

**Chinese-Canadian Pathways to a Diagnosis of  
Dementia in Metro Vancouver: Exploring  
intersections between culture, social determinants  
of health, and system barriers**

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*A Public Lecture for  
SFU's Department of Gerontology  
and the Gerontology Research Centre*

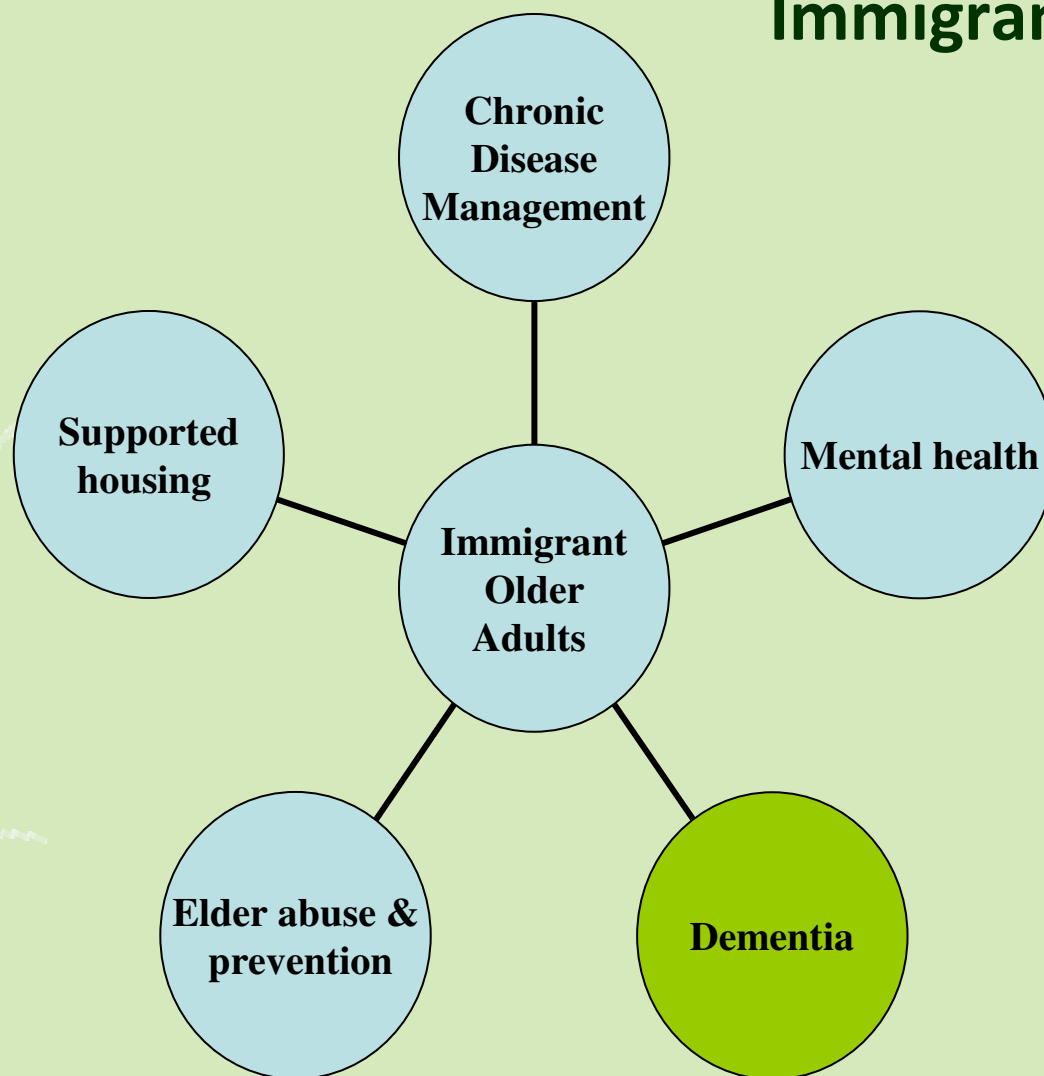
# Outline

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# Situation of Pathways study in my research program

