Do carers of people with intellectual disability identify the early signs of dementia?

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Defining the problem: the Kairos moment

Propositions:
People who have both intellectual disability and loss of cognitive skills are rarely diagnosed with early dementia

Hypotheses:
The difficulties that carers experience in providing information to professionals during assessment contributes to people with intellectual disability not receiving an early diagnosis of dementia
What does the Research say: A systematic review


- A paucity of research in carer involvement in health interventions.
- Identified that using carer provided information is one way of improving the health of people with intellectual disabilities.
- Only 4 studies found on carer dementia reporting.
What does the research say? : Global perspective

Dementia care has become an important and urgent global issue posing a major current and future challenge for health economics.

There were estimates of 35.6 million people living with dementia worldwide in 2010 and this number will increase to 65.7 million by 2030 (Alzheimer’s Disease International, 2010).
Dementia is common among people with Down’s syndrome, yet diagnosis of dementia, particularly in its early stage can be difficult to identify in this population (Deb, Hare, Prior, 2007).

Within Down’s Syndrome, the prevalence of dementia up to the age of 60 years was 16.8%. The history of depression had a strong correlation with people diagnosed with dementia (Copus, Evenhuis, Verberne, Visser, Gool, Eikelenboom & van Duijin, 2006).
Early diagnosis will continue to be of growing importance both to support symptomatic treatment and prevent irreversible neuropathology (Krinsky-McHeale, Silverman, 2013).

While the disability field has for some time recognised the need to develop best practice for the diagnosis of mild cognitive impairment and dementia, there remains a pressing need for empirically based assessment methods and classification criteria (Krinsky-McHeale, Silverman, 2013).
What does the Research say? : Carer involvement in identification of symptoms of dementia.

Carers of people with an intellectual disability frequently need assistance to identify and verbalise changes in a person’s health and behaviours (Whitwhem and McBrien, 2010).

Retrospective carer reports of changes in everyday function were good, however memory change was the only positive identifier of dementia in people with mild intellectual disability. Decline in everyday function was a better indicator with moderate to severe intellectual disabilities (Jamieson-Craig, Scior, Chan Fenton & Strydom, 2010).
Normal changes as people age with intellectual disability

As people age their bodies and capabilities change. Examples of changes people may experience:

- Reduced vision
- Decreased muscle strength or endurance
- Reduced mental processing capabilities
- Increased risk of falls due to balance issues
- Increased risk of illness
- Reduced hearing
- Decreased mobility

Ageing in place

Ageing in place is a term used to describe a person living in their current accommodation for as long as they are able, as they age.

This includes being able to have any services (or other support) they might need over time as their needs change.


Ageing in place is everyone’s right.

This is not different if the person has an intellectual disability.
Why is it important to identify dementia in people with intellectual disability?

**FACTS:**
- People with an intellectual disability, dependant on services to sustain a life in the community, need to have the services reviewed over time to ensure changing needs are identified and met.
- As people age / suffer from dementia, they typically have increased health needs.
- Modern health services can provide medication and therapies to increase quality of life, for people with intellectual disability and dementia.
- Changes in accommodation need assessments and planning THIS TAKES TIME.
The functions of the brain

• The brain is an organ that serves as the centre of the nervous system

• The brain has centralised control over the other organs in the body (The brain acts on the rest of the body by generating patterns of muscle activity and by driving the secretion of chemicals called hormones).

• The brain is the most complex organ in the body (In a typical human, the cerebral cortex (the largest part on the outside of the brain), is estimated to contain 15–33 billion neurons (cells), each connected to several thousand other neurons).

• Brain activity gives rise to consciousness and navigates the world (judgment; memory; orientation; intelligence; liability/mood).

