
Developing a Research Agenda to Address Stigma of Dementia in Rural Communities in Interior British Columbia

Population Health and Aging Rural Research Centre

PHARR

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PHARR

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Welcome

Dear readers,

I am pleased to present this report on our Rural Aging and Stigma of Dementia Workshop that was held in Kamloops on September 5, 2024. The goal of the workshop was to develop a research agenda to address stigma of dementia in rural communities. The event was highly successful and attended with over 70 participants including rural community leaders, health professionals, policymakers, organizational representatives, students, researchers, people living with dementia and care partners.

The workshop's morning consisted of several different activities including poster presentations, guest speakers, and panel presentations by people living with dementia and care partners. In the afternoon, a World Café approach (<https://theworldcafe.com/>) was held to provide a forum for collective dialogue to discuss critical issues and prioritize actions for moving forward to address stigma of dementia in rural communities. This discussion shed light on the pressing need for collaborative research and lived experience to develop robust and innovative solutions.

This report provides a comprehensive overview of the workshop's activities, as well as findings from the World Café styled forum. During the forum, participants engaged in collaborative dialogue to identify research priorities and actions to address issues related to rural aging and stigma of dementia. We believe that this report will be a valuable source of information for policymakers, health professionals, community leaders, and people with lived experience interested in addressing stigma of dementia in rural communities.

We also included quotes from attendees during the World Café forum that emphasize the importance of enhanced dementia awareness, education, and collaboration. Participants shared how the workshop motivated them to engage in action, whether through education, networking, outreach, or individual growth. In particular, student participants expressed how the workshop inspired them to consider advancing their studies in dementia research.

We hope that this report resonates with you, and fuels continued conversation and partnership building to address stigma towards people living with dementia. Together, we can make a difference to address stigma of dementia.

Best wishes,

Juanita

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Executive Summary

Stigma of dementia is one of the greatest challenges for people living with dementia. Dementia-related stigma can lead to poor mental health, social isolation, and a decreased quality of life. Myths, stereotypes, and false information all contribute to stigma of dementia.

Rural older adults experience unique challenges to accessing dementia care, compounded by limited public transportation, financial restraints, education, and geographic distance. However, documenting these challenges alone does not provide workable solutions; addressing dementia-related stigma requires lived experience and collective input. Only through collaborative partnerships and lived experience can we develop innovative solutions to address stigma of dementia in rural communities.

This report shares findings from a workshop on rural aging and stigma of dementia that was funded by the Michael Smith Health Research BC, 2023 Convening and Collaborating (C²) Fund. Drawing on a World Café approach (<https://theworldcafe.com/>), this project aimed to develop a research agenda to address stigma of dementia in rural communities. This report provides a comprehensive overview of the workshop's activities as well as the actions identified to move forward in reducing stigma of dementia in rural communities.

Purpose

This project's purpose was to support collaboration and knowledge exchange between researchers and research users to identify research priorities to reduce stigma of dementia. Our objectives were to: i) develop a research agenda to identify action areas to reduce stigma of dementia; and ii) support knowledge exchange and dissemination on rural aging and stigma of dementia.

Our project aligns with the C² Program's purpose by promoting knowledge exchange and collaboration and by supporting researchers and research users in collectively developing a research agenda to address dementia-related stigma in rural communities.

The Workshop Agenda

Developing Research Agenda to Reduce Stigma of Dementia in Rural Communities:

