

Improving dementia care in rural and small town settings: A view from Ontario

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Goals

- Challenge assumptions about dementia
- Introduce geographic thinking to some of you
- Explore the provision and experience of care
- Discuss improvement in a rural context

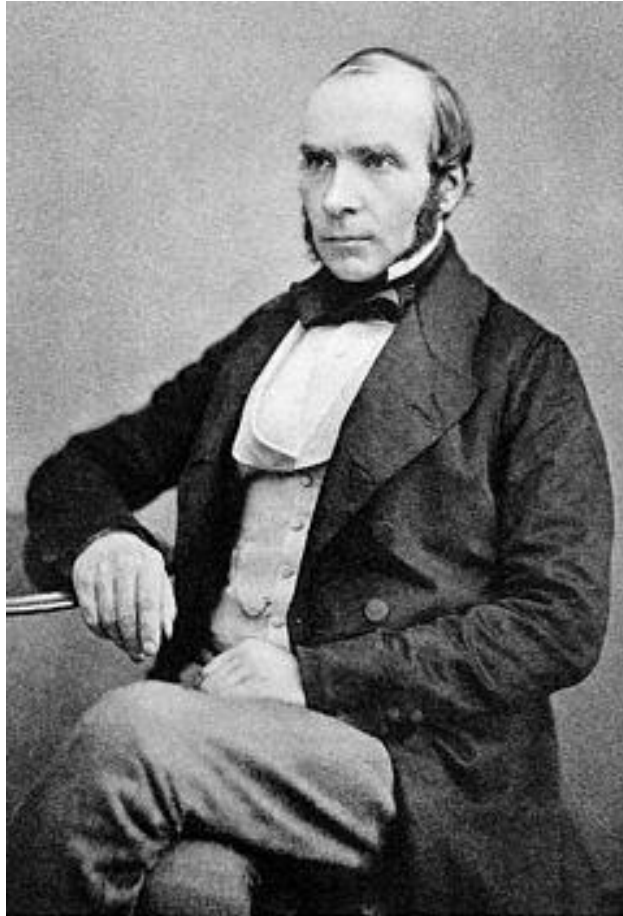


Viewing dementia

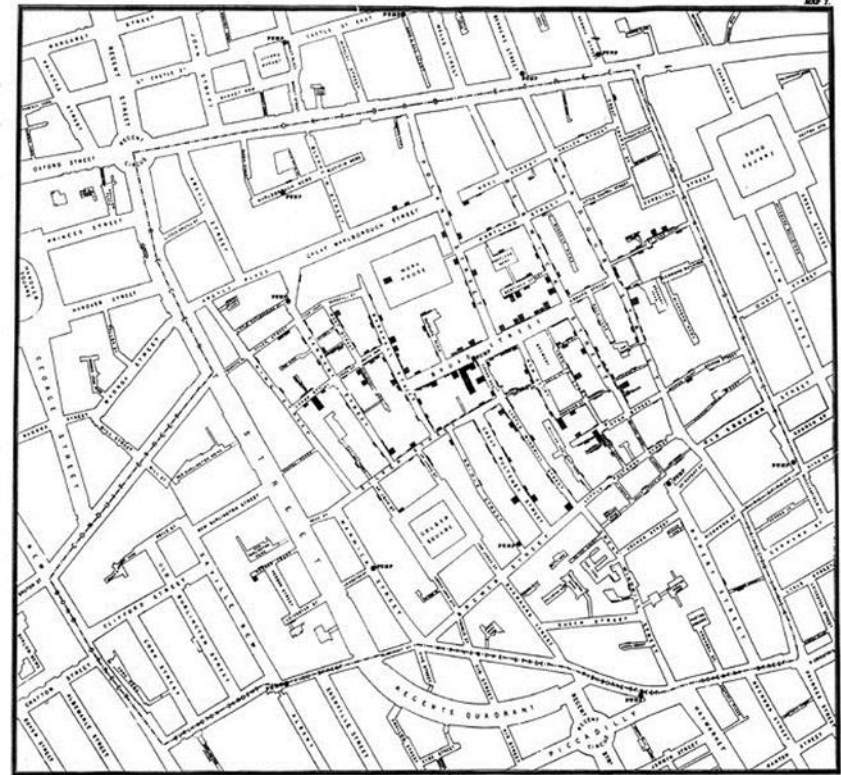


Dementia Advocates, By Permission

Geography and dementia?



