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

- What do we know?
- What don’t we know?
- Where to from here?
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 ceased 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 Dx

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
  o Cheaper(?) than residential care
  o Different economic models
  o 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 & Monaghan 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\(^1\)

\(^1\) 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 \(^2\), disorientation and fractures (and # NOF less likely to receive rehab)

1. Australian Commission on Safety and Quality in Health Care 2013
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 \(\rightarrow\) 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 \( \approx 1/2 \) of new facilities embrace design recommendations\(^1\)

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 EA¹
- 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 depression 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
≈ $6 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
- 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 psychotropic 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