Enhancing Early Diagnosis and Culturally Sensitive Support and Care of Dementia

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Geriatric Services Conference 2018

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Disclosure and Conflict Management

No affiliation (financial or otherwise) with a commercial organization.

Background

- Dementia is a complex disease requiring a multifaceted interdisciplinary approach involving a range of health care professionals (specialist and primary care).

- The challenges of diagnosing and supporting people with dementia and their families and caregivers are expected to increase as prevalence rates in Fraser Health (FH) are anticipated to rise by 72% over the next 10 years (from 16,128 cases in 2009 to 27,749 cases in 2024).\(^1\)

- This challenge is further compounded by FH’s large South Asian community who may be at greater risk due to increased prevalence of cardiovascular risk factors.\(^2,3\)
Prevalence of Dementia in BC's Lower Mainland

Projected dementia cases in BC among individuals 45+ by HA

Note: Projections are determined based on the 2009/10 dementia prevalence rates among people ages 45+ and population growth rates.
Source: Blue Matrix 4.0(2005/10), Planning and Innovation Division, BC Ministry of Health, PEOPLE 12, BC Stats.
Evidence suggests that dementia, especially in early stages, remains under-detected, under-diagnosed, under-disclosed, and under-treated/managed.4

This may be magnified in the South Asian community due to the cultural context, perceptions, and knowledge of aging and dementia; stigma; and access to culturally sensitive services.5,6

Many primary health care practitioners report a lack of confidence and the skills required to provide a diagnosis of dementia.7,8

Educational and interdisciplinary consultation support from specialists such as geriatricians, geriatric psychiatrists and neurologists have the potential to support improvements in early diagnosis.9
Early Diagnosis and Management

- Receiving an early diagnosis of dementia will:
  - Result in earlier treatment which is proven to be more effective for maintaining quality of life
  - Gain earlier access to dementia information, support and services
  - Allow time to plan for the future
- **Reversible dementia**: there are certain, treatable conditions such as vitamin B12 deficiency, low thyroid, depression among others which present as early dementia and should be diagnosed early as possible.

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Early Dementia Strategy

- Launched in 2015, our goal is to enhance the role of specialists in supporting primary care practitioners to increase their knowledge and confidence in early diagnosis and culturally sensitive treatment and management of people with dementia and their families.
Key Streams

This overarching goal is being achieved through the development and implementation of activities in three key streams:

1. Integrated, interprofessional collaborative practice guideline/pathway
2. Competency-based dementia education program
3. Development of culturally-sensitive resources focusing on South Asian population

FHA News Release on November 14, 2017

Over the next year, FHA is piloting new initiatives in the communities of Surrey-North Delta, White Rock-South Surrey, and Langley.
Integrated collaborative practice pathway

- **Core activities:** Development of leading practice dementia-specific, interprofessional guideline.

- **Goal:** To develop a strong foundation of dementia knowledge and competency to enhance access and support for early diagnosis.

Collaborative Practice Dementia Pathway

- Guidelines for recognition, diagnosis and management of early dementia, in alignment with BC Cognitive Impairment Guidelines

- Dynamic PDF Pathway, to be uploaded to desktop/EMR, and includes links to relevant resources
Collaborative Practice Dementia Pathway

**DIAGNOSIS**

- Diagnostic algorithms
  - 1. Complete medical history
     - a. 4Ms Focused History
     - b. Cognitive and functional assessment
     - c. Physical examination
     - d. Physical characteristics
       - 1. Cognitive assessment: 
         - 1.1. Determine if there is a change in behavior or if there is a change in behavior that is not immediately obvious
         - 1.2. Routine care needs assessment (e.g., falls, memory, continence)
         - 1.3. Nutritional status assessment
         - 1.4. Physical examination
   - 2. Obtain collateral history from family and caregivers
  - 3. Cognitive assessment
  - 4. Physical characteristics
  - 5. Return to care plan

**DIAGNOSIS**

- Rule out non-critical causes of cognitive impairment
  - 1. Memory
  - 2. Focus
  - 3. Attention
  - 4. Communication
  - 5. Personality
  - 6. Sleep
  - 7. Depression
  - 8. Traumatic brain injury
  - 9. Stroke
  - 10. Epilepsy
  - 11. Metabolic disease
  - 12. Medication

**MANAGEMENT**

- Non-Pharmacological Management of Dementia
  - General Care and Support for Community-Dwelling Patients
  - Physical and Functional Assessment
  - Psychological and Social Support
  - Medication Management
  - Activities of Daily Living
  - Safety and Security
  - Transportation
  - Meal Planning and Preparation
  - Community Involvement
  - Technology Use