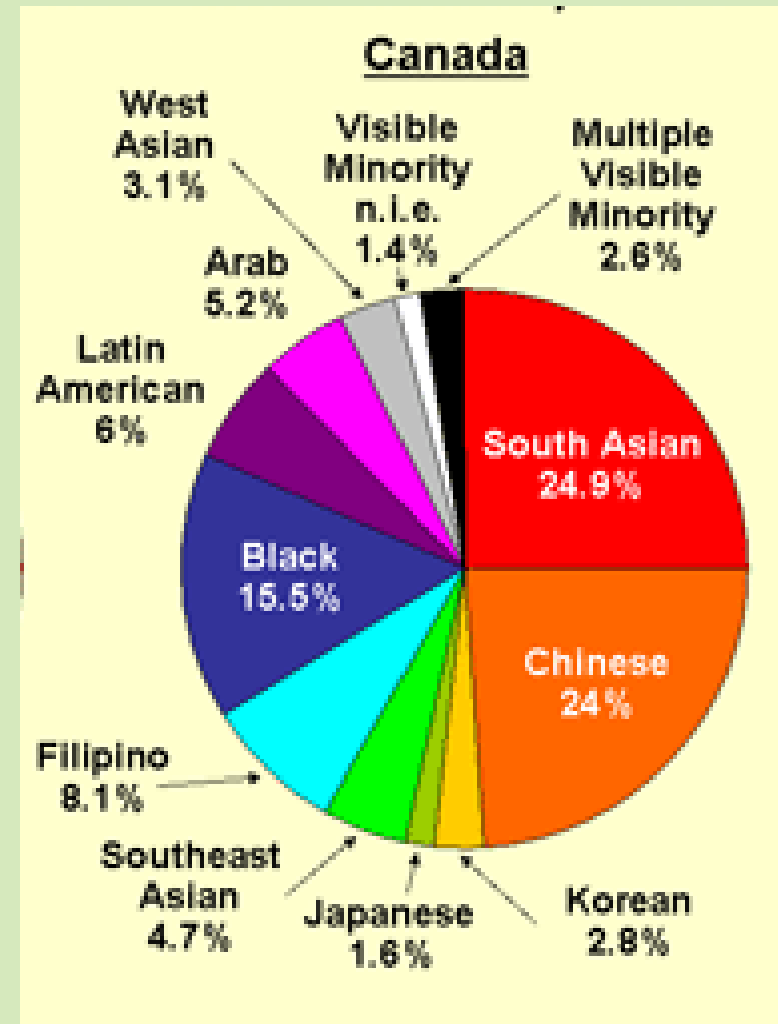


# Enhancing Quality of Life through Quality of Care for Immigrant Older Adults

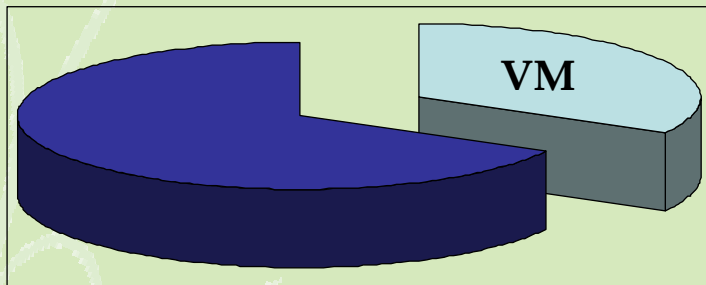


# Pathways Study

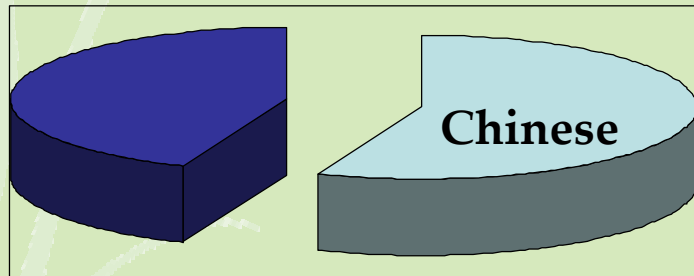
## Demographic and epidemiological context



