

Eradicating stigma of dementia through lived experience, education, and research

CCNA Brainxchange

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Presentation overview

Introduction: Harold's story

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Postdoctoral research

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Findings

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Discussion

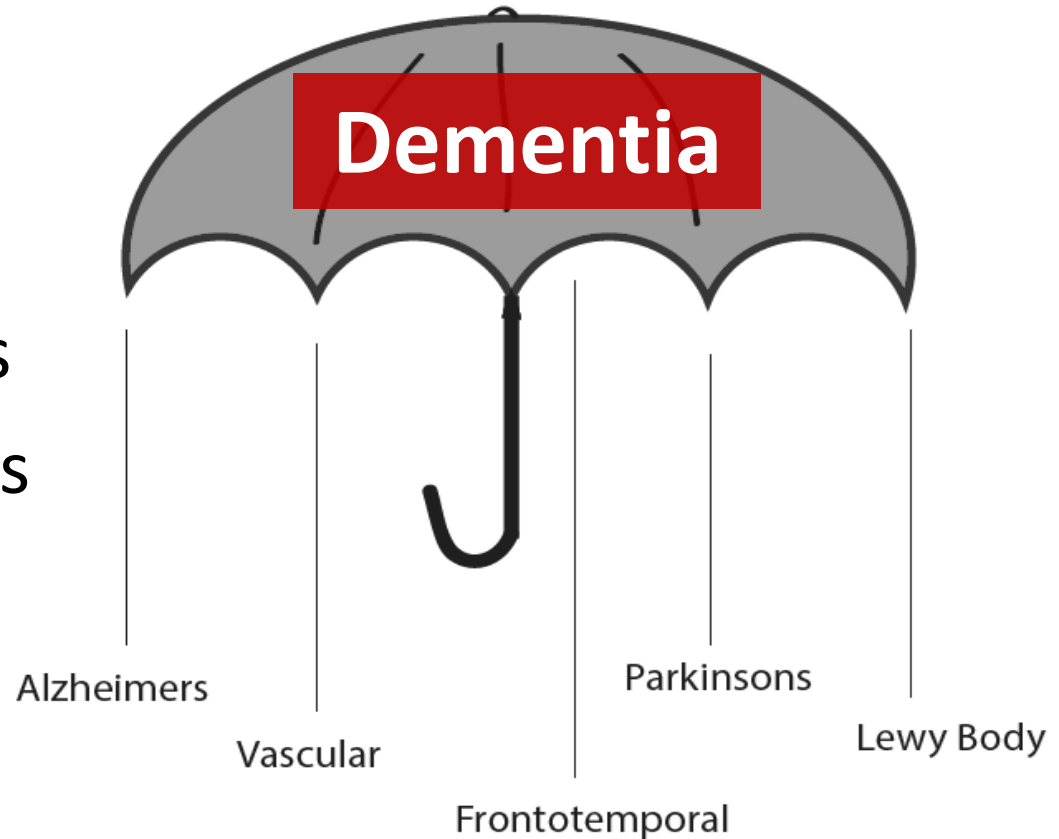
“Harold’s” Story

**I think she has dementia...
but I haven’t told the kids
it’s somewhat of
a taboo topic.**



Background: Dementia

- Overall term for range of symptoms caused by disorders affecting the brain.

