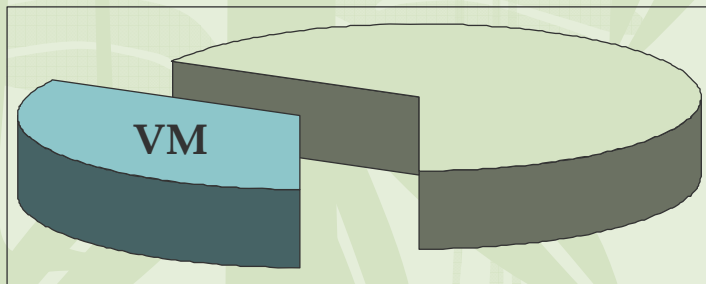


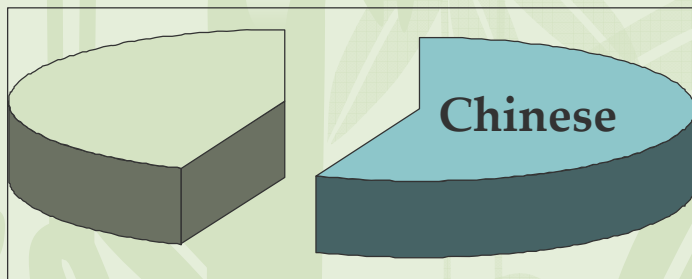
A Non-Essentializing View of Chinese-Canadian Pathways to a Diagnosis of Dementia in Metro Vancouver

Sharon Koehn
Melanie Spence, Jean Kozak,
Linda Garcia, Karen Leung,
Lynn McCleary, Carole Cohen,
Neil Drummond

Chinese older adults in Vancouver



Persons aged 65+ in Vancouver



Visible minorities aged 65+ in Vancouver



Pathway elements: overview

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

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.

Symptom appraisal: 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).

- Half of the PWDs interviewed spoke of their initial symptoms as normal facets of aging:
cultural or preservation of self?

Decision to seek care - our data

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

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

➤ **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).*

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!

Contact:

skoehn@providencehealth.bc.ca

Slides available at:

<http://centreforhealthyaging.ca/>