Clarifying the presentation of Dementia

• Each person experiences dementia in their own way however, for the carer it is often better to see the disease as progressing through stages

• Dementia usually begins gradually with very minor changes in the persons abilities or behaviour. The changes are often identified only as the client condition progresses

• Dementia is a disease that eventually claims the persons life. Life expectancy usually 7 to 10 years after early diagnosis

• There are many types of dementia

NOTE: People with intellectual disability are not often diagnosed until the disease has progressed - so much shorter time frame. Retrieved from: alzheimers.org.uk on August 15th 2014
Frequency of dementia in community

- As people age, their risk of developing dementia increases. [Link](http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp) on August, 25th 2014

- Dementia affects 25% of the general population over the age of 85 years. [Link](http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp) on August, 25th 2014

- Many syndromes within the spectrum of intellectual disabilities age at a faster rate. [Link](http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp) on August, 25th 2014

- In 1929 life expectancy for People with Down syndrome was 9 years. In 1989 it was 57 years. (Deb, Hare, Prior, 2007).

- Studies suggest that more than 75% of people with Down syndrome aged 65 and older have dementia. [Link](http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp) on August, 25th 2014
Anatomy of the human brain

What happens to the brain in dementia

https://www.google.com.au/search?q=dementia&hl=en-GB&rlz=1T4GGHP_en-GBAU591AU595&source=lnms&tbm=isch&sa=X&ei=FcVeVLK7Come8QX2IoHYDA&ved=0CAkQ_AUoAg&biw=1366&bih=589
What happens to the brain in dementia (PET)
Diagnostic overshadowing can lead to attributing (and therefore dismissal) of symptoms of disease process within a person with intellectual disability (Brown, 2005; Sowney & Barr, 2006).

The failure to see a problem because the symptoms are attributed to another disability (Psychology dictionary, 2014).

Diagnostic overshadowing refers to the process of over-attributing a patient’s symptoms to a particular condition, resulting in key comorbid conditions being undiagnosed and untreated (Vahabzadeh, 2014).
See the whole person and look for changes

Living Well with Long-Term Conditions  www.scotland.gov.uk
Diagnostic overshadowing: Implications

Observation: Problems with the identification of changes [in a person’s] presentation

• The carer or clinician does not seek to define the symptoms; they often don’t have the words. They do not document changes or seek further advice

• The carer often dismisses changes in the person and attribute them to something else

• The carer does not convey changes in the presentation because they do not understand the significance of what they observed

• A paid carer can change positions

• A carers often doesn’t understand the significance of a diagnosis
The population of people with an intellectual disability is rising; this is partly due to greater survival of premature babies but also to the greater longevity (Gibbs, Brown & Muir, 2008).

Maladaptive behaviour including self-injurious behaviours, temper-tantrums or violence towards carers are common among aging adults with intellectual disabilities. These factors contribute towards difficulties with health assessment, diagnosis and treatment of people with intellectual disabilities (Chu, 2014).
Presentation to health services: Diagnosis of dementia

Owing to their often complex and co-morbid health problems, people with intellectual disability are frequent users of the allied health and the health system (Brown, 2005; Sowney & Barr, 2006).

Observations / questions

• People with dementia are being reviewed by allied health and health professionals everyday; we see them everyday and often we don’t see the changes.
• Why don’t they attract the diagnosis of dementia?
• Even if a diagnosis of dementia is made; actions or plans are rarely made.
Three stages of dementia: Early stage.

Gradual onset with very minor changes in the persons abilities or behaviour.

- Forget about recent conversation or events.
- Repeat themselves.
- Become slower at grasping new ideas and find it difficult to learn new things.
- Lose track of the conversation or what they are doing.
- Can become confused about what is happening around them.
- Often show poor judgement and find it hard to make decisions.
- Often lose interest in life long activities or social events.
- Cover their forgetfulness; they will blame people for moving things they can not find.
- Reluctance to anything new; become anxious and withdraw

Retrieved from: alzheimers.org.uk.
Three stages of dementia: Middle Stage

As dementia progresses the changes in the clients abilities and emotional stability become more evident.