Planning and Partnership Development Workshop

September 5, 2024

Sandman Signature Hotel - Kamloops, British Columbia

- 9:00 am - 9:30 am **Registration and Breakfast**
- 9:30 am - 9:35 am Introduction - Juanita-Dawne Bacsu
- 9:35 am - 9:50 am Elder Welcome and Land Acknowledgement – Elder Colleen Seymour
- 9:50 am - 10:00 am Overview of Morning – Heather Neale Furneaux
- 10:00 am -10:25 am **Care Partner Panel: Rural Stigma of Dementia**
- Jennifer Morrison, Tammy Kotyk, Sherry Carroll
- 10:25 am - 10:55 am **Coffee break and Poster Viewing**
- 10:55 am - 11:00 am **Panel Introduction**
- 11:00 am - 11:25 am **Lived Experience Panel: Stigma of Dementia**
- Myrna Norman, Jim Mann, Christine Aiken
- 11:25 am - 12:00 pm **Table Reflections on Panel and Report Back**
- 12:00 pm - 12:50 pm **Lunch Served** (Poster Presentations 12:30- 12:50 pm)
- 12:50 pm - 1:05 pm Alzheimer Society of B.C. and Importance of Addressing Stigma of Dementia - Kim McKercher
- 1:05 pm - 1:15 pm Overview of **World Café Methodology** – Heather Neale Furneaux
- 1:15 pm - 2:45 pm Small Group Deliberations and Moving Tables
- 2:45 pm - 3:05 pm **Coffee Break** (Poster Sessions)
- 3:05 pm - 3:40 pm Facilitated Discussion Summarizing Research Priorities – Juanita-Dawne Bacsu
- 3:40 pm - 3:45 pm **Wrap-Up and Evaluation Forms** – Juanita-Dawne Bacsu

Knowledge Synthesis Poster

Marie Bartlett, a visual graphic design artist, created a knowledge synthesis poster to capture the knowledge transfer and exchange as individuals shared their thoughts, ideas, and experiences surrounding dementia-related stigma.

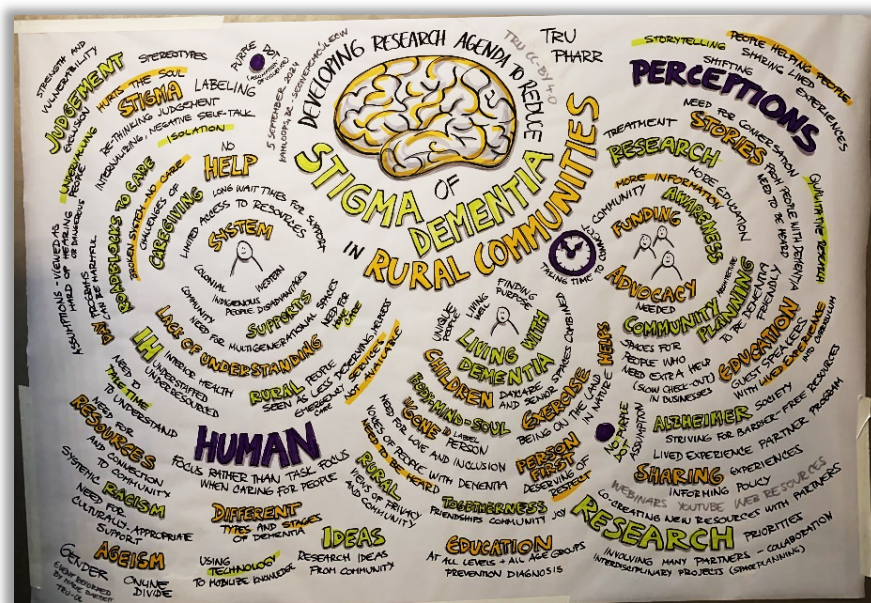


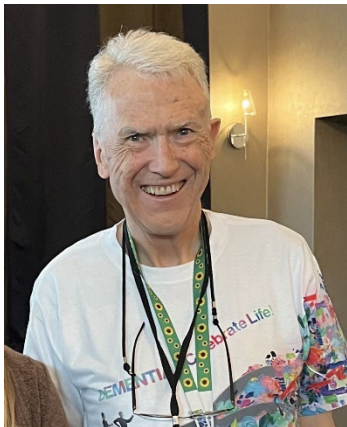
Photo: Marie Bartlett standing next to knowledge synthesis poster.

