



Dementia, stigma, and rural aging: "It's somewhat of a taboo topic"

Alzheimer Society of Canada Webinar
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Juanita-Dawne Bacsu, PhD
Postdoctoral Fellow
Rural Dementia Action Research (RaDAR) Team
University of Saskatchewan

Presentation overview

- Introduction: Harold's story
- Background
- Postdoctoral research
- Methods
- Findings
- Next steps
- Discussion

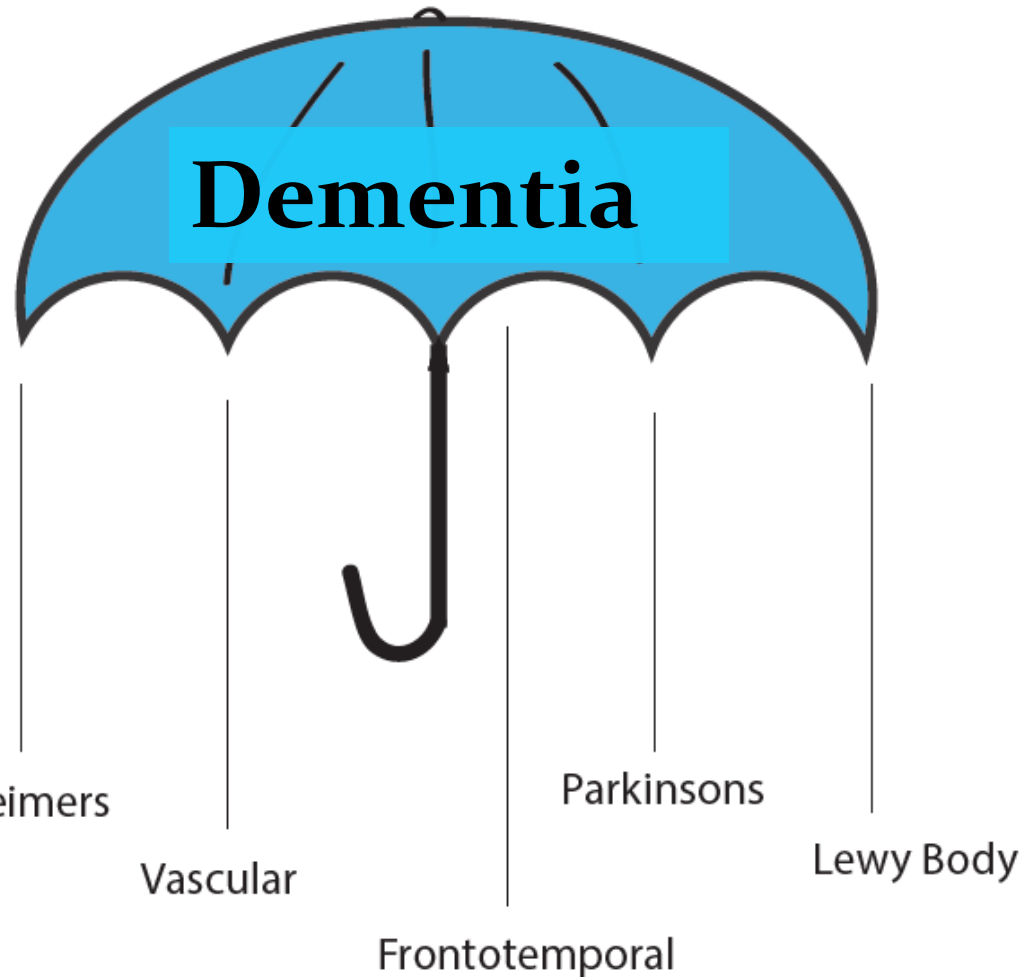
“Harold’s” Story

**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.



Rural Aging & Dementia

- Rural older adults often face unique dementia care challenges compounded by limited public transportation, finances, health services, access to information, and stigma.¹



What is stigma of dementia?



Why is stigma important?

- Decreased quality of life
- Social isolation
- Spousal hiding
- 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 on capacity-
building



Investigate what
works



Ask questions,
rather than give
answers



Identify attainable
actions.⁵



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.
- **Thematic analysis** to identify key themes in data.

Community Workshop



Findings: Key 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 cope with dementia and 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/language

- *“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. Fundraising

- *“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 your 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

- *“Meet with senior clubs and bring information forward... Have a physician or spokesperson come and speak, someone who specializes in aging.”*

Sharing Findings

- Developing knowledge translation and communication materials to share study findings.



Journal Articles

Canadian Journal of Public Health

<https://doi.org/10.17269/s41997-019-00241-0>

COMMENTARY



Check for updates

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

Juanita Bacsu^{1,2} · Nuelle Novik³ · Shanthi Johnson^{4,5} · Marc Viger⁶ · Thomas McIntosh⁷ · Bonnie Jeffery⁸ · Nazeem Muhajarine⁹ · Paul Hackett¹⁰

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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.

Newspaper & Magazine Articles



CARE – Fall 2020 | Eight Ways to Support Brain Health for Rural Older Adults - Issuu
Age is the greatest risk factor for developing ...

 [issuu.com](https://www.issuu.com)

Brain Power Edition Newsletter

Healthy Aging in Place
Brain Power Edition

Spring 2020

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


Podcasts on Aging



Journey Forward

- Goals are to acquire a faculty position and secure funding to expand and evaluate interventions to address stigma against dementia.
- Build research capacity and community-based partnerships to continue to advance the quality of lives for rural people living with dementia.





*Better is possible.
It does not take genius.
It takes diligence.
It takes moral clarity.
It takes ingenuity.
And above all,
it takes a willingness
to try.*

- Atul Gawande

Group Discussion



What do you think is the best way to **share information** on dementia in rural communities?



What **actions** do you think would help to address stigma of dementia in rural communities?

Thank you to my supporters & funders!

- Alzheimer Society of Canada
- Alzheimer Society of Saskatchewan
- Saskatchewan Centre for Patient-Oriented Research

Société
Alzheimer
Society
CANADA

Research Team

Community Partners

- Noreen Johns, Young Community Partner
- Elaine Frey, Young Community Partner

Researchers

- Juanita Bacsu, Faculty of Kinesiology and Health Studies, University of Regina
- Shanthi Johnson, School of Public Health, University of Alberta
- Marc Viger, Department of Family Medicine, University of Saskatchewan
- Farrah Mateen,

Organizational Partners

- Alzheimer Society of Canada
- Saskatchewan Centre for Patient-Oriented Research



**For more information on
dementia...**

Alzheimer Society of Canada

<https://alzheimer.ca/>

Mayo Clinic

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