Talking About Dementia

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Conflicts of Interest

- None to report

Orders from Paul

- Intended as introduction to dementia
  - What is dementia and the commoner types (specific request to talk about frontotemporal dementia)
  - Progression
  - Causes, reducing risk, and prevention
  - Treatment options
  - Quality of life for person with dementia and their family members
  - Research updates
- Questions that have come up at recent events

Hope You Brought Lunch!

Doesn't Mean You Have Dementia Every Time You Forget Something

- We all forget things – about once per day
- Normal aging – some things improve and there is a lot of variability but typically
  - Mild decline in memory (retrieval - get with cueing, "tip of the tongue")
  - Trouble with attention (difficulty focusing/ more distractible)
  - Not as fast
  - More challenges with tasks that require taking in & analyzing new information

Concern That Should be Checked

- AD8 questionnaire – 2+ change in the last several years caused by cognitive problems in following 8 areas
  - Judgment problems, less interest in hobbies/ activities, repetition, trouble learning how to use tool/ appliance/ gadget, forgetting month or year, trouble handling complicated financial affairs, trouble remembering appointments, daily trouble with thinking and/ or memory

Mild Cognitive Impairment

- Also called ***Mild Neurocognitive Disorder***
  - DSM-5 (5th version of Diagnostic and Statistical Manual of Mental Disorders)
- Boundary area between normality & early dementia
  - Thinking complaint (usually memory)
  - Impaired on testing
    - Recall of information from paragraph read to them
  - Preserved general thinking abilities & still independent
    - Complicated tasks may take greater effort, adaptation or compensation)

Mild Cognitive Impairment

- While not all people with *Mild Cognitive Impairment* get worse (many stay the same or get better), about 10-15% per year progress to dementia
- What do you do?
  - Search for cause, advance planning, healthy living, monitor for change (may be target group for interventions in the future)

Dementia

- Also called ***Major Neurocognitive Disorder***
- Acquired impairment in thinking
  - Usually includes memory and other aspects of thinking (like decision-making and speech)
  - Severe enough to interfere with your ability to live independently
  - Can't be better explained by something else like depression or acute confusion (delirium)

Causes of Dementia

- Many potential causes of dementia - alone or in combination
- Commonest (middle-aged and older adults)
  - Alzheimer disease
  - Combinations (especially as we get older)
  - Dementia with Lewy Bodies
  - Vascular Dementia
  - Frontotemporal Degeneration
- Rarer causes
  - Includes alcohol-related, traumatic brain injury/ chronic traumatic encephalopathy (CTE), and many others

Commoner Causes

- Alzheimer dementia – starts with recent memory problems
- Lewy body dementia – visual hallucinations, vary from day to day, features of Parkinson disease, sleep problems – act out dreams
- Vascular dementia – evidence of strokes/ damage from cerebrovascular disease by history, examination, and brain imaging
- Frontotemporal dementia – starts with language or behavioural problems

Progression of Dementia

- Depends on person, general health, type of dementia, and other factors
- Alzheimer disease - worsen over time though rate varies; 4-8 yrs after diagnosis (mild stage)
  - Preclinical: Changes in the brain related to Alzheimer years before any signs of the disease
  - Mild Cognitive Impairment – problems on testing
  - Mild – start to have functional problems
  - Moderate – symptoms more evident & more of an impact (tends to be the longest)
  - Severe or advanced – in need of 24-hour care

How It Is Diagnosed

- Evaluate if suspicion (like AD8)
  - Starts with family doctor
- History from the person – thinking, function, behaviour
- Interview a family member/ someone who knows them well
- Examination
- Cognitive (thinking) test & depression screen
- Laboratory tests
- Brain imaging in many

Would Hope It Never Occurs

- If we address tobacco, poor diet, physical inactivity, high BP & cholesterol, obesity, & diabetes might reduce the likelihood of developing (up to 20% over 20 years), progression, & severity of dementia
- Could possibly add to this by encouraging protective factors (stimulating our brain, social engagement, sleep) & minimizing other risky ones (traumatic brain injury, excessive alcohol intake & substance abuse, depression/ stress/ neuroticism [tendencies to respond negatively to threats, frustrations, or losses], poor hearing) but research needed

Now and the Future

- The aging of Canadian society is expected to lead to a large increase in the number of people with dementia
  - Estimated in 2016 that there were 564,000 persons in Canada living with dementia
  - By 2031, it is estimated that the number will increase to 937,000 – Prevalence and Monetary Costs of Dementia in Canada. Alzheimer Society of Canada 2016