John Snow

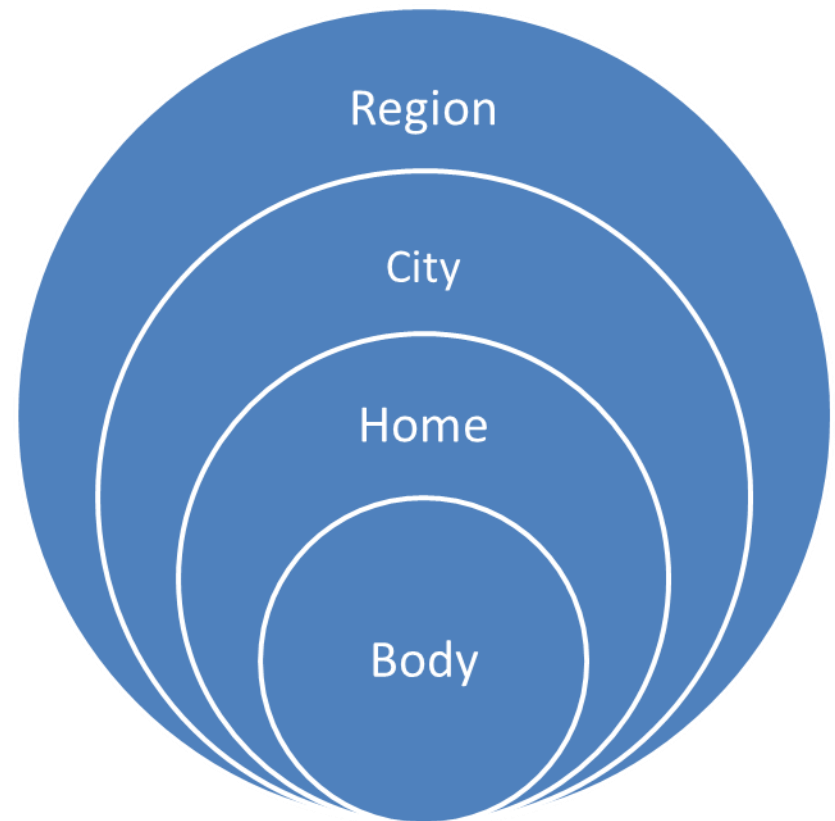


Map of cholera cases,
London, 1854



Geographic tools

- A) Scale
- B) Location
- C) Place
- D) Migration
- E) Distance and access
- F) Public vs. private



Why rural?