# Chinese older adults in Vancouver



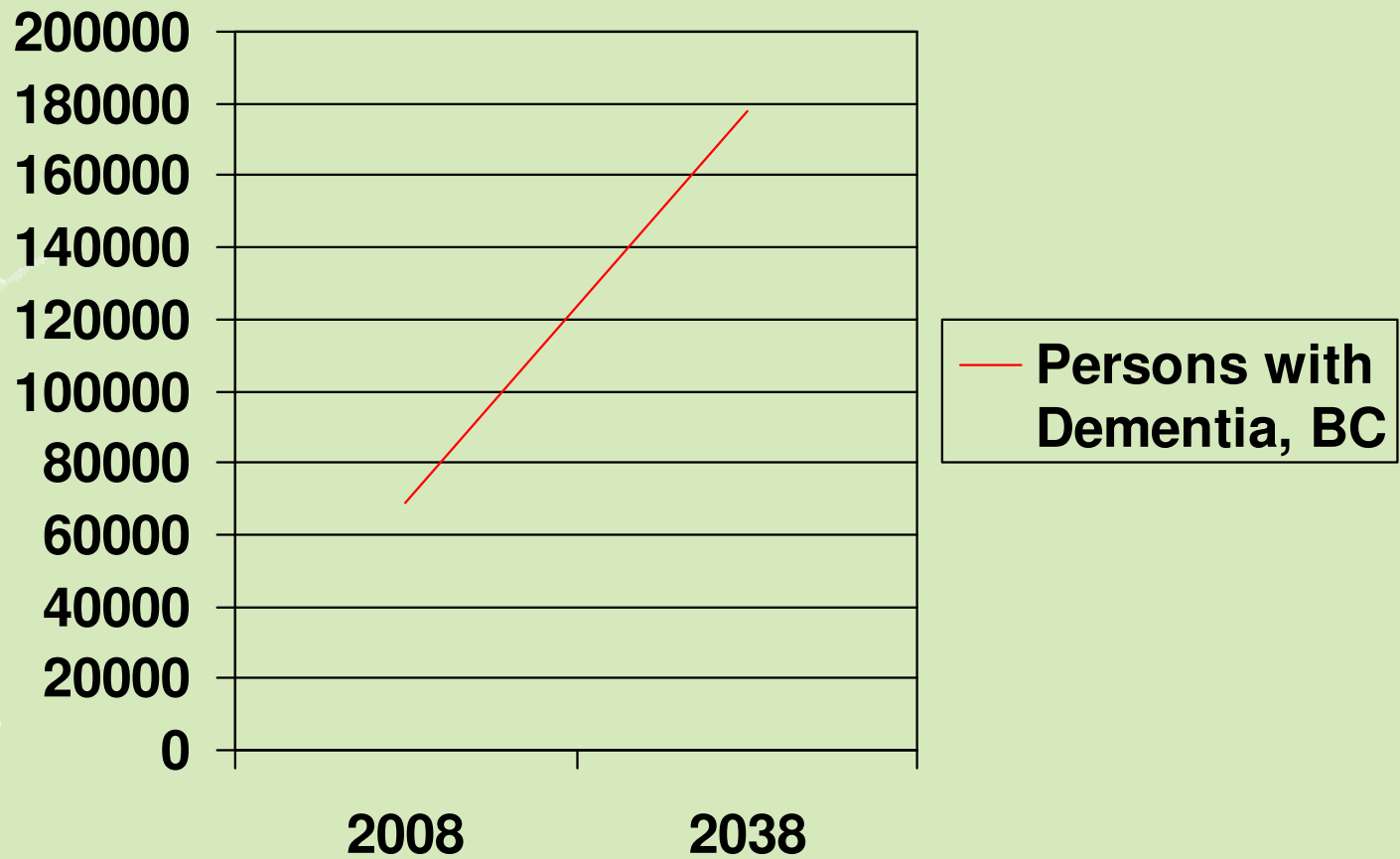
Persons aged 65+ in Vancouver



Visible minorities aged 65+ in Vancouver



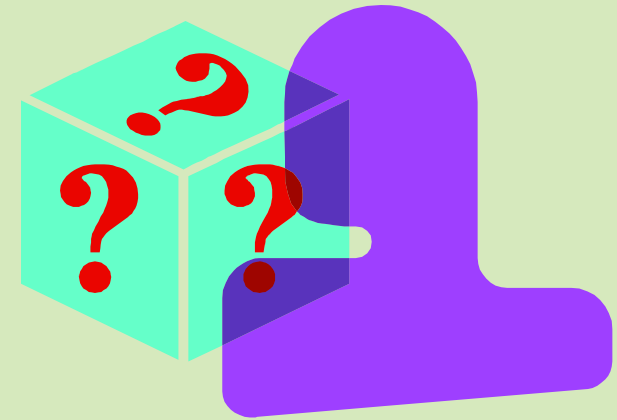
# Dementia in BC



# Why study pathways to a diagnosis?

- ➔ Providing a timely diagnosis and care for individuals with dementia and their families is a health care priority
- ➔ Prompt clinical assessments may:
  - Identify reversible causes of cognitive declines
  - Initiate pharmacological therapies for people with early Alzheimer's disease
- ➔ Obtaining diagnosis may:
  - enable families to find supportive resources
  - promote future care planning
  - encourage discussions about observed and expected changes and safety risks