- Can become very upset, angry or aggressive; perhaps because they are feeling frustrated.
- Clients can also become very “clingy” as they don’t know what they are doing or where they are.
- Often become confused; may walk off and become lost.
- Become confused about the difference between day and night.
- Start putting them selves and others at risk due to behaviours e.g. forgetting to lock doors; wander into traffic.
- Behave in ways that are unusual e.g. taking clothes off.
- Difficulties with perception e.g. illusions or hallucinations.

Retrieved from: alzheimers.org.uk
Three stages of dementia: Late stage

Needs help with all aspects of daily living as they forget how to do tasks. Often forget the names of life long carers; unable to recognise familiar object or surrounding e.g. long term home.

- The client will become increasingly frail.
- Unsteady on feet, shuffle when they walk and fall frequently. Eventually the will be confined to a bed or wheelchair.
- Difficulty in eating and drinking (dysphagia).
- Considerable weight loss (brain forgets to tell the body to digest the food).
- Incontinence as they lose control over their bladder and bowel.
- Gradual loss of speech; they may retain a few words which they repeat.
- Often become restless and appear as if they are looking for something.
- May become increasingly distressed and agitated.

Retrieved from: alzheimers.org.uk
Pause for Reflection

- Clinicians often rely on carer reports to identify change in the person with ID.

- Retrospective carer reports of changes in everyday function was good, however memory change was the only positive identifier of dementia in people with mild intellectual disability. Decline in everyday function was a better indicator with moderate to severe intellectual disabilities (Jamieson-Craig, Scior, Chan Fenton & Strydom, 2010).

Question:
- How do Clinician identify changes; what do we ask carers?
Identified areas of decline.

- Downs Syndrome – experience an earlier appearance of Frontal Lobe dysfunction (Deb, Hare & Prior. 2007).

Remember: **J.O.M.I.I.L**

- **Judgment** – loss of ability to assess a situation and make a decision.
- **Orientation** – to time, place and person
- **Memory** – Reduced short term memory is often the first thing people notice; this decline eventually effects long term memory
- **Irritability** – often have escalations of agitation and aggression with no evident antecedent
- **Intelligence** – experience loss of previous knowledge and unable to rationalise information
- **Lability** – frequently experience unstable mood

Diagnosing dementia: Cognitive considerations
Early signs of dementia checklist

Reference:

This document can be purchased from Docstoc.
Other dementia assessments

http://editthis.info/psy3241/Mini_mental_state_exam

Mini-Mental State Examination

Section | Score | Task
--- | --- | ---
Orientation | 5 | What is the date: year, season, date, day, month
| 5 | Where are we: county, country, town, hospital, floor
Registration | 3 | Name three objects – 1 second to say each, then ask the patient to recall all three, repeat until the patient has learnt all three. Count and record trials
| 5 | Serial 7s: one point for each correct. Stop after 5 correct. Alternatively spell "world" backwards
| 3 | Ask for the 3 objects repeated above – Give an example of each
Language | 2 | Name a pencil and watch
| 1 | Repeat the following: "no, it, ands or busa"
| 3 | Follow a 3-stage command: "take a piece of paper in your right hand, fold it in half and put it on the floor"
| 3 | Read and obey the following: "close your eyes", "write a sentence", "copy a design"

Score: 30

Score results:
30–20 normal
25–18, marked cognitive dysfunction; dementia may be diagnosed
< 17, severe dysfunction; severe dementia

Diagnosis of dementia: Physical considerations

Identified areas of need:

1. Full medical assessment (often have declining health):
   • Are there any contributing medical conditions?
   • Does the person qualify for dementia delaying medication. e.g. Cholinergic treatments?
   • Is there any syndrome specific information that is relevant. e.g. Downs Syndrome?
2. Ongoing monitoring
3. Assessment for safety
4. Allied health support as needed (mobility, swallowing, nutrition, carer training in behaviour management)
5. Ongoing assessment for support levels
6. Education for carers
7. Special equipment ordered as needed
8. Accommodation needs assessment
Communication for carers is often the problem

**Definition:**
A process of sending and receiving messages between two or more individuals attempting to achieve an action or effect. It can be verbal (all aspects of speech) and non-verbal (body signals, eye contact, facial expression, posture and gesture) (Spethenson, 2008. Dictionary.com, 2013. Webster Dictionary, 2013).

