Dementia – Where are we up in Science of Care?

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Today’s topics

• Diagnosis & post-diagnostic care
• Community Care
• Acute care
• Residential care
• Care of behavioural and psychological symptoms (BPSD)
• Caregivers
• Conclusion
Diagnosis and post-diagnosis in primary care
Diagnosis – what do we know?

• 2-3 year gap to diagnosis
• ≈ 50% of persons with dementia are not diagnosed in primary care
• Only 42% expected cases diagnosed in UK
• Early diagnosis allows people to plan, strategies to reduce cognitive and neuropsychiatric symptoms, access social and voluntary care

1 Connolly A et al Aging and Mental Health 2011 15, 978–984.
2 Walker IF et al Primary Health Care Research & Development, 2017 DOI: https://doi.org/10.1017/S146342361700007X
3 Livingston G et al, PLoS Medicine 2017
Diagnosis – what do we know?

- Family carers report difficulty in obtaining a diagnosis of dementia for their relative
- Delays cause anxiety and carer burden
- People with memory problems are reluctant to consult their GP about it and deny problems

Livingston G et al, PLoS Medicine 2017
Diagnosis – what do we know?

- Barriers to seeking help or diagnosis:
  - fear, stigma, GP disinclination, negative responses from other family members, normalisation of symptoms, lack awareness about dementia signs

- Barriers for GPs – attitude, knowledge, nihilism, time, lack of rebate, fear of alienating patient, etc

Diagnosis – what do we know?

In Australia:
- Academic detailing did not improve diagnosis in 1994 but did improve identification in 2016\(^1,2\)
- Systemic review of interventions for GPs
  - GPs’ ability to diagnose could be increased but not their rate of diagnosis \(^3\)

\(^1\) Pond D et al Fam Pract (1994) 11 (2): 141-147
\(^2\) Pond D et al, in prep
Diagnosis – what do we know?

Initiatives to attain timely diagnosis in UK:

- 2014 £55 bounty for GP diagnosis abandoned March 2015

- W. Midlands: 2017, introduced £150 for each pt. diagnosed and treated to reduce wait for memory clinic appointments!

- Target patients rather than GPs
  - RCT of letters to GP attendees → more attendances but not more referrals for Dx¹

¹ Livingston J et al, PLoS Medicine 2017
Diagnosis: what do we know?

- Swedish registry (*SveDem*)\(^1\)
  - significant improvements 2011 → 2015
    - completed basic investigations increased by 23%
    - diagnosis of “dementia not otherwise specified” decreased by 15%
  - GPCOG > efficient than MMSE, >14 languages\(^2\)

Dx in primary care: what we know?

- Interventions can improve knowledge and skills but do not always translate into action
- GP & patient interventions alone don’t work
- Low referral rates → specialist, Alz Assoc
- After assessment, paucity of information re:
  - Diagnosis
  - Management
  - Prognosis

1 Brodaty et al, 1990; 2 Low LF et al, under review
Primary Care Diagnosis & Management: What don’t we know?

- How to improve GP practice
- What is best model for primary care diagnosis?
  - Financial incentive X, education?
  - Practice nurses?
  - Memory clinics?
- How to move to Re-ablement\(^1\) from Prescribed disengagement®\(^2\)

\(^1\)Low L et al, submitted, \(^2\)Swaffer 2016
Primary Care Diagnosis & Management: where to now?

• Reduce stigma, nihilism
• Improve diagnosis & post-diagnosis
• Different model – positive living with dementia
  • Prescribed engagement
  • Rehabilitation program cf stroke
  • Lifestyle – exercise, cognitive rehab, diet
• Blood test could be a game changer but it is far from enough
• Assessment is much more than diagnosis
Community care
Community care: what we know?

- Community nursing, aged care workers, home help, community transport, day centre, respite care
- Variable provision internationally
- Desired by consumers
- Desired by government
  - Cheaper(?) than residential care
  - Different economic models
  - Long-term care insurance in some countries
Community care: what we know?