Panelist Speakers

People Living with Dementia



Myrna Norman was diagnosed with Frontal Temporal Dementia in 2011. Following her diagnosis, Myrna took up the cause of dementia advocacy and attended the Dementia Strategy Conference in Ottawa. She now speaks for the Purple Angel Ambassadors and is a member of the Alzheimer's Society of British Columbia's leadership council. Myrna is driven to educate others on how those who have dementia can enhance their quality of life and live well with dementia. In June 2020, she joined the CCNA's Engagement of People with Lived Experience of Dementia.



Jim Mann is living with Alzheimer's and is a dementia researcher and published author who focuses on issues of consent, ethics, and quality of life. Jim was co-chair of a Canada-wide advisory group through the Alzheimer Society of Canada that led to the development of an ethical framework and a resource guide for engaging people living with dementia in meaningful research, which led to the development of the Canadian Charter of Rights for People with Dementia. Jim has had a significant impact on decreasing the stigma associated with dementia and raising awareness of the fact that individuals living with the illness may still meaningfully contribute to their communities. He focuses on reducing the stigmatism surrounding these diseases. Jim was awarded an honorary Doctor of Law degree in 2020 by the University of British Columbia for this work.



Christine Aiken is an author and advocate for people living with dementia. She was diagnosed with vascular dementia at the age of 55. Christine is a board member of Dementia Alliance International and a member of Dementia Advocacy Canada. Her newly published book "For this I am Grateful," living with dementia, delves into her life and all things she enjoys. She is well-known for her positive attitude and her sense of humour. Christine developed and taught a course on end-of-life care and dementia care for nursing students at local colleges. She also created a program on unattended sorrow, focusing on all the deaths the workers witnessed and their cumulative effects. She also has a blog called "Chrissy's Journey," where she discusses life after diagnosis.

Panelist Speakers

Care Partners



After the loss of her mother, Sherry Carroll is a community advocate for individuals with dementia and their care partners. She helps others facing similar struggles. Sherry organizes support groups for those dealing with loss, creating a safe space for sharing and healing. Her compassion drives her to advocate for mental health resources in her community, ensuring no one feels alone during their most challenging times.



Tammy Kotyk is a devoted daughter managing the care of both of her parents, who are living with dementia. Tammy advocates for better care options and resources for families affected by dementia, emphasizing the importance of understanding and compassion in caregiving. She educates others on effective communication strategies and self-care practices through local workshops.




Jennifer Morrison is a wife and caregiver to her Nlaka'pamux Elder husband, who has dementia. Jennifer brings both expertise and empathy to her caregiving role. She creates a structured and supportive environment at home, incorporating daily routines that help her husband maintain a sense of familiarity with the land and respects his cultural integrity as an Elder living off reserve. Through her advocacy work, she strives to raise awareness about dementia and the challenges caregivers face, emphasizing the need for cultural and community support.



Poster Session

The Rural Aging and Dementia Workshop provided attendees, including people with lived experience, policymakers, health professionals, students, and researchers with the opportunity to share research, network, and learn about current studies on rural aging and dementia.

 **Understanding Stigma of Dementia during COVID-19: Implications and Mitigation Strategies**

Juanita-Dawne Bacsu¹, Kate Nanson¹, Chantelle Stone¹, Zahra Rahemi², Myrna Norman³, Claire Webster⁴, Raymond J. Spiteri⁵

¹Thompson Rivers University, ²Clemson University, ³Engagement of People with Lived Experience of Dementia (EPLD), ⁴Caregiver Crosswalk, ⁵University of Saskatchewan

INTRODUCTION

- Stigma is one of the greatest barriers for people living with dementia.
- However, little discussion examines stigma of dementia during COVID-19.
- This presentation aims to: 1) identify the implications of dementia-related stigma in the COVID-19 pandemic; and 2) describe mitigation strategies to reduce stigma of dementia during the pandemic.

METHODS

- Guided by Arksey and O'Malley's (2005) scoping review framework, a review was conducted to examine literature from Jan. 2020 to Jun. 2023.
- Electronic databases searched included: CINAHL, EMBASE, Google Scholar, Medline, PsycINFO, and Web of Science.
- From the 278 records, fifteen articles met our inclusion criteria.