- Pharmacological Management
  - Antidepressants
  - Antipsychotics
  - Anticonvulsants
  - Antidementia drugs
  - Other medications

**MANAGEMENT**

- Cognitive Stimulation
  - Exercise
  - Social activities
  - Cultural activities
  - Food
  - Music
  - Environmental
  - Occupational therapy

- Behavioral Management
  - Cognitive-behavioral therapy
  - Medications
  - Physical interventions

- Caregiver Support
  - Education
  - Training
  - Resources
  - Support groups

**fraserhealth**

- Walks through steps to diagnose dementia in a patient
- Covers non-pharmacological management of dementia
Covers pharmacological management of dementia

- 7 Numbers for Early Dementia:
  - Surrey
  - Langley
  - White Rock - South Surrey

Available at: https://ubccpd.ca/dementia-education-mentoring-resources
Excerpted from the Collaborative Practice Pathway

For more information or access to the Pathway, please connect with Project Manager Sarah Metcalfe (Sarah.Metcalfe@fraserhealth.ca)

Collaborative Practice Dementia Pathway

**Projected Outcomes:**

- Increase confidence in the diagnosis of early dementia
- 75% of newly diagnosed individuals with dementia receiving guideline care
- Efficient use of specialist resources

*Launched pilot testing of Pathway in Education Mentoring Program*
2 Dementia Education Mentoring Program

- **Core activities:** 8 specialists (Mentors) grouped with 24 GPs and NPs (Mentees) engaging in practice-relevant small group discussions focused on risk reduction, early diagnosis and referral to community supports.

- **Goal:** To develop a strong foundation of dementia knowledge and competency to enhance access and support for early diagnosis.

- Program Kick-Off Meeting held on Sept 25, 2017
  - Completion: May 2018

- CME Accreditation (40.5 Mainpro+ credits)

3 Culturally-sensitive resources

- **Core activities:** Development of culturally-sensitive dementia information, clinical tools and community supports for the South Asian population.

- **Goal:** To enhance awareness, access, and appropriateness of dementia care services for the South Asian community.
Needs Assessment Survey Results

- Conducted in 3 diverse, community venues within South Asian population.

- In the respondents’ opinion the following reasons could prevent early diagnosis of dementia:
  1. Lack of knowledge or awareness of dementia.
  2. Belief that not remembering things is a normal part of aging after 60 years of age.
  3. Language barrier
  4. Embarrassed of what people may say
  5. Patient and/or family does not want to get help or diagnosis

Culturally-sensitive elements of dementia care

- Fluency in English and health literacy are major health and clinical challenges in South Asians greatly impacting ability to be aware of dementia knowledge and their uptake and continued use of health care services for dementia.

- Many South Asian elderly are dependent on their children for commuting, handling finances and also communicating which makes them vulnerable for social isolation and planning for later stages of the disease.

- Social control and socialization are essential functions of the family system. Stigma surrounding dementia can be a huge barrier for the patient or family.

- The South Asian community is far more likely to view caring as their duty, and are less likely to move their family member into care outside the family;
  - this traditional view of caring can prevent caregivers from engaging and sharing the care responsibilities with a variety of service providers.
Supporting South Asian Persons with Dementia

- Conduct a MoCA in the language they are comfortable in.
- Encourage South Asian persons with dementia and caregivers to enroll into support groups or meet other persons living with dementia for connection and support.
- Approach interpreter services or use a member of your staff to convey information if they do not understand English very well. Give them translated material if available.
- Always keep family members in the loop while making decisions such as starting medications, as sometimes the older adults do not have the health literacy to understand what they are saying yes to.
- Discuss their diet with them as well as their caregiver who might be responsible for the cooking and caretaking.
- Be open about how alcohol drinking might impact their condition. Alcoholism is a huge issue in the South Asian community.

Culturally-Sensitive Resources

- Tools and Resources:
  - Punjabi MoCA: completed translation and cultural adaptation of the Montreal Cognitive Assessment Tool (MoCA) which is now available for world-wide use on www.mocatest.org
Culturally-Sensitive Resources

- Language and cultural adaptations to Punjabi MoCA:
  - Addition of elephant – more culturally known animal
  - Recall memory words are more culturally relatable
  - Replacement of culturally appropriate names of persons

- MoCA is available in 50+ languages online to reduce impact of language differences in administration of cognitive assessment and subsequently the diagnosis

Culturally-Sensitive Resources

- Translated Punjabi MoCA instructions include table of Months and Days in Punjabi for reference
Culturally-Sensitive Resources