Research questions

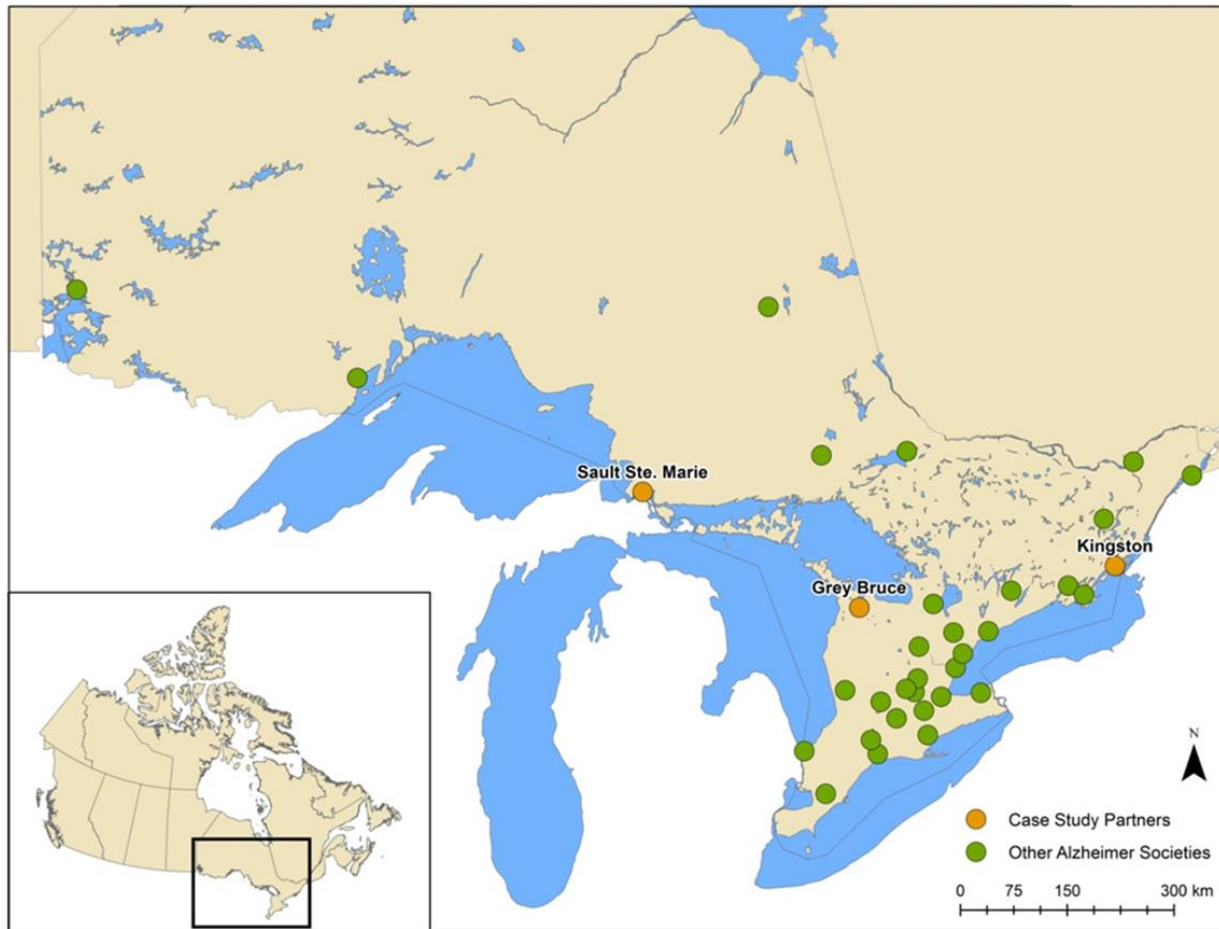
- 1) What services are available across the province of Ontario?
- 2) What services do people living with dementia in rural places need and use?
- 3) How do persons living with dementia experience care services and sites of care in rural places and over the course of the illness?
- 4) How can the lives of rural people with dementia and their care partners be improved?

Research design and methods

- Surveys of Alzheimer Societies in Ontario (N=20)
- Qualitative case studies in three regions:
 - Frontenac, Lennox and Addington; Grey-Bruce; Sault Ste. Marie Algoma
 - Interviews with persons with dementia (N=46) and partners in care (N=43) and former partners in care (N=27)