# Research Methodology



# National study

## ➔ Four sites:

- ➔ Calgary (Anglo-Canadian)
- ➔ Ottawa (French Canadian),
- ➔ Toronto (Indo-Canadian)
- ➔ *Vancouver (Chinese Canadian)*

## ➔ Interviewed dyads:

- ➔ Persons with dementia-PWD; principle family caregivers

## ➔ Inclusion criteria:

- ➔ People with Alzheimer's disease, vascular or mixed dementia (ADRD)
- ➔ Aged over 65y
- ➔ Diagnosis within the previous year, and their principal caregiver
- ➔ Community-dwelling

# Research questions

- ➔ How and when do individuals and their caregivers identify a problem which is later diagnosed as dementia?
- ➔ Who do they consult for help?
- ➔ What are people's experiences in the pre-diagnostic period?
- ➔ What are people's expectations of the illness and its care?
- ➔ What socially-constructed meanings and values are embodied in respondents' discourse

## Data collection & analysis

- ➔ **Recruitment:** referrals from ASBC – Chinese Resource Centre
- ➔ Separate personal **semi-structured interviews** in the language of their choice with PWDs and caregivers
- ➔ **Limitations included:**
  - PWD may not recall details of the pathway
  - Interviewer bias
  - Small sample prohibits over-generalization
- ➔ Saturation of categories attained & meaningful contribution to knowledge

# Vancouver Chinese-Canadian participants

Number of people with dementia	10
Gender Ratio	8 men : 2 women
Number of caregivers	10 primary, 1 secondary
Gender Ratio	<b>Primary:</b> 1 man : 9 women <b>Secondary:</b> 1 man
Relationship to PWD	<b>Primary:</b> 8 wives, 1 husband, 1 daughter; <b>Secondary</b> - 1 son

# Analysis

- ➔ All interviews were simultaneously translated and transcribed into English for analysis
- ➔ Themes and pathways identified using Atlas.ti 5.0
- ➔ Inductive themes clustered into higher-order themes that matched help-seeking model used by Levkoff *et al.* (1999):
  - (1) disease and symptom experience,
  - (2) symptom appraisal
  - (3) decision to seek care
  - (4) contact with care providers

# Critical constructionism

- ➔ People in a given environment 'are involved in the construction of the meaning of phenomena'
- ➔ Realities are co-constructed with others through interaction
- ➔ Constructions are not benign; they are mediated by power relations that are socially and historically constituted
- ➔ Power is linked to knowledge, which may be very context-specific

# Intersectionality

Intersectionality considers the **simultaneous interactions between multiple dimensions of social identity** (e.g. gender, age, sexual orientation, visible minority and immigration status) that are **contextualized within broader systems of power, domination and oppression** (such as sexism, ageism and racism)

*“Statuses and their intersection influence a person’s life chances, in terms of education, labour force participation, living arrangements, health status, and ultimately, the quality of life in old age”* (McDonald, 2008, p. 139).

# What the literature says



## Symptom appraisal: stigmatization and delayed recognition

- ➔ Cognitive impairment is stigmatized like other mental illness which discourages “*many Chinese families [from seeking] . . . dementia services until the disease is quite advanced*” (Zhan, 2004).
- ➔ The behaviour of the PWD is thought to threaten the harmony, unity and survival of the family and hence brings shame to the family and the community.
- ➔ Symptom normalization is common and delays recognition

## Decision to seek care: the ideal of filial piety



Children and their spouses (particularly the wife of the first-born son), ***“must obey and care for their parents without question or resentment.”***

## Decision to seek care – male-dominance

- ➔ Traditional Chinese family ideals prescribe roles for family members relative to gender, age, and birth order, with men and older persons claiming the greatest authority.
- ➔ Eldest sons dominate family decision-making when a parent has dementia.

## Physician appraisals

- ➔ Shared language and cultural awareness critical to accurate assessment and diagnosis
- ➔ Chinese-American physicians are also reported to stigmatize and/or normalize dementia symptoms. This results in
  - ➔ failure to diagnose appropriately
  - ➔ failure to screen for treatable causes of memory loss
  - ➔ delayed intervention

# Findings



# Pathway elements: overview

- ➔ Disease and symptom experience
- ➔ Symptom appraisal
- ➔ Decision to seek care
- ➔ Contact with care providers

# Disease and symptom experience

Initial experiences of cognitive deficits:

- repetitious questioning
- “wordiness”
- problems with name recall
- going to the wrong room (kitchen instead of bathroom)
- leaving the tap on
- forgetting how to change lanes while driving
- losing a parked car
- misplacing money, etc.