Promising News

- Recent studies suggest that in high-income countries, the risk of dementia at specific ages may have declined over the past 25 years
- National American study compared rates in 2000 & 2012
  - Likelihood of dementia decreased from 11.6% among those 65+ in 2000 to 8.8% (24% decline)
  - May be partly accounted for by education (1 year more on average) & better treatment of cardiovascular disease but don't fully understand

Care of the Person with Dementia

- Complex – needs change over time & also caregiver ("hidden" patient); most non-drug related
  - Inform the person with dementia (& family) of diagnosis/ answer questions they may have
  - Identify if there is caregiver & how they are doing
  - Assess safety, advance planning/ decision-making abilities, Alzheimer Society, & provide information of treatment options (drug/ non-drug)
  - Agree on a plan (update as needed)
  - Follow over time – monitor response to interventions
  - Mobilize resources as needed

Drug Treatment

- Available drug therapies for the commoner types of dementia such as Alzheimer's disease are only modestly effective and don't work for all
  - Cholinesterase inhibitors most commonly used
- Recent trails for new drugs have been disappointing but are still on-going
  - Treatment started too late?
  - Don't fully understand the underlying cause/ causes in a particular individual
  - Complex disease where one drug on its own may not work

Living Well with Dementia

- "**Our aim is that all people with dementia and their carers should live well with dementia.** There is no doubt that the dementias are a devastating set of illnesses and that they have profound negative effects on all those affected, be they people with dementia or their carers. However, it is also clear that there is a vast amount that can be done to improve and maintain quality of life in dementia." - Living Well with Dementia: A National Dementia Strategy

Factors Affecting Ability to Live Well with Dementia

- Assets and resources
  - Social (contact, relationships, help & support), housing, economic, physical, & psychological (self-esteem, optimism) factors
  - Access to/ use of services
- Challenges
  - Severity of dementia & symptoms experienced
- Adaptation
  - How we manage & cope with the challenges dementia brings

What Persons with Dementia Find Helpful in Dealing with Their Illness

- Engaging with life
  - Seeking pleasure and enjoyment, keep going, love and support
- Engaging with dementia
  - Facing it/ fighting it, humor, hope
- Identity and Growth
  - Giving thanks, “still being me” (Still Alice), growth and transcending – Aging & Mental Health 2016, 20: 676-699

Dementia-friendly Communities

- Help people with dementia feel included & supported in the places they work, live and play; began in Japan and then spread to the United Kingdom
- Focuses on stigma reduction and the inclusion of people with dementia
  - People are educated about dementia and know that a person with dementia may sometimes experience the world differently
  - People living with dementia feel supported by their community members wherever they are
- The term “community” can mean a location like a neighborhood but can also include groups of people with shared interests or features

Questions

- Examples from prior sessions
- Qualifications
  - Represent my opinion
  - Provide a general response but not specific
  - “Context is all” (Margaret Atwood)

Questions

- Do drugs cause dementia?
  - *When association found it can be very hard to know if*
    - *It is by chance;*
    - *Explained by the reason the person is taking the particular medication – could be an early feature of a dementing illness or risk factor for its later development; or,*
    - *The drug*
  - *Some drugs might be associated with a higher **risk** but unlikely to be the sole cause (make-up/ genes, exposures during life, and time/ age)*
    - *Anticholinergics and sedatives*
  - *On balance need to determine whether a drug is more beneficial or harmful*

Questions

- Down Syndrome and dementia
- Traumatic Brain injury (TBI)
  - *Moderate-severe TBI leads to a greater risk of developing Alzheimer later in life but no evidence single mild TBI increases dementia risk*
  - *Emerging evidence suggests repeated mild TBIs, such as what can occur in contact sports like boxing, football, and hockey may be linked to a greater risk of a type of dementia called chronic traumatic encephalopathy (CTE)*
- Is Alzheimer contagious?
  - *No - Alzheimer disease is not a contagious disease and transmissible by, for example, caring for someone with Alzheimer; there is work looking at whether viruses we carry in our bodies may incite changes in the brain that lead to Alzheimer changes*

