

# Patient Oriented Research? Learning from Dementia

ALISON PHINNEY, PHD, RN  
UNIVERSITY OF BRITISH COLUMBIA  
SCHOOL OF NURSING  
VANCOUVER, CANADA



# Acknowledging the land

I AM HERE ON THE TRADITIONAL,  
ANCESTRAL AND UNCEDED TERRITORY OF  
THE COAST SALISH PEOPLES - THE  
SḶWḶWÚ7MESH (SQUAMISH),  
STÓ:LŌ, SƏLÍLWƏTƏʔ/SELILWITULH (TSLEIL-  
WAUTUTH), AND XʷMƏΘKʷƏYƏM  
(MUSQUEAM) NATIONS.



# Mentorship

*“the mind is not as a vessel to be filled, but a fire to be kindled”*

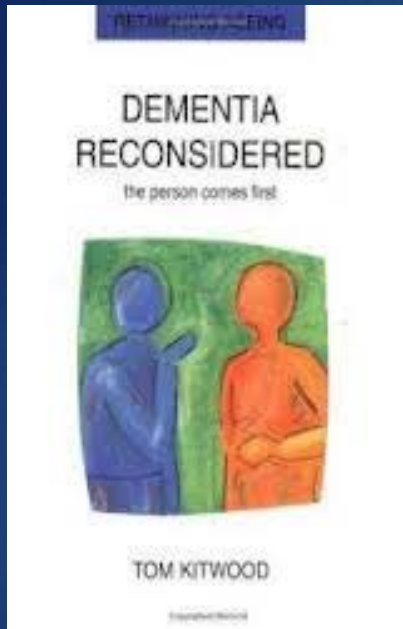


# Mentorship

*“the mind is not as a vessel to be filled, but a fire to be kindled”*



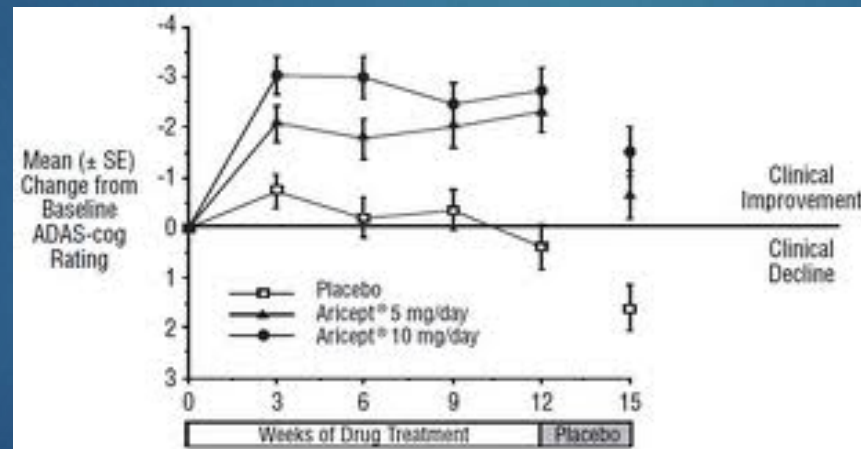
# Dementia in the 1990's



Volume 9, Number 1 *The Journal of Clinical Ethics* 35

**Voices of Alzheimer's Disease Sufferers:  
A Call for Treatment Based on Personhood**

*Steven R. Sabat*



# First steps

*The Persistence of Meaning  
in the Midst of Breakdown:*

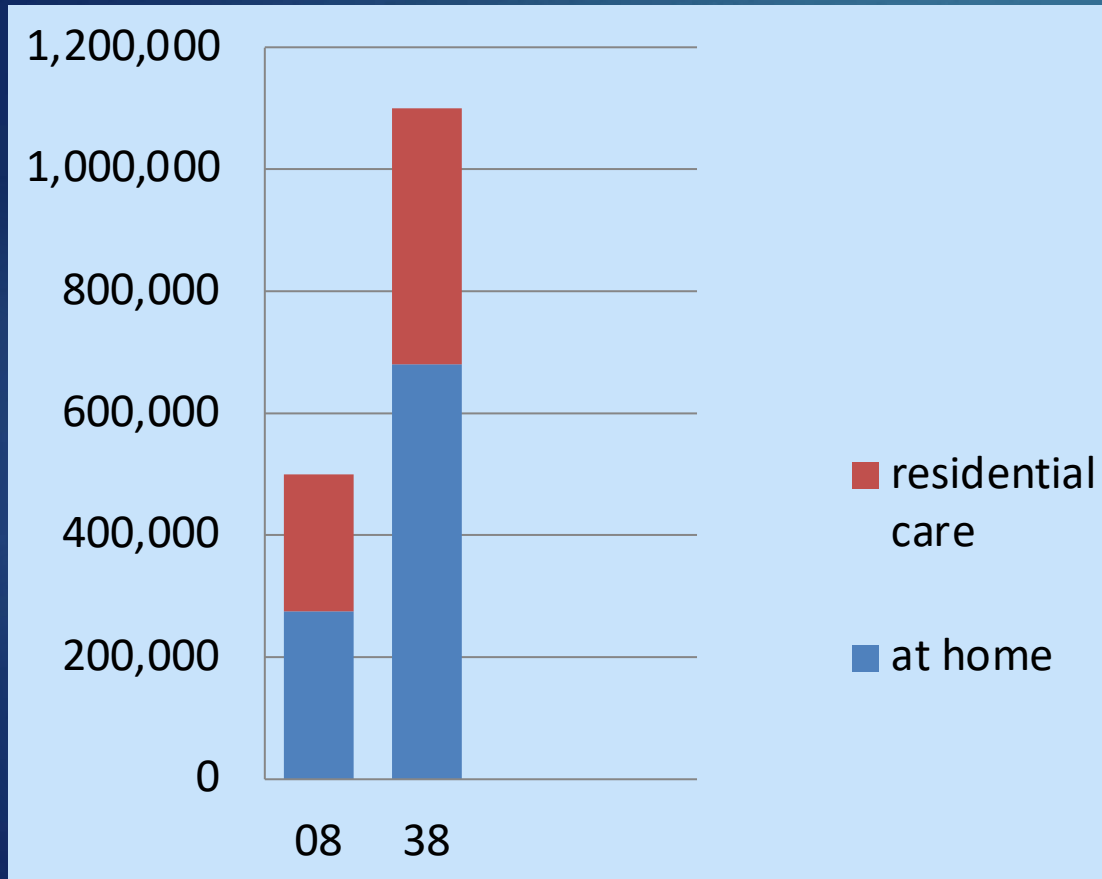
*An Interpretive Phenomenological  
Account of Symptom Experience in  
Dementia*



# Building a program of research



# The Rising Tide



“Canada needs an integrated system of care, linking health care services with a wide range of community supports”

ASC, 2010



Where are these community supports?  
What should they be like?



*What if we replaced the persistent rush to establish “what is the case” and began to ask, “what kind of world could we build?”*

*Kenneth Gergen, 2016*

# Engaging 'patients' as partners

- ▶ Researchers in gerontology are increasingly being held accountable to **engage with patients as partners** in the research process.
  - ▶ *Patient Centered Outcomes Research (PCOR)*
  - ▶ *Patient and Public Involvement (PPI)*
  - ▶ *Strategy for Patient Oriented Research (SPOR)*
- ▶ Such engagement entails **“meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation”**

# Who are these 'patients'?

- ▶ Individuals with “personal experience of a health issue”, including informal caregivers (e.g. family, friends)
- ▶ What does this mean in the case of dementia?
- ▶ Partnering with people with lived expertise of dementia



# What are we learning?



# Flipping Stigma

## Putting Social Citizenship into Practice: Reducing Stigma and Promoting Social Inclusion of People with Dementia

(CIHR, 2018-2022), A. Phinney, D. O'Connor & J. Mann