- To provide culturally-sensitive support to persons in the South Asian community living with dementia and their families
- One year pilot of Punjabi-speaking South Asian Support and Education Coordinator, **Baljeet Judge**, at Alzheimer Society of BC’s First Link program (ending Oct 2018)
- **South Asian Dementia Helpline** (604-449-5003, M-F 9am-4pm)
  - Toll free #: 1-833-674-5003

Culturally-Sensitive Resources

- Available in Punjabi and Hindi at [https://ubccpd.ca/dementia-education-mentoring-resources](https://ubccpd.ca/dementia-education-mentoring-resources):
  - 7 Numbers for Early Dementia
  - Keep your Brain Healthy brochure
  - Simplified HandyDART instructions
- In Revision:
  - Intercultural Online Health Network (iCON) Getting to Know Dementia Booklet, South Asian Edition (Punjabi)
needs assessment survey results

- In the South Asian population, roughly 1 in 5 do not speak English. Other than English the most commonly spoken language is Punjabi (68%).

- 94% of the respondents specified that they would like to know more about dementia.

- Respondents preferred the following mediums to find out more information about dementia:
  1. Live talks/Events
  2. Newspapers/Magazines
  3. Television
  4. Radio

culturally-sensitive resources

- Public Awareness Campaign:
  - Series of live-talks, radio, TV, and newspaper engagement in the South Asian community from November 2017 to present
  - Series of newspaper articles published approx. monthly in Indo-Canadian Voice (English) and Awaaz (Punjabi) newspapers by Dr Jason Bains and Dr Leena Jain
  - iCON Healthy at Home – South Asian Health Forum held on March 4th 2018
Results So Far: Post-talk surveys

- **236 completed surveys**
- **80%** of attendees stated their understanding of the difference between normal aging and dementia to be more than before.

<table>
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<tr>
<th>Response</th>
<th>Chart</th>
<th>Percentage</th>
<th>Count</th>
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</thead>
<tbody>
<tr>
<td>More than before</td>
<td>Green</td>
<td>80%</td>
<td>163</td>
</tr>
<tr>
<td>Same as before</td>
<td>Yellow</td>
<td>10%</td>
<td>21</td>
</tr>
<tr>
<td>I don't know</td>
<td>Pink</td>
<td>10%</td>
<td>21</td>
</tr>
<tr>
<td><strong>Total Responses</strong></td>
<td></td>
<td><strong>205</strong></td>
<td></td>
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</tbody>
</table>

- **80%** of attendees stated their understanding of the signs and symptoms of dementia to be more than before.

<table>
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<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than before</td>
<td>Green</td>
<td>80%</td>
<td>168</td>
</tr>
<tr>
<td>Same as before</td>
<td>Yellow</td>
<td>8%</td>
<td>18</td>
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<td>I don't know</td>
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<td>12%</td>
<td>26</td>
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<tr>
<td><strong>Total Responses</strong></td>
<td></td>
<td><strong>212</strong></td>
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Results so far: Post-talk surveys

- After the talks, the attendees stated:
  - **97%** understood that they should talk to their doctor if anyone in their family or in themselves have signs of dementia,
  - **82%** increased their knowledge of risk reduction for themselves and their family, and
  - **84%** understood how to get information regarding dementia if needed.

*Very knowledgeable, now I know what my sister is going through. THANK YOU, You guys are doing a great job*

*Excellent talk, great knowledge, great communication style*

*Well thought out and beautiful, had a mix of good examples and information.*
How can we help manage this phenomena?

- Notice signs in patients and diagnose dementia early
- Appropriate connections with community resources
- Appropriate, culturally-sensitive care and resources
- Education, resources, and support to caregivers
- Appropriate referrals to First Link
- Hand out 7 Numbers for Early Dementia

An interdisciplinary approach is needed to stand up and tackle the tsunami of dementia cases in the next decade. Let’s help make this possible together.

Thank you for your partnership.
Questions/Comments?

- For more information or to access the tools and resources mentioned in this presentation, please connect with Project Manager Sarah Metcalfe (sarah.metcalfe@fraserhealth.ca)

References

1 Blue Matrix 4.0 (2009/2010), Planning and Innovation Division, BC Ministry of Health; PEOPLE 12.
1. Alternating Trail Making:

**Administration:** The examiner instructs the subject: “Please draw a line, going from a number to a letter in ascending order. Begin here [point to 11] and draw a line from 1 then to 2 then to 3 and so on. End here [point to 9].”

