DEMENTIA: STRATEGIES FOR SUCCESS

SUBE BANERJEE
BRIGHTON AND SUSSEX MEDICAL SCHOOL

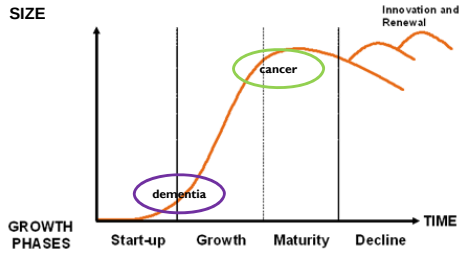
ISSUES IN DELIVERING QUALITY IMPROVEMENT IN DEMENTIA

1. Developmental stage
2. Understanding and acting in complexity
3. Managing uncertainty in strategy and intervention

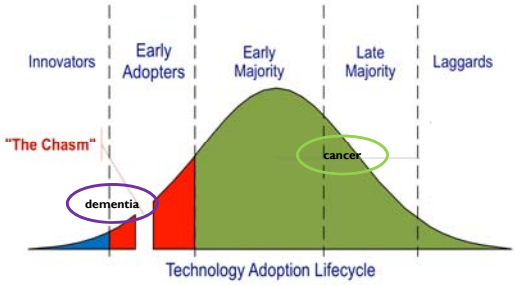
1. DEVELOPMENTAL STAGE

UNDERSTANDING WHERE WE ARE

LIFE CYCLE OF POLICY, STRATEGY, PRACTICE, RESEARCH…



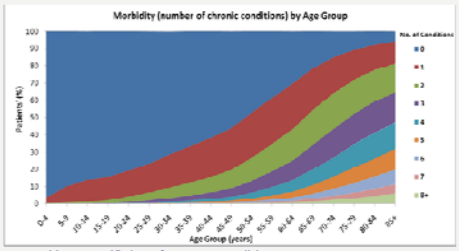
ROGER'S INNOVATION ADOPTION CURVE



2. UNDERSTANDING AND ACTING IN COMPLEXITY

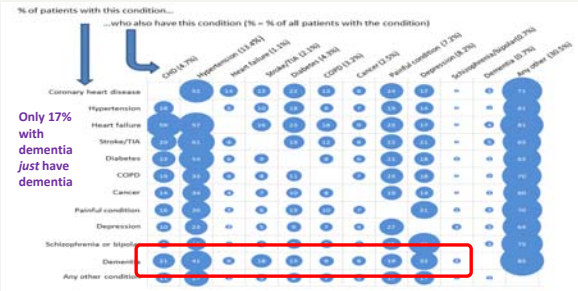
DEMENTIA IS ALL ABOUT COMPLEXITY AND THE RULES FOR ACTING IN COMPLEXITY MAY BE DIFFERENT

STUFF HAPPENS TO OLDER PEOPLE - MULTIMORBIDITY (*BARNETT ET AL, 2012*)



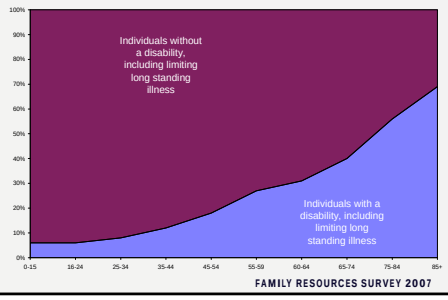
- Most over-65s have 2 or more conditions
- Most over-75s have 3 or more conditions

MOST PEOPLE OF ANY AGE WITH ANY LONG TERM CONDITION HAVE MULTIPLE CONDITIONS (*SCOTTISH SCHOOL OF PRIMARY CARE, 2012*)



Only 17% with dementia *just* have dementia

Prevalence of disability rises with age

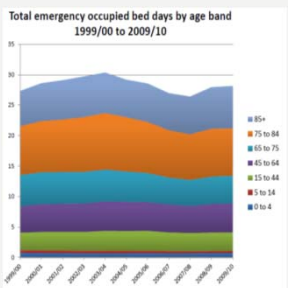


FAMILY RESOURCES SURVEY 2007

COMORBIDITY IN PRIMARY CARE

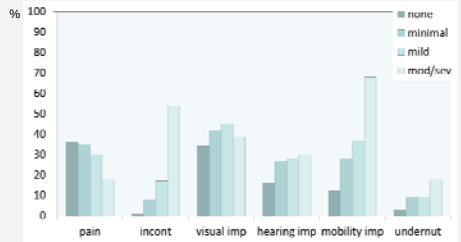
- People with dementia report fewer symptoms (McCormick et al, 1994)
- Undiagnosed but treatable medical disease in almost half (Larson et al, 1984)
- Wishard Health Services, Indiana US (Schubert et al, 2006) people with dementia n=107/3,013
  - Mean 4 chronic medical conditions
  - Prescribed 5.1 medications
  - 82% hypertension
  - 39% diabetes mellitus

