for the use of KMb to uplift the voices of the community so that the issues impacting them can be effectively addressed. Our participants also recognized that when and where appropriate, research was able to provide space and opportunity for community to share traditional knowledges, culture, and languages within, across and outside of communities. Participants seem to feel that KMb was moving in a good way, but wanted to continue in a reflective way, constantly linking previous research harms to their ongoing impact. This included drawing attention to the role KMb has not only to 'reconcile' or restore relationships damaged by research, but to uplift and give back to community by continuing to highlight the value of community outcomes and deliverables that strengthen community and go much further and deeper than 'scientific' or 'intellectual' merit.

LIMITATIONS

The first author, MMN, is a settler of mixed Canadian Japanese heritage, who does not live in the ISR and therefore does not have a full understanding and experiences of Inuit knowledge and culture. This may have limited MMN's ability to fully understand the context of KMb challenges in the ISR. This project focused on researchers and community leaders who have been working with communities and Inuvialuit in the ISR for many years, and experience with KMb products from their research-community collaborations, but do not all have lived experience with food insecurity and northern climate impacts. Future studies on KMb in the ISR should include more community members, and co-developers of KMb that have lived experience of fighting for food sovereignty to determine how the goals, challenges, successes, and recommendations for KMb differ from the perspective of primarily non-Indigenous researchers.

RECOMMENDATIONS FOR FUTURE KMB

Our participants generally did not state recommendations for how to do KMb 'better' in the future. There was more of a collective vision of the good direction the participants felt KMb was going and what aspects of their work were helping to create this. This collective vision including thinking more about collective team and community capacity, involving policy decision makers earlier in the research process, utilizing more creative, engaging forms of KMb such as social media, podcasts, and video, advocating for research to be evaluated and assessed based on its own merits, and more formal evaluation of KMb.

As researchers doing food sovereignty work in the ISR across six different communities at several different academic institutions, being a coordinated, cohesive team that supports each other and gives each other energy to do this work was an important part of the collective vision for future KMb. Participants also wanted to continue the practice of inclusive, transparent approaches to research that are intentional about involving policy and practice decision makers in regular

status-update meetings about the issues community members are evoking.

Participants recognized that academic research funders, reviewers, and evaluators are starting to place more value in KMb and community outputs, but that there is still work to be done. For example, the Declaration on Research Assessment (DORA) for scientific research acknowledges the problems with basing funding and hiring practices on Journal Impact Factors, and other journal metrics, assessing research on its own merits rather than on the journal, and exploring new indicators of impact.⁴¹ Our participants saw part of their goal of effective KMb to be advocating for changes in research evaluation and funding priorities in the future.

One recommendation from the Flynn and Ford literature review component was the importance of formal KMb evaluation that is currently not common in Arctic research¹⁹. The same was true for this study. Our participants seemed to feel that the constant, interactive feedback process was adequate, and that formal evaluation would be beneficial, but was not necessarily feasible, given the barriers. One participant in this study stated formal evaluation was beyond the capacity of an undergraduate thesis like this one, having the potential to be a whole other study in and of itself. If feedback and continued engagement is done throughout the entire research process then perhaps formal evaluation is not as necessary. However, there are a few examples of community based evaluation of KMb in northern Indigenous communities,⁴² and urban Indigenous communities in Ontario,⁴³ and in Aboriginal and Torres Strait Islander primary health care, in so-called Australia⁴⁴ that allowed for significant learnings for future KMb processes. Evaluation of the KMb process by community-defined measures of success, may be an important tool of future use for improving future KMb.^{16,19}

CONCLUSION

Our study identified five core themes on effective KMb in food sovereignty and climate change-related research in the ISR: Effective Communication, Relationship Building Process, Recognizing Colonial and Research Harms to do Good KMb Moving Forward, Actioning Knowledge, and Having Capacity. These core themes aligned closely with previous research on KMb for climate related research in the Canadian and American Arctic more broadly.

This study showed that KMb in the ISR is fundamentally relationship-based and relies on strong communication and collaboration. Additionally, this study provided a focused insight into what KMb looks like in the ISR, and what tools are being used to achieve effective KMb. The findings are encouraging and suggest that KMb practices are shifting in a good direction as KMb is continuing to receive more recognition from communities, funders, regional organizations, and policy decision makers. Future research on KMb in the ISR should focus on community members' perspectives of the goals and challenges of KMb. Continuing to build community research capacity, actively uplifting the voices of those with lived experience, being mindful of community and research team capacity, and engaging policy decision makers earlier in the research process are all important considerations for future KMb in the ISR.

ACKNOWLEDGEMENTS

Many thanks to those who took part in the interviews for this study, your insight is greatly appreciated. Funding for

transcriptions was provided by the CIHR Team Grant 'C4FS: Community Capacity for Climate Change and Food Security Action in the NWT' held by nominated principal investigator Dr. Kelly Skinner at the University of Waterloo. Christina Tjandra (CT) advised MMN on the interview questions and methodology at the outset of the project. Christina Tjandra is a Research Associate in Northern Research Knowledge Mobilization at Wilfrid Laurier University. MMN was supervised by KS for her undergrad thesis. There are no conflicts of interest to be declared for this study.

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Research Questions	Interview Questions
RQ 1: What are the KMb goals and what tools are being used to achieve those goals?	<p>Q1: What methods/tools/products have you used to do KMb in community research in the ISR? (i.e., tools used)¹</p> <ul style="list-style-type: none"> • How do you determine what KMb methods/tools to use? • How do you determine who should be involved in the KMb? • What types of KMb are being requested by partners/communities? <p>Q2: Would you be willing to share a physical example of a KMb method/tool/product that you have used, for context? (Can be either effective KMb, or one that needs improvement)</p> <p>Q3: Please describe your role in the most recent KMb initiatives/projects that you have been a part of?²</p> <ul style="list-style-type: none"> • Would you describe your role as developing, designing, facilitating, leading, co-developing KMb, or as something else? <p>Q4: In your opinion, and based on your experience, what do you see as the goals of effective KMb?</p> <ul style="list-style-type: none"> • Why? • Could you provide an example of a KMb method/tool/project, or aspect of a project that you felt was effective/successful?
RQ 2: What are the successes and challenges of the KMb strategies?	<ul style="list-style-type: none"> • What aspects of the KMb method/tool/project made you consider them to be successful? Why? <p>Q5: What are some challenges you have experienced when developing KMb initiatives/projects?</p> <ul style="list-style-type: none"> • What are the most significant or pressing challenges to KMb? • What challenges to KMb do you personally think you have the capacity to change/respond to and how would you respond? • What are other challenges that you feel you don't have the capacity to change? Why?
RQ 3: What are researchers, co-developers, and community members envisioning for future KMb strategies?	<p>Q6: Do you ask for feedback or evaluate your KMb?</p> <ul style="list-style-type: none"> • Why or why not? • If yes, what do you want to know from participants, what kinds of questions did you ask? • If yes, what kinds of feedback did you receive? • If yes, did you follow-up on feedback? • If yes, did you encounter any challenges in responding to the feedback? • If no, why don't you ask for feedback? <p>Q7: Are there any recommendations you have for developing future KMb in the ISR?</p> <ul style="list-style-type: none"> • Are there any tools for KMb that you think could be used more? • Are there elements of inspirational KMb you have seen that you would like to try implementing? <p>Q8: Is there anything else you would like to add that we have not yet discussed?</p> <p>Q9: If there is anyone from the community that you can think of who has experience participating in KMb in food sovereignty and climate change-related research in the ISR, would you be willing to forward the initial study information email to them to see if they would be interested in participating?³</p>

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