Case study areas and partners



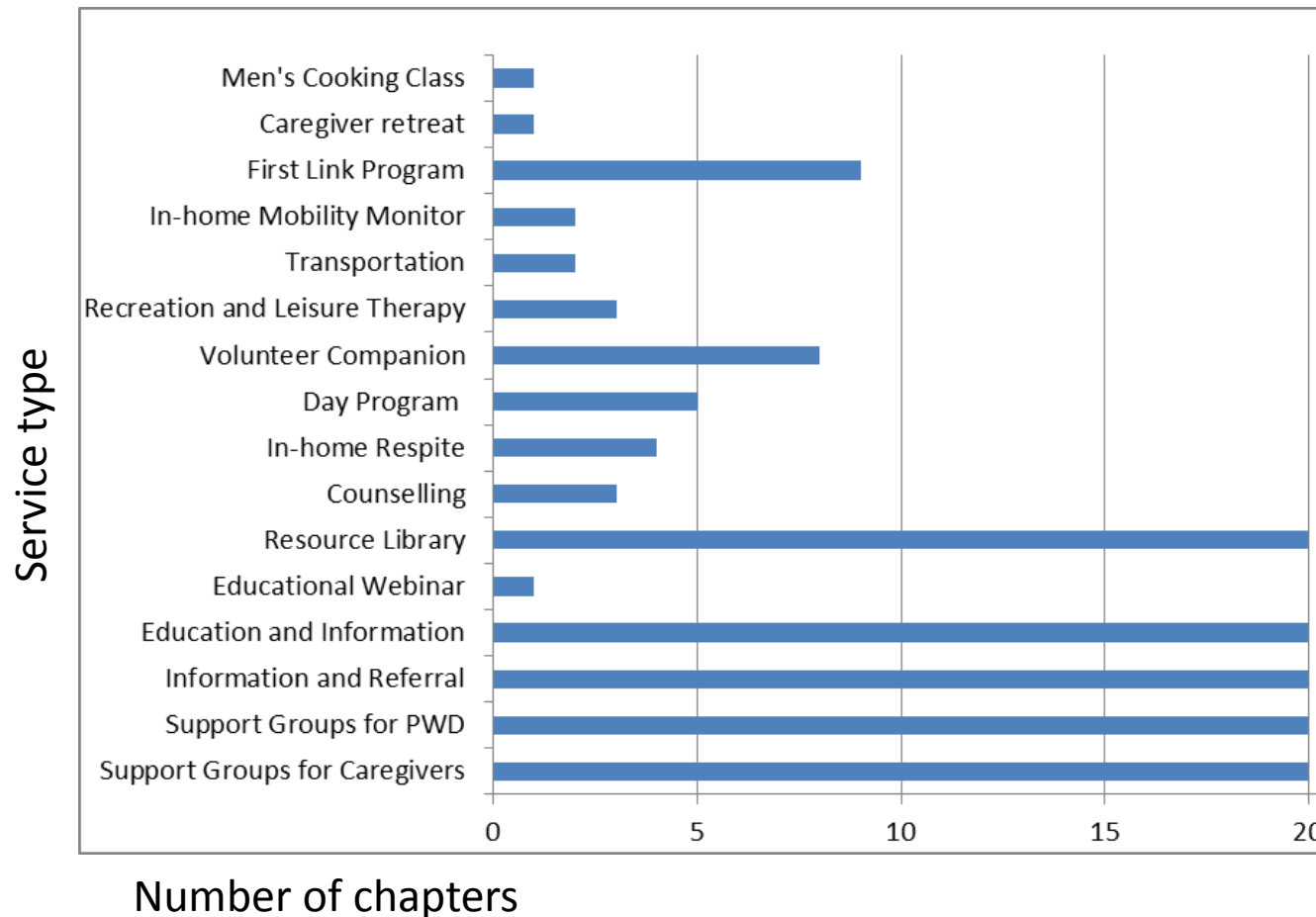
Interview participants

		Sex n (%)		Care Partner Relationship n (%)							
Site	Age Range	Male	Female	Spouse	Spouse/ Son	Spouse/ Daughter	Spouse/ Children	Other	None	<4 Years since Diagnosis Range	>5 Years since Diagnosis Range
Kingston	60-88	10 (50)	10 (50)	18 (90)		1 (5)		1 (5)		15 (75)	5 (25)
Owen Sound	56-89	8 (67)	4 (33)	10 (83)			1 (8)		1 (8)	11 (92)	1 (8)
Sault Ste. Marie	64-90	8 (57)	6 (43)	9 (64)	1 (7)	1 (7)	1 (7)		1 (7)	13 (93)	1 (7)