RESULTS Implications of dementia-related stigma consisted of 4 themes


Ethics and human rights issues (confinement, elder abuse, isolation, understaffing, and overmedication)	Cultural inequities and racism (institutional discrimination and racism)	Inequitable access to health services (acute care, and life-saving resources)	COVID-19 stereotypes (highly vulnerable, suffering, and near death)
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DISCUSSION

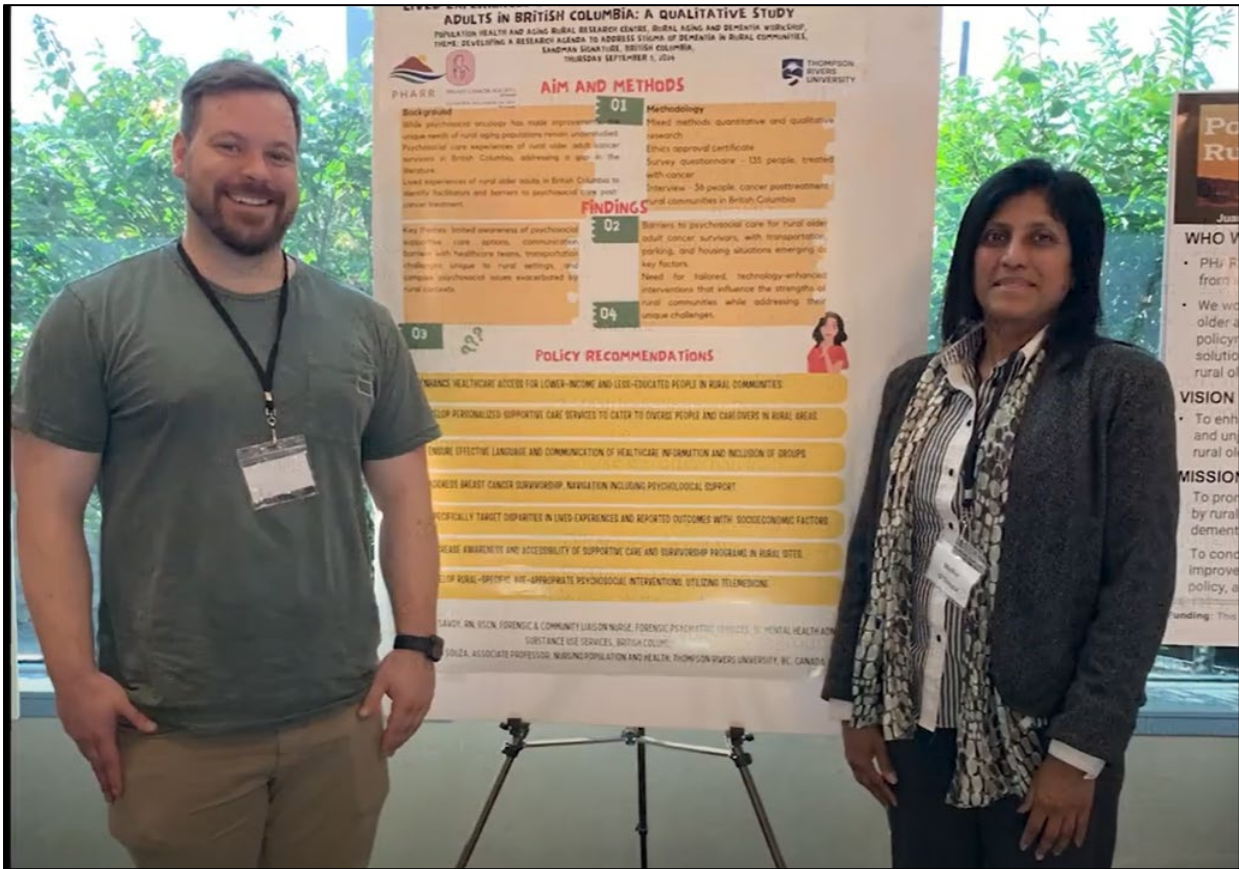
- Although articles described implications of dementia-related stigma, only a few articles identified strategies to reduce stigma.
- Further research is needed to develop, implement, and evaluate strategies to address stigma of dementia during the pandemic and beyond.