**Scoring:** Allocate one point if the subject successfully draws the following pattern:

\[1 \rightarrow 2 \rightarrow 3 \rightarrow 4 \rightarrow 5\]

without drawing any lines that cross. Any error that is not immediately self-corrected earns a score of 0.

2. Visuoconstructional Skills (Cube):

**Administration:** The examiner gives the following instructions, pointing to the cube: “Copy this drawing as accurately as you can, in the space below.”

3. Visuoconstructional Skills (Clock):

**Administration:** Indicate the right third of the space and give the following instructions: “Draw a clock put in all the numbers and set the time to 10 past 11.”
4. Naming:

**Administration:** Beginning on the left, point to each figure and say: “Tell me the name of this animal”.

**Scoring:** One point each is given for the following responses: (1) **lion** or **sher** (2) **elephant** or **Hāthī** (3) **camel** or **dromedary** or **oot**.

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5. Memory:

**Administration:** The examiner reads a list of 5 words at a rate of one per second, giving the following instructions: “This is a memory test. I am going to read a list of words that you will have to remember now and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn’t matter in what order you say them”.

The list of words to be read out in order are: **chehra** (face), **gurdwara**, **resham** (silk), **gutaab** (rose), **laal** (red).
6. Attention:
Forward Digit Span: Administration: Give the following instruction: “I am going to say some numbers and when I am through, repeat them to me exactly as I said them”. Read the five number sequence at a rate of one digit per second.

Vigilance: Administration: The examiner reads the list of letters at a rate of one per second, after giving the following instruction: “I am going to read a sequence of letters. Every time I say the letter [A], tap your hand once. If I say a different letter, do not tap your hand”.

The words to be read out in the exact order are:
Fafa, Baba, Aaed, Sasa, Muma, Numma, Aaed, Aaed, Jaja, Kaka, Laka, Baba, Aaed, Fafa, Aaed, Kaka, Dafa, vede, Aaed, Aaed, Aaed, Jaja, Aaed, Muma, Uda, Fafa, Aaed, Aaed, Baba
Serial 7s: Administration: The examiner gives the following instruction: “Now, I will ask you to count by subtracting seven from **100** (saun), and then, keep subtracting seven from your answer until I tell you to stop.” Give this instruction twice if necessary.

Listen for the following numbers during the subtraction:
100 (saun) – 93 (taranve) – 86 (chayasee) 79 (Donasee) – 72 (Bhattar) – 65 (Pehant)

For more assistance with numbers in Punjabi, please visit the following link for visual and audio aid: https://quaplet.com/16314436/punjabi.numbers.1-100.flash-cards/

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7. Sentence repetition:

Administration: The examiner gives the following instructions: “I am going to read you a sentence. Repeat it after me, exactly as I say it [pause]: I only know that Parminder is the one to help today.” = “Mainu bas ena pata hai ki mera Parminder hee meri mudaad karega.”

Following the response, say: “Now I am going to read you another sentence. Repeat it after me, exactly as I say it [pause]: The cat always hid under the couch when dogs were in the room.” = “Jado kuttae kamreheh which hundeh sun donon billee safte hait look jandi see.”
8. Verbal fluency:

Administration: The examiner gives the following instruction: "Tell me as many words as you can think of that begin with a certain letter of the alphabet that I will tell you in a moment. You can say any kind of word you want, except for proper nouns (like Bob or Boston), numbers, or words that begin with the same sound but have a different suffix, for example, love, lover, loving. I will tell you to stop after one minute. Are you ready? [Pause] Now, tell me as many words as you can think of that begin with the letter [letter] (= F). Time for 60 sec. Stop."

9. Abstraction:

Administration: The examiner asks the subject to explain what each pair of words has in common, starting with the example: "Tell me how an orange (orange) and a banana (banana) are alike". If the subject answers in a concrete manner, then say only one additional time: "Tell me another way in which those items are alike". If the subject does not give the appropriate response (fruit), say, "Yes, and they are also both fruit." Do not give any additional instructions or clarification.

After the practice trial, say: "Now, tell me how a train (train) and a bicycle (bicycle) are alike". Following the response, administer the second trial, saying: "Now tell me how a watch (watch) and a scale (scale) are alike". Do not give any additional instructions or prompts.
11. Orientation:

Administration: The examiner gives the following instructions: "Tell me the date (Tareekh) today". If the subject does not give a complete answer, then prompt accordingly by saying: "Tell me the [year, month, exact date, and day of the week] = [jaal, meheena, tareekh, din]." Then say: "Now, tell me the name of this place (Logah), and which city (Shehar) it is in."

The months of the year and days of the week can be stated differently (but correctly) in the Punjabi language. Please refer to the tables below when scoring.