Questions

- Is Alzheimer hereditary*?*
  - *In a small (< 5%) proportion it is caused by mutations of certain genes + there are a number genes that can increase your susceptibility; there are genetic risk factors*
- Does MS (Multiple Sclerosis) cause dementia?
  - *Some people with MS experience a loss of mental abilities if damage caused by the MS occurs in certain parts of the brain; the mental abilities most likely to be affected are memory, concentration and problem solving; there may also be emotional problems, such as mood swings; the term "dementia" is not generally used in association with multiple sclerosis because the decline is not usually that severe*

Questions

- Is Alzheimer type 3 diabetes?
  - *Some researchers believe that Alzheimer represents a form of diabetes that selectively involves the brain and has features that overlap with both type 1 and type 2 diabetes*
  - *Type 2 diabetes increases your risk of developing Alzheimer disease (but not likely sole cause)*
  - *Deterioration of the brain's ability to use and metabolize glucose in Alzheimer*
  - *Diabetes medications have been/ are being studied as therapy for Alzheimer disease (not proven)*

Questions

- Sleep and Alzheimer disease
  - *Poor sleep may be bad for the brain and increase the risk of Alzheimer's disease + people with Alzheimer disease tend to sleep poorly and spend more time awake at night (hard to know what is causing what – may go both ways)*

Questions

- Is it possible to have amyloid plaques in the brain and not have a dementia?
  - *Yes –amyloid plaques is a pathological hallmark of Alzheimer (if you don't have abnormal amounts of amyloid or tau in your brain, you don't have Alzheimer) but they can be seen in the brains of about a quarter of older persons who have no cognitive concerns - may not be enough (or not in critical areas), may be with time problems will occur, or it may be that some can "work-around" these changes*

Questions

- Tests for early diagnosis of Alzheimer
  - *The approach I outlined*
  - *Before the onset of any symptoms can search for a number of the rare mutations that can cause Alzheimer (but this would only affect those few people where there is a high suspicion of inherited Alzheimer)*
  - *There are emerging tests for amyloid deposition in the brain but not recommended at this time if no symptoms as not everyone will develop Alzheimer dementia*

Questions

- Care
  - Should you tell the person who has the disease that they have it? *Yes*
  - How should family members handle talking about a diagnosis of dementia? *Acknowledge it when it comes up but don't insist person "accepts" it*
  - Once an individual receives the diagnosis of Alzheimer who is the best caregiver? *Depends*

Questions

- Care
  - When to decide that a person with dementia needs to move into a facility*? Balance between their needs/ types of problems encountered and available resources*
  - Are routines helpful for someone with dementia? *Yes*

Questions

- Behavioural issues
  - Referred to as behavioural expressions, responsive behaviours, behavioural and psychological symptoms of dementia, and neuropsychiatric symptoms of dementia
  - Common – 90% at some point
  - While progressive deterioration of thinking underlies these problems, consider the person, precipitants (e.g., unrecognized pain or the environment/ over stimulation) & the impact of your reaction
  - Non-drug treatment should be considered first

Questions

- Behavioural issues
  - Examples that ***may*** occur include changes in mood (apathy, depression), repetitive behaviour, anxiety/ agitation, shadowing (following you closely around the house like a shadow), delusions & hallucinations, sundowning (more confused, anxious or restless later in the day), wandering, and aggressive behaviour
  - Denial - not “denial” but lack of awareness (***anosognosia***) - focus on mitigating effects rather than trying making person understand/ accept diagnosis
  - If the answer is upsetting (e.g., asking about someone who has passed away), do you continue to tell them bad news? *No if there is no constructive purpose*
  - Can't recall our last visit but I've been there regularly - do I argue & remind her that I have been there recently? *No*

Questions

- What kinds of research projects /trials are being done in Calgary right now –
  - *http://www.c5r.ca/current-studies/*
  - *http://c5r.ca/c5r-sites/*
- How can one participate in these studies?
  - *Identify researcher/ research project, review study, decide if willing to enrol, and see if meet entry criteria*
- How to deal with the stigma of the disease and how to deal with community or society's response to a diagnosis (fear or sharing it)?
  - *Important & difficult issue*

ArtOnTheBrain

- Web-based application (app) aimed at promoting cognitive health and well-being in older adults aging at home through mentally and socially engaging recreational activity (visual art - https://www.learnplaymingle.com/)
- People with or without mild cognitive problems (can do it with a partner)
- Play with app 2x/week (30 minutes) for 6 weeks
- Two assessments visit (start and end)
- Interested contact Jessica Lee (jessica.lee1@ucalgary.ca/ 403-210-6371)

And …

Thank you