OVER 65S IN HOSPITAL IN ENGLAND – OLDER PEOPLE ARE THE NHS'S CUSTOMERS (HES DATA)



60% admissions
70% bed days
85% delayed transfers
65% emergency readmissions
75% deaths in hospital
25% bed days are in over 85s

THE PREVALENCE OF PHYSICAL IMPAIRMENTS, BY DEMENTIA DIAGNOSIS AND SEVERITY – LATIN AMERICA (PRINCE AT AL 2010)



MULTIMORBIDITY IS COMMON IN DEMENTIA

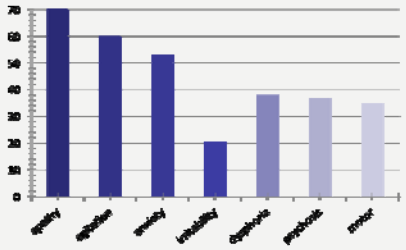
MULTIMORBIDITY IS A COMPLEX PHENOMENON

CO-MORBIDITIES OFTEN POORLY MANAGED

COMORBIDITY WITH MENTAL DISORDER

BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS IN DEMENTIA

FREQUENCY OF BPSD IN DEMENTIA



Lyketsos CG et al. Am J Psychiatry 2000 May;157(5):708-14

MANAGEMENT OF BPSD – A LACK OF SPECIFICITY – EVIDENCE OF DIFFERENCE IN DEMENTIA

Treatments

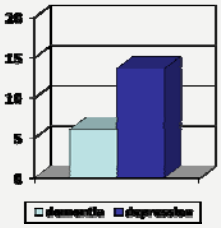
- Anti-dementia drugs
  - Cholinesterase inhibitors i.e.Donepezil, Rivastigmine, Galantamine
  - Glutamatergic drugs i.e Memantine
- Antidepressants
- Antipsychotics
- Behavioural techniques Memory retraining
  - ABC approach
- Novel interventions
  - Bright light therapy
  - Aromatherapy
  - Exercise

Symptoms

- Memory loss, executive dysfunction, aphasia
- Behavioural problems e.g. agitation
- Depression
- Psychosis eg delusions, hallucinations
- Activities of daily living

DEPRESSION IN DEMENTIA – AN EXEMPLAR

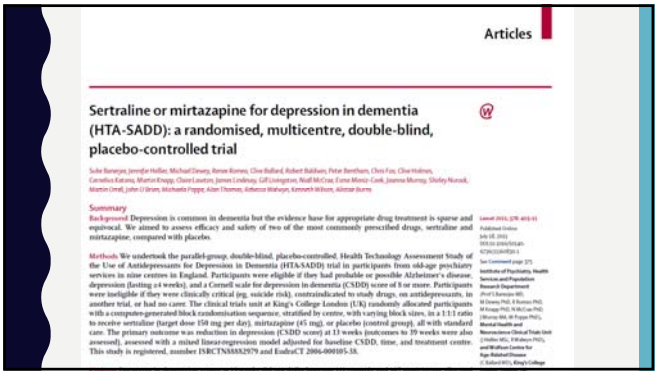
EPIDEMIOLOGY



- Both common in later life
  - 6% dementia
  - 14% depression
- Assorted randomly expect 1% co-morbidity
- Actual co-morbidity is 20%

DEPRESSION IN DEMENTIA – NOT A GOOD THING

- High distress
- Low quality of life
- High carer stress and burden
- High carer depression
- Lowers cognition
- Lowers functional ability
- Placement
- Death
- Often not treated



Articles

Sertraline or mirtazapine for depression in dementia (HTA-SADD): a randomised, multicentre, double-blind, placebo-controlled trial

Sube Banerjee, Jennifer Hellier, Michael Dewey, Renee Romeo, Clive Ballard, Robert Baldwin, Peter Bentham, Chris Fox, Clive Holmes, Cornelius Katona, Martin Knapp, Claire Lawton, James Lindesay, Gill Livingston, Niall McCrae, Esme Moniz-Cook, Joanna Murray, Shirley Nurock, Martin Orrell, John O'Brien, Michaela Poppe, Alan Thomas, Rebecca Walwyn, Kenneth Wilson, Alistair Burns

Summary

Background Depression is common in dementia but the evidence base for appropriate drug treatment is sparse and equivocal. We aimed to assess efficacy and safety of two of the most commonly prescribed drugs, sertraline and mirtazapine, compared with placebo.