- Current model largely episodic and reactive
  - i.e. problem → access → service
- Limited availability, flexibility
- Limited evidence of efficacy
- Alternative model: continuous, proactive
  - Key worker or navigator
What do we know?

Case management approaches to home support for people with dementia

- 13 RCTs, 9615 participants, interventions varied
- Some evidence case management improves some outcomes at certain time points, both in persons with dementia and their carers
- Case management group significantly less likely to be institutionalised at 6 & 18 months but not at 12 or 24 months

Reilly S et al, Cochrane Database Syst Rev. 2015 Jan 5;1:CD008345
Case management approaches to home support for people with dementia

- Some evidence from good-quality studies, reduced admissions to care homes and overall healthcare costs in medium-term
- Not enough evidence to clearly assess whether case management delays institutionalisation
- Some effect on carer burden, BPSD, costs
- QOL, hospitalisation, mortality – no effect
- All studies show increased use of services

Reilly S et al, Cochrane Database Syst Rev. 2015 Jan 5;1:CD008345
Community care - What we don’t know?
Cost effectiveness

• Economic analysis of community-based care model (Ireland)
• 181 people with dementia at home with high risk of residential care admission
• Over 3 years formal costs of community care < 1/2 of potential residential care, but …
• Taking informal costs into account, 3x higher!

O’Shea & Monughan 2017
Consumer directed care

• Attractive concept, Is it working?
• Real choice for consumers?
  – Ability to save unspent funds for future use
  – Ability to choose care workers
  – Flexibility in activities
• Organization and communication?
• High admin costs?

Kaambwa et al. 2015
Gill et al. 2017
Respite care

Day care most commonly investigated

- Carer: decreased carer stress and burden
- Care recipient: reduced behavioural problems and possibly improved sleep
- but, day care alone may accelerate nursing home placement

In-home respite care, limited evidence
Residential respite care, mixed results

Reviews: Neville et al. 2015; Vandepitte et al. 2016; Brodaty & Gresham, 1995
Community care: what don’t we know?

Despite intuitive attractiveness….

• How to prove effectiveness?
• What are best outcome measures?
• What is best model?
• ‘key worker’, continuous, reactive, long-term guide, helper, coordinator
• Evaluation lacking

1 Dawson et al. 2015
Community care: where to from here

- Comprehensive service models
- Societal debate about economic model
- Overcoming barriers¹
  - Better information & access to services
  - Better quality & flexibility of services
  - Caregivers’ beliefs about their obligations
  - Overcoming resistance by care recipients

¹ Macleod et al. 2017
Acute care
Acute Care – what do we know?

- 50% of all admissions via ED are ≥ 65yo
  - > 30% have cognitive impairment
  - 20% dementia, 10% delirium

- Delirium & dementia often undiagnosed

- Pts with dementia twice more likely to experience falls, pressure injuries, infections, delirium and disorientation and fractures (and # NOF less likely to receive rehab)

- ¹ Australian Commission on Safety and Quality in Health Care 2013
  ² Bail K et al, BMJ Open. 2013; ³ Bail K et al, BMC Health Serv Res 2015
Acute Care – what do we know?

• One in 4 persons with dementia → hospital/ yr ¹
• Longer length of stay, more behavioural complications, more hospital-acquired complications; higher rates of discharge to residential care; higher morbidity ²
• Older people in ED with cognitive impairment and long bone # wait 2¼ hours for analgesia (compared to 41’ for younger person without cognitive impairment)³

¹ Draper B et al Int Psychoger. 2011; 23(10):1649-58
² Yates M et al, submitted.
³ Fry, M et al Int Psychoger 2015
Acute Care – what do we know?