References: Arksey, H. & O'Malley, L. (2005). Scoping studies: Towards a methodological framework, *International Journal of Social Research Methodology*, 8, 19-32.

Funding: This work was supported by the Canada Research Chairs Program.



Poster Session



Juanita-Dawne Bacsu, Melba D'Souza, Claudia Gonzalez, Wendy Hulko, Mark Rakobowchuk, Stephanie Victor & Anila Virani

WHO WE ARE

- PHARR Centre is a diverse group of researchers from a variety of disciplines and faculties.
- We work with rural community leaders, clinicians, older adults, people with lived experience, and policymakers to develop community-informed solutions to support the health and wellbeing of rural older adults.

VISION

- To enhance the health equity (unfair, avoidable, and unjust differences in health outcomes) of rural older adults.

MISSION

- To promote community-driven research informed by rural older adults, including people with dementia and care partners.
- To conduct population health research to improve rural aging at the individual, community, policy, and societal levels.

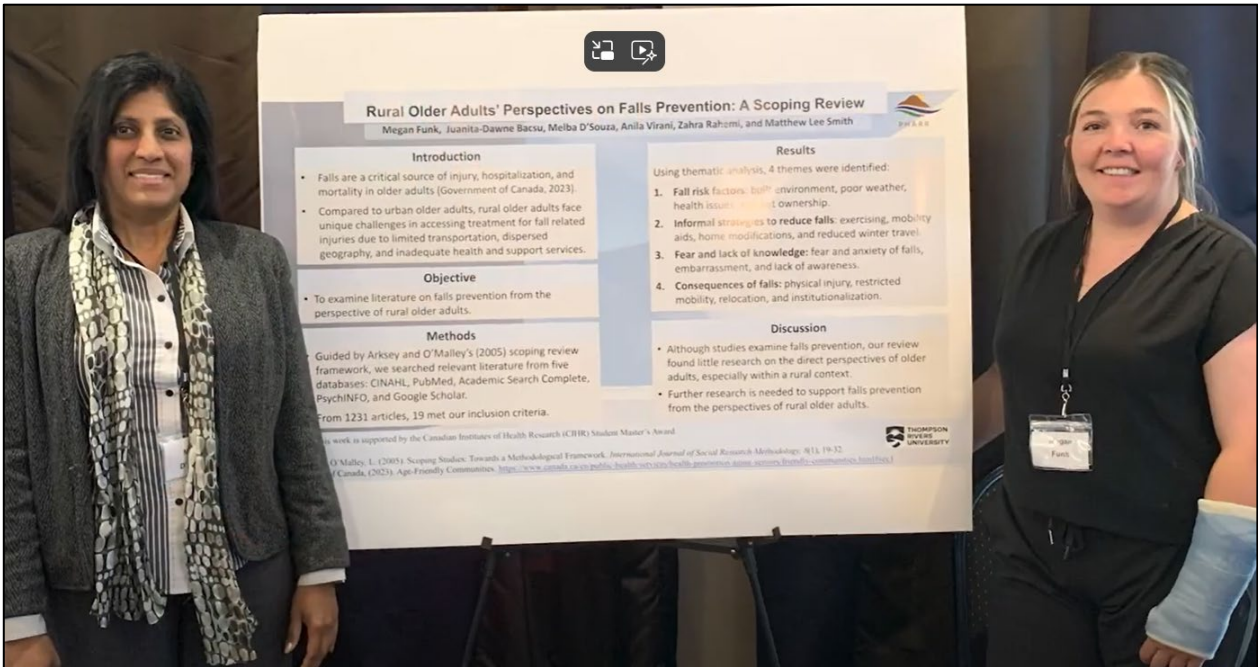
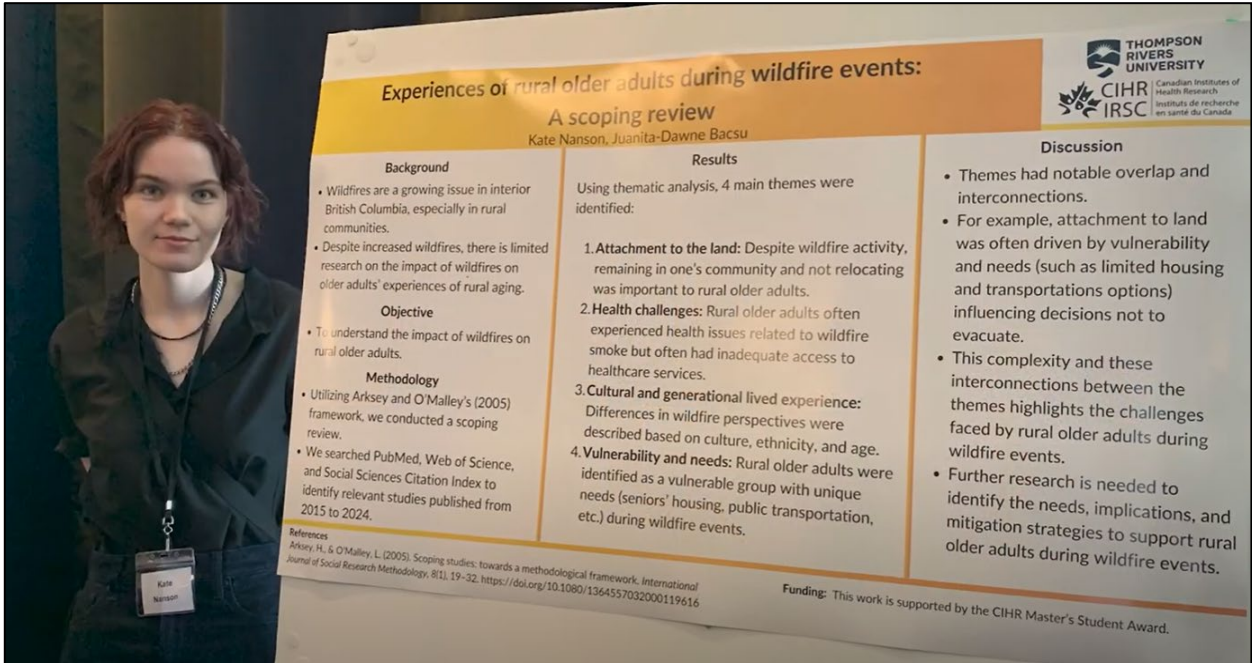
FOUR RESEARCH AREAS