Methods We undertook the parallel-group, double-blind, placebo-controlled, Health Technology Assessment Study of the Use of Antidepressants for Depression in Dementia (HTA-SADD) trial in participants from old-age psychiatry services in nine centres in England. Participants were eligible if they had probable or possible Alzheimer's disease, depression (lasting ≥4 weeks), and a Cornell scale for depression in dementia (CSDD) score of 8 or more. Participants were ineligible if they were clinically critical (eg, suicide risk), contraindicated to study drugs, on antidepressants, in another trial, or had no carer. The clinical trials unit at King's College London (UK) randomly allocated participants with a computer-generated block randomisation sequence, stratified by centre, with varying block sizes, in a 1:1:1 ratio to receive sertraline (target dose 150 mg per day), mirtazapine (45 mg), or placebo (control group), all with standard care. The primary outcome was reduction in depression (CSDD score) at 13 weeks (outcomes to 39 weeks were also assessed), assessed with a mixed linear-regression model adjusted for baseline CSDD, time, and treatment centre. This study is registered, number ISRCTN88882979 and EudraCT 2006-000105-38.

CSDD SCORES BY TREATMENT GROUP, UNADJUSTED MEANS WITH 95% CI

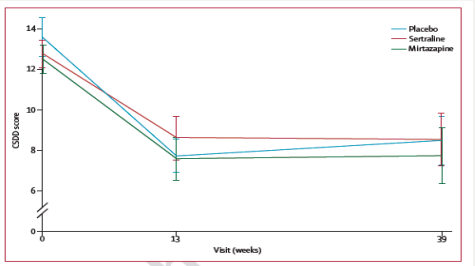


Figure 2: Unadjusted mean CSDD scores by treatment group
Lowest score is best. Error bars show 95% CIs. CSDD=Cornell scale for depression in dementia.

ADVERSE REACTIONS BY WEEK 39

	Treatment Group			Total
	Placebo	Sertraline	Mirtazipine	
Adverse Reaction				
Yes	29	46	44	119
No	82	61	64	207
Total	111	107	108	326

Fisher's Exact p=0.017

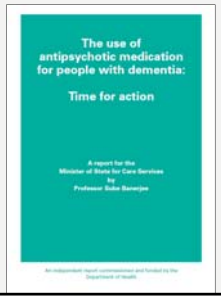
HTA-SADD - CONCLUSIONS

- What do we know?
  - That the evidence has changed
- No superiority of drugs on primary endpoints
- Not
  - Dementia severity
  - Depression severity
  - Depression type
  - Dose reached
  - Drop-out

Depression is different in dementia

ANTIPSYCHOTIC MEDICATION IN DEMENTIA

UK MINISTERIAL REVIEW OF USE OF ANTIPSYCHOTICS IN DEMENTIA



- Published November 2009
- Comprehensive review
  - Negative effects
  - Positive effects
- Analysis of reasons for current clinical behaviour
- Practical clinical plan to deal with problems found

SUMMARY OF RISKS AND BENEFITS AT A POPULATION LEVEL OF THE USE OF ATYPICAL ANTIPSYCHOTICS FOR BPSD IN PEOPLE WITH DEMENTIA

- Treating 1,000 people with BPSD with an atypical antipsychotic drug for 12 weeks would result in
  - an additional 91–200 patients with behaviour disturbance showing clinically significant improvement
  - an additional 10 deaths;
  - an additional 18 CVAEs,
- For UK
  - **1,800 deaths per year**
  - **1,620 severe CVAEs per year**

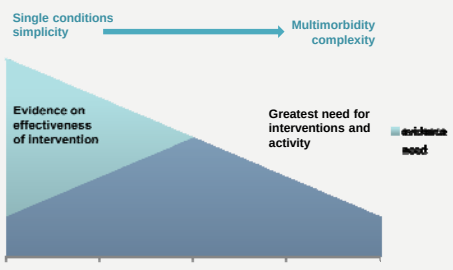
Antipsychotics work differently in dementia

WHAT DOES THIS MEAN?