**Context:**
• Communicating is complex: Greater than 90% of communication is voice inflection, facial expression and body language (Yoder-Wise & Kowalski, 2006).

• The only thing humans do more than communicate is breathe, yet communication is a challenge (Patterson, Grenny, McMillan & Switzler, 2002).

• We can’t help communicating; even the act of non-communication provides some form of communication.
Looking through the eyes of a carer

• Filters in communication distort the messages being delivered.

**Reasons:**
• Personal characteristics and life experience.
• Mental state / Emotional state.
• Assumptions.
• Hidden agendas and intention.
• **Beliefs** (Carolpio & Andrewartha, 2012.. Yoder-Wise & Kowalski, 2006).

**Question:** Who is responsible for making the communication effective?
Carers and the use of jargon, acronyms and the effect of beliefs

- All organisations have their own labels, jargon and abbreviations (acronyms).
- They are a major barrier to communication when services talk to each other.
- Jargon effects the use of everyday words within the community and results in the misuse of words.

Note:
- “Labels” influence the way listening occurs
Health literacy plays an important role in enabling effective partnerships. In order for partnerships to work everyone involved needs to be able to give, receive, interpret and act on information.

When these conditions exist, there is the potential to not only improve the safety and quality of health care but also to reduce health disparities and increase equity (Australian commission of safety and quality in health care, 2014).
That word — BEHAVIOUR

Definition:

• Behaviour is the range of actions, reactions and mannerisms made by the person in conjunction with their environment in any situation. This includes interacting with other people (Webster Dictionary, 2013).
• The word behaviour is a conjoined noun.
• Behaviour can be a result of internal stimuli (e.g. happy, sad), or external stimuli (e.g. hot, cold).
• Can be a conscious decision, subconscious, overt or covert, voluntary or involuntary.
• The word behaviour is not a stand alone diagnosis.
Realisation of a problem

Outcome:
Intellectual disability support staff and carers often use used words differently.

Sender → Message → Receiver

expressive language

Wrong Words

feedback

recipient language

verbal, written, pictorial, visually, behavioural expressive, olfactory, tactile, electronic, record of sound or picture

(Adapted from Marquis & Huston, 2012)
Take home message

• All carers and clinicians need knowledge/awareness of dementia and its related issues (Tsaroucha, Benbow, Kingston & Le Mesurierlf, 2013).
• Document baseline adult function by age 35 years.
• Watch for changes in day to day function.
• Rule out other causes of symptoms (Alzheimer's association, 2014).
• If an older person presents with any changes in functioning level or behaviour. Ask yourself - is this dementia?
• Remember early diagnosis allows for medical reviews, medications and planning for the future.
• Carers/parents need ongoing support and education.
NSW Carers Charter: An excerpt

- Recognise the contribution carers make. Support them
- Listen to carers
- Respect and support carers choices, knowledge and experience
- Find out from the carer what support and services they need
- Take into account the difficulties carers face in accessing services
- Recognise that all carers are different

(NSW Carers Charter, NSW Carer Recognition Act, 2010).


Chu, W.H. 2014. Residential Age Care: older people with intellectual disabilities. The Joanna Briggs Institute


References List 2.


Mini Mental State Exam; Retrieved on October, 10th from: http://editthis.info/psy3241/ mini_mental_state_exam


References List 3.


References List : Pictures


Brain image 1; Image WO52NJH. https://www.google.com.au/search?q=dementia&hl=en-GB&rlz=1T4GGHP_en-GBAU591AU595&source=lnms&tbm=isch&sa=X&ei=FcVeVLK7Come8QX2loHYDA&ved=0CAkQ_AUoAg&biw=1366&bih=589