- **Rural Aging in Place and Dementia Care:** Improving independence and healthy aging for rural older adults including older adults with dementia.
- **Cognitive and Physical Health:** Enhancing the cognitive and physical health of older adults living in rural communities.
- **Navigation of Health and Support Services:** Addressing knowledge needs and access to information on health and support services.
- **Stigma and Social Ex/inclusion:** Addressing issues of stigma and social ex/inclusion of older adults.

KNOWLEDGE TRANSLATION

- We believe that knowledge translation and effective communication of research findings are critical for translating research results into action.
- PHARR Centre's KT strategies include our biannual newsletter, community workshops, and website - <https://pharr.trubox.ca>.

Poster Session



World Cafe Methodology



A World Café session was held in the afternoon of the workshop. The World Café method (www.theworldcafe.com) is a collaborative approach used to foster collective dialogue and insight. It involves 4 main steps with a facilitator to oversee the café discussion:

- 1. Comfortable Environment:** The event is often created to look like a café, with small tables and snacks to create a comfortable atmosphere.
- 2. Small Table Dialogue:** Participants (6-8 people) sit at small round tables to converse about a specific question. Each group spends about 20-30 minutes addressing the question and sharing their ideas.
- 3. Rotating Tables:** After the allocated time, people move tables to collaborate with different participants. A table may have a facilitator and note-taker to support discussion and capture ideas at each table.
- 4. Sharing Findings to Support Action:** Once the small table discussions are complete, all the participants convene in a large group with a facilitator to share findings and create actions for moving forward to address the issue.