		Sex n (%)		Relation to persons with dementia n (%)					
Site	Age Range	Male	Female	Spouse	Son	Daughter	<4 years of care	>5 years of care	
Owen Sound	50-89	2 (25)	6 (75)	5 (63)	1 (13)	2 (25)	2 (25)	6 (75)	
Sault Ste. Marie	46-89	4 (21)	15 (79)	15 (79)		4 (21)	8 (42)	11 (58)	

1: Variation in services available

Number of chapters offering each service type



2. Reaching rural populations

“Transportation, isolation, and stigma are more evident concerns in the rural areas” (AC7).

“Privacy is challenging with smaller/rural populations, either people will want to discuss issues in a local grocery store or not want services in their local community at all” (AC17).

“Lack of other services – therefore total reliance of Alzheimer Society ” (AC8)

3. Connections and contributions

I was going to volunteer at one of the soup kitchens but there's no bus to get me home [she laughed].

~Beatrice's (65, Person with dementia, GB)

I have done a lot in the church...There's things I can't do as well as I used to, but there's still something I can do [she laughed]. Well, if they decide they don't need me, I won't go back to that church. I'll go somewhere else that will take me [she laughed].

~Emma (75, Person with dementia, GB)

4. “Not there yet”: Service delay

Ability

I’m not that childish that I can do kindergarten work, you know. ~(Dorothy, 81, Person with dementia, KFLA)