• People with dementia can have difficulty …
  – Providing a history
  – Remembering & following instructions
  – Completing forms, dietary requests
• Nurses, doctors etc
  – Often lack skill; ageist; organ orientated
• Environment not dementia friendly
• Training can improve diagnosis, attitudes
• Post-discharge: communication X, continuity X
Regular Early Assessment Post-Discharge (REAP) (Cordato N et al, in preparation)

- Prospective RCT of assertive follow-up, NH residents recently discharged from hospital,
- REAP intervention: monthly coordinated specialist geriatrician and nurse practitioner assessments within residents’ NHs for 6m
- 43 NH residents → REAP intervention (n=22) or control (n=21) groups
- ≈ 2/3 fewer hospital readmissions (p=0.03; Cohen’s d=0.73) and ½ # ED visits, ½ costs
Acute Care – what don’t we know?

• How to change policy?
• How to prove cost effectiveness?
• How to change attitudes, improve skill, create dementia-friendly environment?
• How to make changes sustainable?
• How to ensure smooth transition and future care after discharge?
Acute Care – where to now?

- Top down, bottom up approach
- Economic data
- Staff training, supportive management
- Cognitive Impairment Identifier \(^1\)
- Standards for accreditation: cognitive screening on admission for all pts 65+/70+ \(^2\)
  - Better diagnosis, management, design of environment → fewer BPSD, less delirium
- Post-discharge support planning

\(^1\)Yates M et al (submitted); \(^2\)www.bhs.org.au/node/130
Residential Care
Residential Care – What we know?

• High rates of Long-Term Care
• Expensive; projections economically unsustainable
• Excellent services, innovative, creative, hard working vs …
• Scandals, physical, verbal & financial abuse
• High rates of Behavioural and Psychological Symptoms of Dementia (BPSD)
Residential Care – What we know?

- Variable staff ratios, quality & training
- Lack of trained nurses
- Suboptimal medical care in many countries
- High levels of psychotropic medication, including antipsychotics
- Person Centred Care in name, not practice
- Variable design quality - only \( \approx \frac{1}{2} \) of new facilities embrace design recommendations

Residential Care – What we know?

- Residents isolated, many negative relationships
  33% isolated; 33% initiated/received friendship\(^1\)
- Homes isolated from community
- Lack of services for YOD, CALD, LGBTIQ, Indigenous, homeless, other minorities
- Lack of choice for rural communities
- Funding rewards disability, not re-ablement
- Developing countries models differ

\(^1\)Casey A-N, 2016
Residential care: what we don’t know

- Best use of sticks (standards/ accreditation) vs carrots (attract residents/families)
- How well do novel models work, eg Eden Alternative, De Hogeweyk Village
  - Negative outcomes of EA
- Knowledge translation: implementation
- Future projections will change business models

Residential Care: where to now?

- Economies of scale of large homes with benefits of small discrete units
- Novel models – group homes, more tailored facilities, neighbourhood services
- Robots?, assistive technology?
- Actual person centred care
- Nurse Educators/ Champions – case based, onsite mini-tutorials
- Better environmental design
- Competition to drive improvement
Residential Care: where to now?

• Families (where available) part of care team
• Flexible care arrangements e.g. weekdays, night care or day care
• Regular multi-disciplinary team reviews
• Dedicated GPs (&/or Nurse Practitioners)
• Integrate: homes ↔ community
  – Coffee shops, kindergartens, art galleries
• Creativity: Singing, dance, Cultural Concierge¹

¹Arts Health Institute
Behavioural and psychological symptoms of dementia (BPSD)
BPSD – What do we know?

• Nomenclature debate (reflecting theoretical understanding) too simplistic
• High rates in people with dementia
  – 90% of residents in long-term care
  – 60% of people with dementia in community
• High reliance on drug therapy
  – 1 in 2 on psychototropic
  – 1 in 4 on antipsychotic
• Lack of psychosocial strategy implementation
BPSD – pharmacotherapy
What do we know?