The World Café approach fosters partnership-building, collective dialogue, and brainstorming to identify actions for moving forward.

World Cafe Questions

Using the World Café approach, participants discussed three different questions while switching to different tables and exchanging insights with the larger group. The session focused on addressing three research questions:

Research Questions

- 1. How are people with dementia viewed in your community?*
- 2. What Are some common stereotypes and myths about Dementia that you've encountered?*
- 3. hat research priorities/actions do you think could be most effective in exploring ways to reduce myths and stigma of dem*
- 4. entia in rural communities?*



World Café Findings

How are people with dementia viewed in your rural community?

- **Stigma and Fear Surrounding Dementia:**

Dementia is often feared and viewed negatively, with individuals seen as a "burden" and their abilities diminished, contributing to social isolation and stigma. People with dementia often viewed as incapable, helpless, and having no learning capacity.

- *“Negative views of dementia diagnosis – ‘deficit.’”*
- *“Fear of engaging with people with dementia.”*

- **Lack of Understanding and Resources:**

There is a significant gap in education and awareness about dementia, both in the general community and among care staff. This results in insufficient support systems, particularly in rural and Indigenous communities.

- *“Limited dementia awareness and informational resources; lack of understanding even among care staff.”*
- *“Different needs for rural and remote communities; differ in how many neighbors or close communities they have.”*

- **Social Disconnection and Loss of Independence:**

People with dementia often lose social connections and independence, such as their ability to drive or be self-sufficient, especially in rural communities where formal resources are limited.

- *“Friends no longer visit/call due to dementia symptoms – lack of social connection.”*
- *“Losing independence, such as your driver’s license, is a significant loss in rural communities.”*

1. What are Common Stereotypes or Myths about Dementia?

- **Stigma and Misconceptions about Dementia:**

Widespread misconception that dementia equals a “death sentence,” or that life is over after diagnosis, when in fact many individuals can live well with dementia. The focus on memory issues overlooks the wide range of cognitive, behavioral, and physical effects, leading to an oversimplification of the condition.

Issues with misinformation also included assumptions that: dementia only impacts older adults; the assumption that types of dementia are all the same (often equated with Alzheimer’s disease); and the idea that nothing can be done for people with dementia.

- *“It’s a common stereotype that life is over after diagnosis, which is not true. Positivity and the ability to learn hobbies and activities is there which keeps the individual going. There’s lots of life to enjoy.”*
- *“People with dementia can’t do anything.”*

- **Lack of Holistic and Person-Centered Care:**

Care often prioritizes physical health over social, emotional, and spiritual well-being, reflecting a lack of individualized care. People with dementia are infantilized, have their autonomy taken away, and are assumed to be unable to contribute, leading to exclusion from decision-making processes and tasks they are often capable of.

This theme also includes assumptions made about their decline and overlooking the skills they still possess, as well as failing to individualize care to their unique needs.

- *“Prioritizing care tasks rather than social/spiritual wellbeing – lack of holistic view + quality of life, need to follow schedule instead.”*
- *“Doing something for someone because it’s easier and faster, but not because it’s at their benefit. Instead, tasks that the individual feels confident doing need to be prioritized.”*

- **Inadequate Dementia Knowledge and Awareness:**

Care partners, health professionals, and the general public often lack knowledge to understand the complexities of dementia. Inadequate knowledge includes not recognizing the importance of quality of life and balance in activities, healthcare professionals talking across rather than directly to people with dementia, and ageism.

It also includes issues like a lack of recognition of dementia precursors by physicians, overlooking symptoms that overlap with other diagnoses, and a general misunderstanding of dementia’s trajectory.