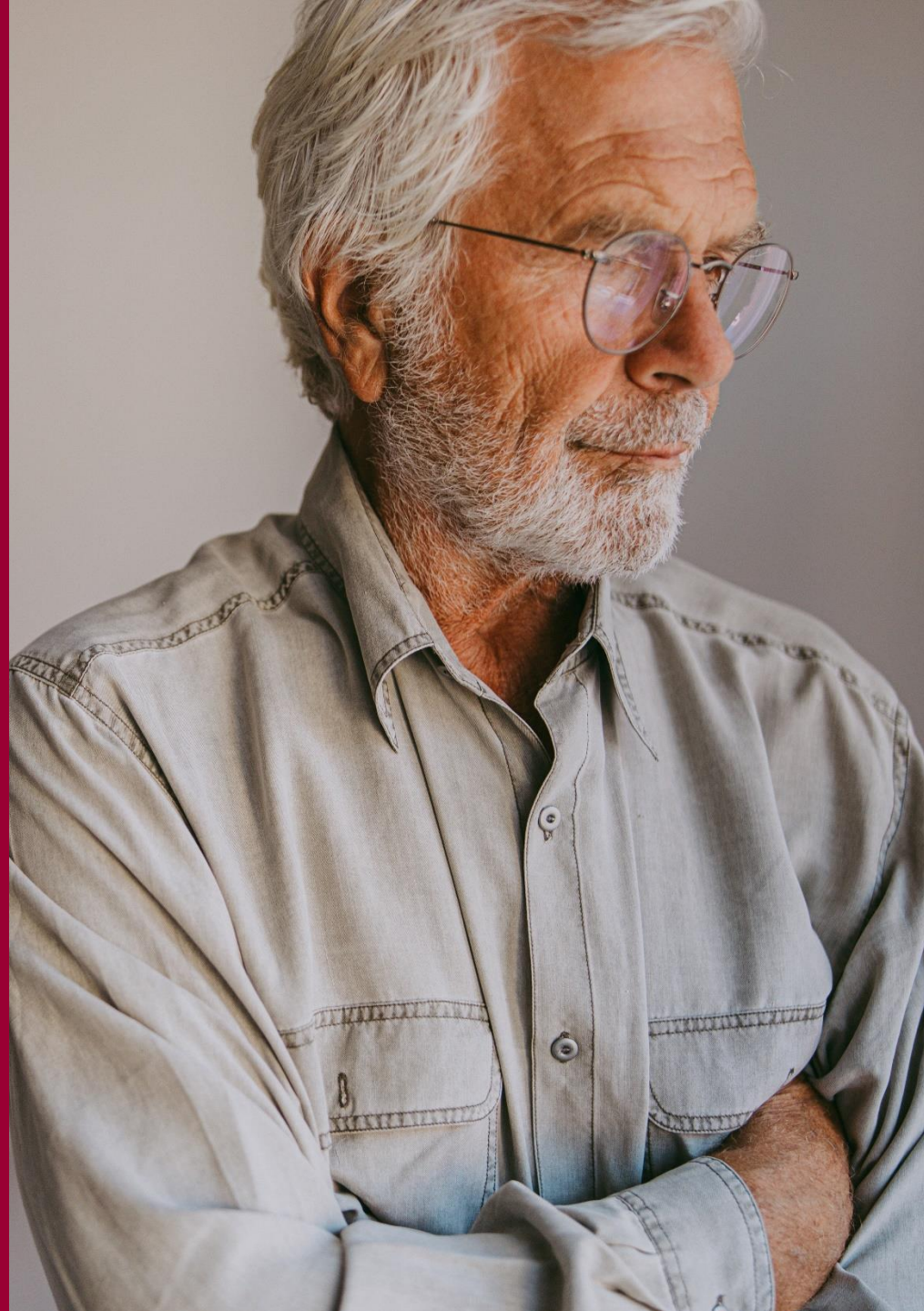


What is stigma of dementia?



Why is stigma important?

- Decreased quality of life
- Social isolation
- Care partner burnout
- Feelings of shame
- Depression
- Delay timely dementia diagnosis.





Research Objectives

1. Understand ways to **reduce stigma of dementia** to improve quality of life for rural people with dementia; and
2. Identify rural older adults' perspectives on actions to **improve attitudes and knowledge** of dementia.

Solutions Focused Theory²

Focus

Focus on capacity-building

Investigate

Investigate what works

Ask

Ask questions rather than give answers

Identify

Identify attainable actions

Community-Based Approach



Community advisory team offered local insight and expertise throughout study.



Provided guidance, helped implement research, and develop communication strategies.

TEAM WORK!!!

Data Collection & Analysis

- **Scoping review** on interventions to reduce stigma of dementia (Bacsu et al., 2022).
- **Interviews** with 18 rural older adults including family, friends, care partners and people with dementia and other types of cognitive impairment.
- **Focus group** with 7 rural community leaders.

Community Workshop



Findings: Take-Aways

1. Talk openly about dementia

“Being open and talking about it would help everybody. It would help me, because I am worried I’m going to get it...”

2. Learn more about it

“Learn ways to be supportive, this would disperse the fear of ‘I don’t know what to say’...”

3. Be a leader

“Share if you are experiencing dementia in the early stages... sharing with someone or a group changes attitudes.”

