Dementia in People with Learning Disabilities

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Overview

- Context
- Challenges
- Current standards
- Local services
- Pharmacological intervention
Why is dementia in learning disability important?

- Increasing life expectancy in people with LD
- Prone to develop age-related disorders such as dementia
- Well recognised association between Down syndrome and Alzheimer’s
Findings from key studies

Dementia rates in **normal population**:
- 60 - 65 = 1%
- 80 - 85 = 13%
- 90 - 95 = 32%

Dementia rates in **Down syndrome**:
- 40 - 49 = 9.4%
- 50 - 59 = 36.1%
- 60 - 69 = 54.5%
- Average onset 54 years
- Average duration from dementia to death 4.6 years

(Prasher, 1995)
People with LD without Down syndrome

• Dementia also about **4 times more common** as compared to general elderly population

• Prevalence
  – Age ≥ 60 = 13%
  – Age ≥ 65 = 18%

(Cooper, 1997, Strydom et al, 2007)
Difficulty in diagnosing dementia in LD

• HOW CAN YOU TELL?

Their baseline functional levels are all different
– Different levels of LD
– Premorbid cognitive deficits
– Diagnostic overshadowing
Pre-morbid cognitive deficits

- Standard assessments e.g. MMSE not appropriate
- Can’t rely on cross-sectional assessment
- Need to more explicitly look for change from an individual’s own baseline
  - Value of baseline cognitive screening?
- Reliance on informant report, but
- Reliable informant history often not available
Atypical presentation

• Often don’t complaint of memory problems themselves

• Functional/ADL decline

• Behavioural and emotional change
  – Rather than memory decline in early stages
    (Strydom et al, 2007; Jamieson-Craig et al, 2010)

• Onset of epilepsy sometimes 1st sign
Moderate to severe LD

- Limited communication skills
- More difficult for carers to notice and clinicians to interpret change
- ‘Floor effect’
Mental, physical and social co-morbidities

E.g.

– Sensory impairment
– Hypothyroid
– Depression
– Poor epilepsy control
– Poor pain management
– Major live events e.g. poor health of carer
– Abuse

» MIS-DIAGNOSIS!
Diagnostic uncertainty

• Difficult to ascertain whether dementia or not in early stages in many cases

• Burden of mis-diagnosing vs. burden of late diagnosis
Current ‘gold standard’ in diagnosis and assessment

- Recently published Joint British Psychological Society and Royal College of Psychiatrists guidelines (CR155)

- Multidisciplinary approach to assessment and management
  - Early: nursing, psychology, psychiatry, OT, care management
  - Late: SALT, nursing, care management, physio
Current service configuration

• Where should referrals go?
  – Mainstream old age mental health / memory clinics?
  – LD teams?

• Lots of variations between boroughs

• Care pathways not yet established in many, but are developing

• Do check with local services if uncertain
Mainstream vs. Specialist service

• Mainstream service
  – Normalisation
  – Better access to wider range of diagnostic services
  – May not have expertise in LD

• Specialist service
  – Expertise in LD
  – More coherent and continuity with rest of LD care package
  – More limited access to diagnostic services
  – Lack of critical mass: more difficult to justify business case and for clinicians to build up same level of expertise in dementia
Possible solutions

• Mainstream services with LD specialists input

• Cross-borough specialist LD dementia service
Oxleas developments

• Reconfiguration work – two dementia pathways
  - Diagnostic / early dementia
  - Mid/late stage
• NICE guidelines audit
• Training
• Care mapping
• Development of user materials
• Carers support group
• Transfer protocol with older person’s services
Bexley

- Monthly ageing issues clinic.
  2008-2009. 26 people discussed - 20 with Down syndrome
  10 Probable dementia (4 since died)
  1 possible dementia
  5 complex issues
  10 unlikely/unknown
- Database (Down’s Syndrome LD and LD)
- Many baselines present
- MDT Care pathway
Greenwich

- Mainstream memory clinic had not accepted somebody with LD
- No age-related clinic within CLDT
- Database
- Different aspects of dementia care provided by different disciplines
- Working group developing care pathways
Bromley

- Monthly clinical meeting within CLDT

- Different aspects of dementia care provided by different disciplines
Acetylcholinesterase inhibitors

- No evidence to suggest they should not be used in LD

- More difficult to determine moderate dementia – can’t use MMSE!

- LD psychiatrists now included as specialists in NICE guidelines

- Shared care protocol
Use of neuroleptics for behavioural difficulties

• Do avoid if possible

• Increased risk of CVA with atypical neuroleptics

• Risk-benefit balance
References


References