- *“Lack of knowledge among caregivers – importance of activities + quality of life without being overstimulating – balance.”*
- *“Healthcare providers talking across and not directly to the individual.”*

2. What research priorities/actions are needed to reduce myths and stigma of dementia in rural communities?

- **Education and Awareness:**

A strong need for educational initiatives across all stages of life and involving multiple platforms to increase understanding and reduce stigma of dementia. Emphasis on lived experiences and community involvement is key to breaking down myths.

- *“Education initiatives to increase quality of life (i.e. learn to bus) – hosting free/open access/workshops/webinars/conferences/podcasts.”*
- *“Lived experiences into the curriculum.”*

- **Community-Based Solutions and Support:**

Rural communities often require grassroots, community-driven approaches to dementia care and education. These approaches emphasize informal support networks, neighborhood groups, and building a sense of inclusion and belonging.

- *“Neighbourhood groups – people helping people.”*
- *“Community forum – funding/networking/awareness; compensate caregivers and people with dementia as true co-developers.”*
- *“Educating people in a fun way, such as podcasts to give an individual a platform.”*

- **Personalized and Culturally Relevant Care:**

Need to recognize the diverse contexts of rural and cultural communities, and adjust care and support based on specific requirements. This includes improving the accuracy of diagnoses, offering appropriate home care, and understanding cultural safety in dementia care.

- *“Cultural/ethnic differences in how people with dementia are cared for.”*
- *“Appropriate use of home care – not everyone needs the same amount of help.”*

Moving Forward: Next Steps

We have included a list of next steps to maintain the momentum and build on the insights collected at the Rural Aging and Stigma of Dementia Workshop to support our continued work in moving forward.

- **Workshop Dissemination Video:** Create a video synthesizing the key goals and activities of the workshop to share with attendees, including policymakers, health professionals, organizational representatives, researchers, and people with lived experience.
 - Update: This step was completed. Please visit following link to access the video, <https://www.youtube.com/watch?v=1Wn-SeZYAjg>.
- **Informational Workshop Website:** Develop a website to share informational materials from the workshop including the workshop report.
 - Update: This step was completed and expanded to include a website to share information for the workshop as well as the PHARR Centre, <https://pharr.trubox.ca/>
- **Biannual Newsletters:** Continue disseminating biannual newsletters to share workshop findings, research activities, and upcoming events to keep our partners and broader community involved and informed.
 - Update: The first newsletter was completed and is available at, <https://pharr.trubox.ca/wp-content/uploads/sites/2712/2024/08/PHARR-Newsletter-2.pdf>



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- **Workshop Report:** Create a report to provide an overview of the workshop's activities, findings, and recommendations for moving forward.
 - Update: This step was completed through the publication of this report.
- **Journal Article:** Write a journal article to share the workshop's findings including the world café's recommendations on research priorities and actions reduce stigma of dementia in rural communities.
- **Research Grant Submission:** Identify grant opportunities to secure funding for future projects to build on the workshop's findings to reduce dementia-related stigma and enhance the quality of life of rural people living with dementia and care partners.



Appreciation

Planning Committee

Interdisciplinary Faculty Members

- Wendy Hulko
- Anila Virani
- Florriann Fehr
- Melba D'Souza
- Mark Rakobowchuk
- Claudia Gonzalez

Community Partners

- Heather Cooke, Alzheimer Society of B.C.
- Sarah Wu
- Jessica Clement, Ashcroft Hub
- Sherry Carroll (Lived Experience)
- Myrna Norman (Lived Experience)
- Marc Viger, Orchard Walk Medical Clinic

Student Trainees

- Kate Nanson, MSN Graduate Student, TRU
- Megan Funk, MSN Graduate Student, TRU
- Christine Conanan, MSN Graduate Student, TRU
- Stephanie Victor, BSc Student, TRU
- Dylan Fiske, BSc Student, TRU
- Samantha Lautrup, BSN Student, TRU
- Avery Pottle, Medical School, Queens University
- Adesewa Adeyemi-King, Psychology Student, TRU
- Ashwin Nairy, BSc Student, University of British Columbia



Funding and Support

Thank you for your Support!



CANADA RESEARCH CHAIRS (CRC) PROGRAM