- ▶ PURPOSE → using participatory action methods to (1) work with an **action group of people with dementia** to develop a practical understanding of social citizenship; and (2) show how community programs can apply that understanding to more effectively support social citizenship of people with dementia.

# Building Capacity

15

## Building Capacity for Meaningful Community Participation by People Living with Dementia

(PHAC, 2019-2023), A. Phinney & E. Wiersma

- ▶ PURPOSE: to adapt, implement and evaluate an *asset-based community development approach* to grow innovative initiatives (e.g. arts, social, fitness, and volunteer activities) so people with dementia can remain active and connected in their communities.



# LESSON 1

## Leadership matters





## Invitation for People Living with Dementia

**You are invited to join the conversation** on issues related to stigma on ageing and dementia. **Putting Social Citizenship into Action** is a research project seeking strong community involvement.

### Many people living with dementia talk about being:

- devalued
- socially excluded
- discriminated against



### As a result, they experience:

- negative physical and mental health consequences
- diminished sense of self
- multiple barriers to services
- sense of despair
- loneliness and isolation

Please join us in this opportunity to **share your voice and experience**. We will be a small group meeting monthly with the aim of **identifying strategies for addressing stigma and promoting inclusion** in our local communities.

If you wish to learn more, please contact Project Manager Ania Landy  
[ania.landy@ubc.ca](mailto:ania.landy@ubc.ca) || 604-822-7503



This study is being co-lead by Jim Mann, Deborah O'Connor, and Alison Phinney.

# LESSON 2

## Being comfortable with uncertainty



## LESSON 3

# Building a community

- ▶ Listening
- ▶ Watching and using non-verbal communication – facial expression, gestures
- ▶ Listening
- ▶ Keeping questions simple
- ▶ Giving each other time – don't be afraid of a little silence
- ▶ Not letting meetings drag on

## LESSON 4

# Listening, and other good ways to communicate

## LESSON 5

# Location matters





## LESSON 5

# Location matters

# Building Capacity

Asset-Based Community Development and "Nothing about us without us"

## Vancouver



## Thunder Bay





## LESSON 6

# Building confidence & creating excitement

# Final thoughts and questions?

24