## Disease and symptom experience

- ➔ For some, personality changes and behavioral challenges (e.g. delusions about the spouse having an affair) emerged relatively early in the progression of the disease
- ➔ For others, symptoms seemed to plateau for some time or decline very gradually.

# Pre-diagnosis interval

The interval between recognition of symptoms and diagnosis

Our data:

➔ **Range: < 6 months to 4 years**

➔ **Average: 1.6 years**

In the literature (*all* older adults):

➔ **Most studies report 2-3 years\***

➔ **One source reported some > 5 years\*\***

No greater delay for our sample vs. others

## Symptom appraisal – “normalization”

- ➔ Only 1 of 10 caregivers did not recognize the symptoms of dementia at all prior to diagnosis. Her H continued to drive and crashed the car. His AD was diagnosed in the ED as a result:

*“I thought that people get old, always like that, forget this or forget that. ... do things in a wrong way, cannot perform a task in a short time, happen a lot. Old people are like that. So I did not think of him with a disease” (Ya Mei).*

# Symptom appraisal – “threshold”

The factors leading to an informal caregiver’s pursuit of a diagnosis

- ➔ Knowledge of dementia symptoms a key factor
- ➔ For some (e.g. Ya Mei), there was a definitive moment at which acknowledgement of ‘something wrong’ occurred
- ➔ For most, repetition of unusual behaviours that eventually stimulated them to seek an explanation

## Symptom appraisal – PWDs

Half of the PWDs interviewed spoke of their initial symptoms as normal facets of aging:

*“[Int: What kind of help do you want to receive from the doctor?] Nope, it is nature, as getting old, it is a normal process, I forget thing I will not tell doctor because it is normal. [Int: Did your doctor say you have memory impairment?] Nope. . . . I am not a special one; people getting old should have memory loss” (Peter\*).*

# Decision to seek care

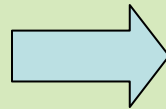
Who made decision to seek care?	No. of dyads & gender of caregiver
Physician in acute care	2 (F)
Spouse (independently )	4 (F)
Spouse + younger family members	4 (3F, 1M)
Daughter	1 (F)

## Decision to seek care: new immigrants

*“I did not know [about support services] because although I was here for nearly three years, I was at home. I don't know many people here. I did not come across these social services and their information before. . . . I was totally blank with these concepts. . . . Secondly, I did not come across friends or relatives with these experiences. Moreover, I do not know what type of social services are available to these patients in Canada” (Ping).*

## Contact with care providers

Family physicians were the first point of contact for 70% of our dyads



**BUT** only two received diagnoses from FPs, each after a 2 yr pre-diagnosis interval

All family physicians, geriatricians and neurologists consulted were of Chinese background and spoke the PWD's language.



**BUT 60%** experienced delays in diagnosis because family physician dismissed caregiver's appraisal of symptoms

# Contact with care providers: denial of diagnoses

*“[T]he family doctor said ‘No’ in the beginning, he did not think of it. He felt that I might be too sensitive”*

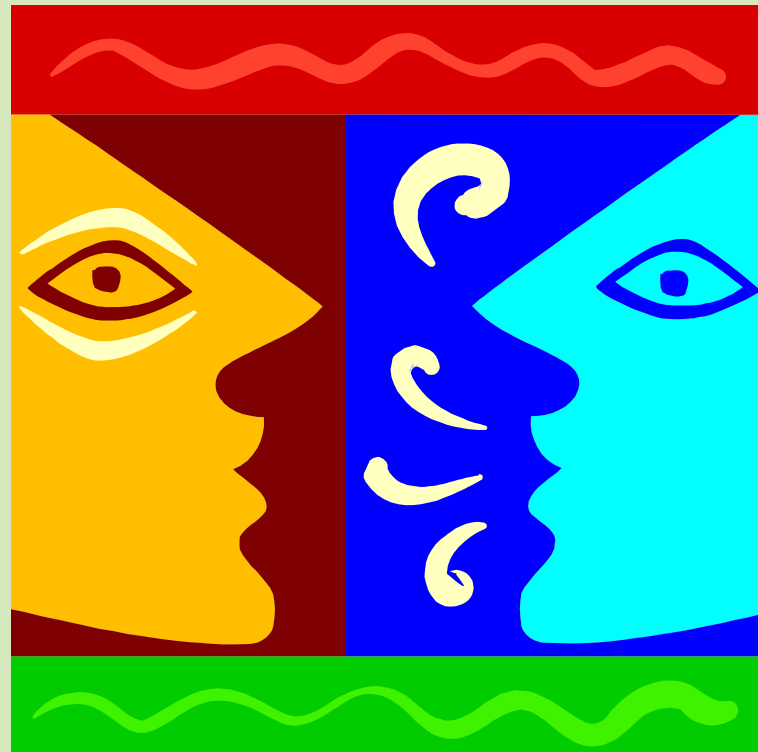
(Lisa).