4. Avoid hurtful jokes

“We sometimes talk about dementia in a joking way, probably because of fear... That’s what I do when I’m scared, I make a joke... People may get hurt by that and have hurt feelings, so you got to be careful.”

5. Be inclusive

“Talk and socialize with people with dementia, don’t shun, talk past, or ignore them... Pick them up, include them, and bring them to coffee row.”

6. Fundraise

“At one time breast cancer was at the same place where Alzheimer’s is now, and it never really got discussed... Fundraising always brings things to the forefront.”

7. Intergenerational programs

“We need to make it so kids understand it. Someday I may get dementia and I want my kids to know about it and to treat me the same way.”

8. Organize a workshop

“Bring information forward... Have a physician or spokesperson come and speak, someone who specializes in aging.”

Sharing Findings

- Developing communication materials to share findings on reducing stigma of dementia.





CARE – Fall 2020 | Eight Ways to Support Brain Health for Rural Older Adults - Issuu

Age is the greatest risk factor for developing ...

issuu.com

Newspaper & Magazine Articles


Journal Articles

Canadian Journal of Public Health
<https://doi.org/10.17269/s41997-019-00241-0>

COMMENTARY



Addressing the needs of rural and remote people in a national dementia strategy for Canada

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Abstract

A number of organizations such as the Canadian Academy of Health Sciences have identified the growing need for a National Dementia Strategy in Canada to improve the quality of life for people with dementia. This commentary highlights the necessity of addressing stigma, social inclusion, and supports for people affected by dementia, specifically those living in rural and remote communities. Drawing on Saskatchewan-based examples, we discuss the importance of recognizing the unique needs of rural and remote communities in developing a National Dementia Strategy for Canada. We believe that a national strategy needs to be built from the ground up and not imposed from the top down. Only through the development of evidence-informed research and collaborative partnerships can we ensure that there is equitable access to services and supports for people with dementia in rural and remote communities.

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Saskatchewan Population Health & Evaluation Research Unit, University of Regina

Covid-19: A Message from our Team

We hope this newsletter finds you safe and well during the Covid-19 pandemic. We are sending positive thoughts and warm wishes your way. These are difficult times, but remember to stay positive and that a smile goes a long way! We hope you enjoy this edition of our Brain Power Newsletter. Take care and stay safe.

Researchers Present at Dementia Care Summit

Our team presented two posters at the 12th Annual Summit of the Knowledge Network in Rural and Remote Dementia in Saskatoon on November 5-6, 2019. The posters shared findings on social isolation among rural older adults, and interventions to reduce stigma of dementia.



Drs. Bonnie Jeffery and Juanita Bacsu

The summit featured presentations by leaders in rural dementia care, including Drs. Debra Morgan and Rachel Herron. Dr. Morgan is the Director of the Rural and Remote Memory Clinic at the University of Saskatchewan and Dr. Herron is the Canada Research Chair in Rural and Remote Mental Health. The summit highlighted recent developments in dementia care in Canada.

Presentation Shares Findings on Dementia and Aging in Rural Communities Study

Marc Viger, Juanita Bacsu and Breanna Reed shared findings at a community presentation in Young on November 1, 2019. The presentation shared findings from the Dementia and Aging in Rural Communities Study. Approximately 25 people attended the presentation including community leaders, older adults, representatives from local businesses, and friends and family members of people living with dementia.



Juanita Bacsu and Breanna Reed

A glowing red rectangular sign with the words "ON AIR" in white, bold, sans-serif capital letters. The sign has a 3D effect with a dark red border and a bright red glow. It is centered on a dark background.

ON AIR

Podcasts

Next steps

Addressing stigma is critical to improving quality of life for people with dementia and their care partners.³⁻⁷

Further research necessary to explore key factors and interventions to reduce stigma of dementia in rural communities and beyond.



Pearl of Wisdom

- What advice would you give to help someone overcome issues of stigma against dementia?

Acknowledgements

- Alzheimer Society of Canada
- Alzheimer Society of Saskatchewan
- Saskatchewan Centre for Patient-Oriented Research
- Canadian Consortium for Neurodegeneration on Aging (CCNA)

For more information on dementia

- **Alzheimer Society of Canada**

- <https://alzheimer.ca/>

- **Mayo Clinic**

- <https://www.mayoclinic.org/diseases-conditions>

- **Canadian Consortium for Neurodegeneration on Aging**

- <https://ccna-ccnv.ca/>

Questions

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