• Antidepressants – major trials, no benefit over placebo for dep^n but more Adverse Effects
• Antipsychotics – some evidence for benefit for aggression and agitation, but …. …concern about AEs, especially stroke, death
• Other medications – sparse or no evidence
• Family caregivers can successfully reduce BPSD

¹ Brodaty & Arasaratnam, Am J Psych, 2012; 169(9):946-53
BPSD – What do we know?
Person centred care in NHs...

• Less agitation, less depression
• Better quality of life for person with dementia
• Less use of antipsychotic medications
• Greater staff satisfaction, less turnover
• Cost effective

Examples: CADRES, SMILE and HALT studies
Dementia Care Mapping & Person Centred Care for agitation

Cost for PCC
\[ \approx $6 \text{ to reduce a point on CMAI} \]

Chenoweth et al.
Lancet Neurology 2009
Humor therapy: SMILE study

- 20% reduction in agitation
- Effect size = antipsychotic medications for agitation
- Adjusting for dose of humour therapy
  - Decreased depression
  - Improved quality of life

Low LF et al BMJ Open 2013
Brodaty et al Am J Ger Psych 2014
Low LF et al JAMDA 2014
HALT study

- Resident on long-term antipsychotics
- Family consent, GP detailing, nurses trained in person centred care, pharmacists recommended deprescribing schedule to GPs
- 94.7% of participants ceased antipsychotic(s)
- 75-80% remained off antipsychotics over 12 m
- Regular & prn antipsychotic low during follow-up
- Behaviours did not increase despite stopping Rx
Internet Guide
www.dementiaresearch.org.au

- APP for clinicians BPSD
- APP for caregivers Care4dementia
BPSD: What we don’t know/ Where to

- How to translate knowledge into practice
  - Standards, regulations eg hospitals, NHs?
  - Education of consumers → drive demand?
  - Education of providers → quality of care?
  - Economic models – reward good care, innovation?
- Multidisciplinary care, planning, education
- More nuanced use of psychototropic Rx, regular review, informed consent
‘Families have been, currently are, and will continue to be the primary therapeutic agents in dementia care’ Gitlin & Hodgson 2015

‘The mainstay of treatments for AD is supportive care from family ..’ Scheltens P et al, Lancet, 2016:388:505-17
Caregivers – what do we know?

Effects on caregivers
- High rates of depression, distress
- ↓ physical health, ↑ social isolation, ↑ mortality

Interventions
- Counselling → less depression $^{1,2}$
- Comprehensive training programs → less psychological morbidity, care recipients stay at home longer, cost effective $^{3,4,5}$

Dementia Carers Program: survival at home over 7 years

- Multidisciplinary
- ↓ CG psychological morbidity @ 12m
- Person w. dementia stayed home longer
- Saved money

Brodaty & Gresham BMJ 1989
Brodaty et al Int Psychoger 1991
Brodaty et al IJGP 1997

Odds ratio 5.03 (1.73-14.7)
Tailored Activity Program

• In-home training for CGs to manage BPSD
• 4-month (8 sessions) occupational therapy intervention tailored based on neuropsychological and functional testing
• Fewer problem behaviours (specifically for shadowing and repetitive questioning)
• Greater participant activity engagement
• Caregiver benefits (fewer hours on duty)
• Cost-effective

Many other issues in science of care

- Palliative care
- Western vs Asian vs Developing countries
- Importance of policy, consumer involvement
- Methodological challenges in research
- Competitive disadvantage for funding
- Communities of researchers
  - Interdem in Europe
  - PROMOTE in Asia-Pacific
- Internet based care and prevention
  
  http://www.maintainyourbrain.org/
Conclusions

- Despite care science being difficult in practice and to fund..
- We know a lot but ....
- Major issue = knowledge translation
- Future – partnership between consumers, researchers, economists and policy makers
Thank you

www.cheba.unsw.edu.au
www.dementiaresearch.org.au