*“I told Doctor K. about my husband’s condition and requested him to introduce the specialist for him to check up. Dr. K. said this was a normal aging, even [though] I told him my husband must have something wrong”* (Ju Fen).

## Contact with care providers: Medications

*“[Shu takes] one tablet a day. \$5 a day. [Int: Do you have to pay yourself?] Yes. The government does not cover. I heard that if Dr. S. applied for her, she could be covered by the government. Join the government research project, can save the \$150 [a month] drug fee. But I asked her family doctor several times, he would look rather torn as he said the procedures were long, a lot of steps, very complicated. He said that it would be very difficult to apply for it. So he was unwilling to help my mother to do this application. Actually, my mother is categorized as low-income” (Ping).*

# Discussion & Conclusions



## Role of culture in PWD's appraisal of symptoms

- ➔ Culturally-based normalization or presentation of a 'competent' self (coping, self-protection)?
  - PWDs overall tend to normalize symptoms in order to preserve a sense of Self and to cope with the changes that dementia brings (Sabat, 2001; Clare, 2002)
  - Persons labeled 'mentally abnormal' or 'demented' lose a sense of agency and Selfhood because others no longer treat them in the same way; they become powerless relative to healthy others (Cotrell & Schulz, 1993; Sabat, 2001).

# Decision to seek care: Limitations of filial piety

## The case of Shu (PWD) & Ping (D):

- Shu lived with S & D-in-law in Canada for 10 years
- Ping moved to Canada with baby 3 y.a. - lived with her B, his W, and Shu
- Recognized Shu's dementia, sought diagnosis, became primary caregiver.
- Ping's H sponsored – Shu to live with them in another house when he arrives.

# Limitations of filial piety

## Two caregiving wives:

*“We have no children, I cannot depend on relatives. I must face all the problems by myself. Now I can handle it, I do not know whether I can handle as he gets worse” (Judy).*

*“I was very depressed and disappointed in my sons. In our concept, they should take care of us when we are getting old. They cannot help me. I feel lonely because one of son is in Taiwan, one is in US: they are far away. When I have trouble, they cannot help me. I have blamed them, ‘Why I born them? They are useless!’ (Fong).*

# Physician under-diagnosis

## To what extent is culture a factor?

- ➔ Western-trained Chinese physicians who retain a stigmatizing view of aging and cognitive impairment as akin to mental illness may fail to diagnose appropriately and “delay timely interventions for AD patients.

### HOWEVER

- ➔ Numerous studies have identified physician under-diagnosis of dementia as a problem – diagnosis rate < 50%

# Summary & Implications

Our data differs from that collected in studies of Chinese-Americans in that we **do not** have substantive evidence of

- longer pre-diagnosis intervals due to normalization or stigmatization
- male-dominated hierarchical decision-making structures within families that stifle attempts by female caregivers to seek a diagnosis

# Summary & Implications

Probable explanations:

Chinese immigrants are heterogeneous:

➔ SES, length of time in the country, immigration class, English-language skills etc. influence understandings of dementia and of the health care system and the ability to access services.

Few studies take a critical perspective that recognizes the power imbalances that arise from the intersections between multiple dimensions of difference

# Summary & Implications

Focusing on culture rather than structural barriers to accessing care shifts the onus of responsibility to the patient and caregiver

What is needed:

- Outreach to new immigrants
- Strategies to enhance the ability of family physicians to diagnose dementia and to provide/refer caregivers to appropriate supports
- ...

***Thank you!***

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**Slides available at:**

<http://centreforhealthyaging.ca/>

# Next Steps

# Questions?