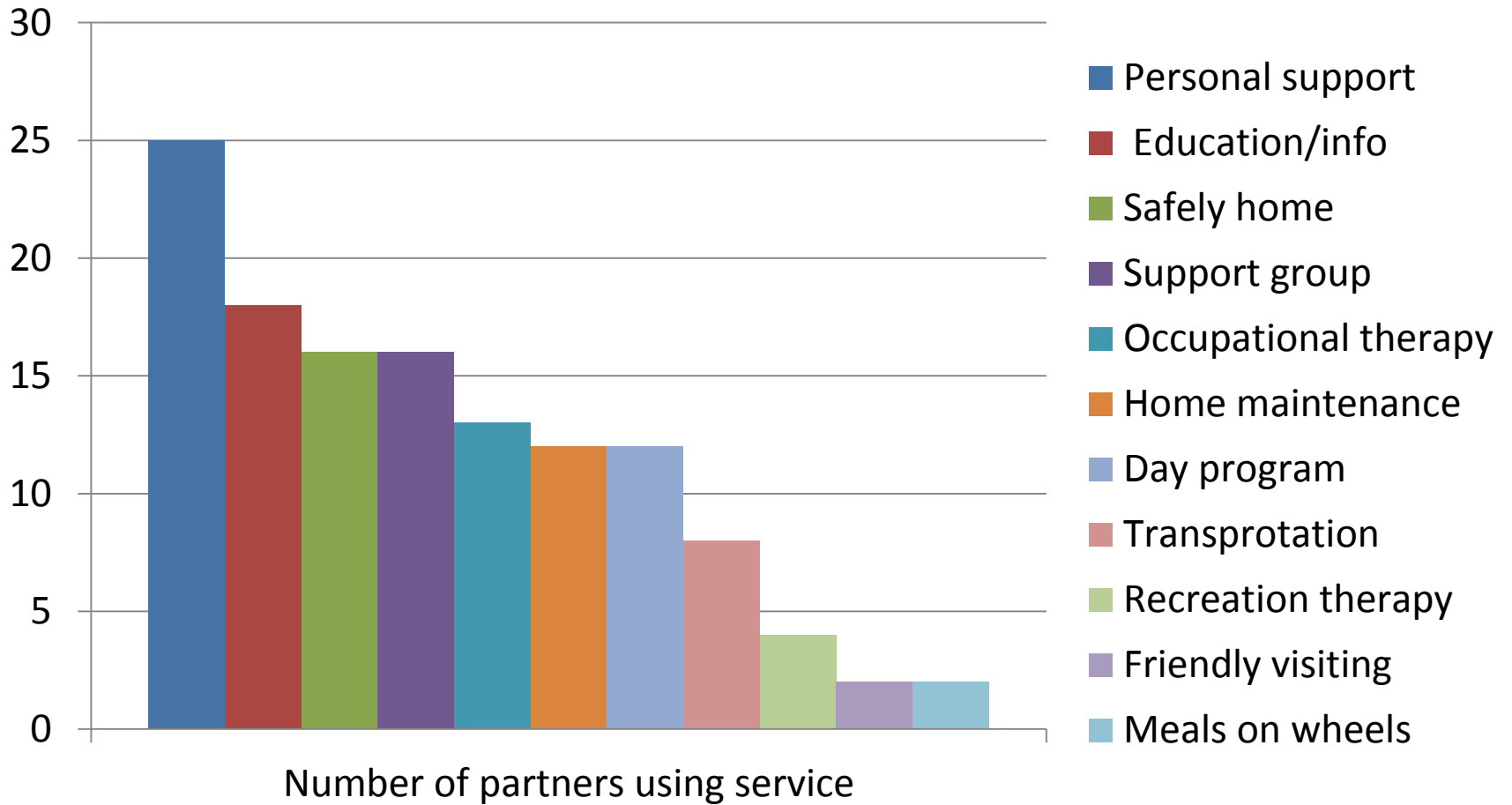
Dignity

We saw some really sad cases... ~(Edward, 71, Partner in care, KFLA)

Gender

Yah if I could take my chainsaw in and carve out some figurines or something or the axe but not, you know, not writing poetry or something. ~(Sam, 79, Person with dementia, KFLA)

5. Navigating the system



6. Constraining care

“I would go around this little block and he would stand at the window and wave each time I did a loop so that I could get some exercise and then when the caregivers came [from CCAC], I would, when the bath lady came I often went split kindling or something just to get out of the house” (Jean, Spouse, 65).

“He didn’t want to go and he said you know you’re a traitor pushing me out the door there’s no reason why I have to go. Just awful” (Anna, Spouse, 68).

7. Responding to “aggression”

“...he was a 6 foot man and some of them I think they were afraid of him because he might hit them or he might push them or whatever so I just said I’ll do the showering” (Mary, Spouse, 75).

“He put on his shirt, couldn’t get it buttoned up properly I guess. I heard the buttons flying. He pulled every button off the shirt. He put another one on and the buttons went on that one and I locked myself in the bathroom...” (Pam, Spouse, 78).

8. Lack of end of life care

“I knew what would happen if he went to a nursing home. He couldn’t tell anybody what he wanted. He had to be toileted. He couldn’t tell when he needed to go to the bathroom. He would just be put in a wheelchair and when they could get to him, they would get to him” (Mary, Spouse, 75).

Challenges and opportunities

- Variation in services and variation in mobility
- Rural care takes time
- Need to carefully recognize contributions of persons with dementia
- Need to develop alternative spaces of care for various stages of dementia
- Need to recognize partners in care



Limitations

- Retrospective/care dyad interviews
- All types of dementia included (e.g., lewy body dementia)
- The lived realities of Aboriginal people caring for someone with dementia within the case study areas have been excluded from this analysis
- Those not diagnosed not included

Future research

- Aggression at home
- Dementia-friendly communities
- Gender and community support in rural communities
- Manitoba



Acknowledgements

Thanks to the Alzheimer Societies of Sault Ste. Marie & Algoma District; Grey-Bruce; Kingston, Frontenac , Lennox & Addington, Dr. Garcia, Dr. Mulroy, and Dr. Severia.



Thanks to Dr. Mark Rosenberg, Tier I Canada Research Chair in Development Studies. This research was undertaken, in part, thanks to funding from the Canada Research Chairs program.