- Depression (and psychosis) are different in dementia
- Psychopharmacology is different in dementia
- Need to be very careful in generalising findings from non-demented populations to people with dementia
  - **Effects**
  - **Harms**

MULTIMORBIDITY IS ALL ABOUT COMPLEXITY – DIFFERENT RULES APPLY

THE PARADOX OF EVIDENCE AND NEED



TIME FOR DEMENTIA

RE-BALANCING UNDERGRADUATE HEALTHCARE EDUCATION
CHANGING ATTITUDES
BUILDING UNDERSTANDING

TIME FOR DEMENTIA PROGRAMME

BUILDING POSITIVE PROFESSIONAL ATTITUDES AND UNDERSTANDING

- Four year programme £1.7m, funded by HEE
- Collaboration between BSMS, Alzheimer's Society & University of Surrey
- To build an understanding in students of
  - What it is to be old an ill in society
  - What it is to have a long term condition
  - The role of family and carers
  - Dementia
  - Compassion, empathy, understanding

DELIVERY

- Sept 2014 and 2015 intakes
- Alzheimer's Society managing network of 300 families
- Students visit families in pairs
- 4 visits per year
- Reflective individual and group work and assessment

- High quality iterative development and multi-method evaluation to enable wide implementation if successful
- Aim to deliver across all undergraduate healthcare programmes in region in three years

METHOD

- Baseline, one year and two year quantitative student measures for intervention and control groups of
  - Knowledge of and attitudes towards dementia,
  - Compassion and empathy
  - Career preferences
  - Satisfaction with the programme
- Baseline, one year and two year quantitative student measures of the quality of life of people with dementia and carers
- Comparison with non-participant medical and nursing students

- Qualitative assessments to answer 'why' questions

STUDENT ASSESSMENTS

- **Alzheimer's disease Knowledge Scale** (Carpenter et al., 2009) - a brief 30-item questionnaire designed to assess students' knowledge of AD
- **Dementia Knowledge Questionnaire** (Shanahan et al., 2013) - a brief 20-item questionnaire designed to assess dementia knowledge;
- **Approaches to Dementia Questionnaire** (Lintern et al., 2000)- a 19-item questionnaire designed to assess attitudes toward dementia patients
- **Dementia Attitude Scale** (O'Connor and McFadden, 2010) - a 20-item questionnaire designed to assess attitudes toward dementia;
- **Medical Condition Regard Scale** (Christison et al., 2002) - a measure of biases, attitudes and emotions in relation to specific medical conditions
- **Jefferson Scale of Empathy: Health Professional/Medical Student Version** (Hojat et al., 2001) - 11 item questionnaire of empathy in healthcare students
- **Student Satisfaction Survey -**

PATIENT/CARER ASSESSMENTS

- **Standardized Mini-Mental State Examination** (Molloy and Standish, 1997) – a global measure of cognitive function
- **DEMQOL** (Smith et al., 2007) – 28-item interviewer-administered questionnaire answered by the individual with dementia, dementia-specific health-related quality of life measure
- **DEMQOL-Proxy** (Smith et al., 2007) – 31-item interviewer-administered questionnaire answered by the caregiver on the individual with dementia, dementia-specific health-related quality of life measure
- **Zarit Carer Burden Inventory** (Zarit et al., 1980) – 22-item self-report questionnaire
- **Patient Satisfaction Survey**
- **Carer Satisfaction Survey**

INTERIM RESULTS - FEASIBILITY

- First cohort
- Delivered to all 348 students using a network of 174 families
- 310 (89%) of the students and 158 (91%) of the families gave their content to participate
- Feedback from students and families is positive

STUDENT EXPERIENCE – POSITIVE ASPECTS

- Spending time with the family
- Families enjoyment of programme
- Increased awareness of the family perspective
- Improved understanding about how families view professionals
- Different learning experience
- Changing perceptions about dementia
- Skill development

Removed my "fear" - knowledge has made me more confident. I used to worry about how I would communicate or help people with dementia as I know little about it, but now I know more, I feel better equipped

FAMILY EXPERIENCE – POSITIVE ASPECTS

- Enjoyment of the social interaction
- Continuity – having the same student learners
- Shared learning
- Student professionalism
- Good organisation

- **Feeling listened to**

The students enlighten me…they listen to me. It bought me to life (person with dementia)

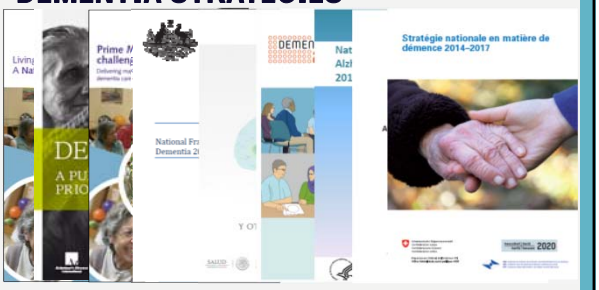
- **Making a difference**

Having had some of the experiences we've had in hospitals…it was a good opportunity to give voice to those…if people can be caught early in their careers those problems shouldn't keep repeating (Carer)

3. STRATEGIES FOR IMPROVEMENT

DIVERSITY OF INTERVENTIONS DOING THINGS DIFFERENTLY

DEMENTIA STRATEGIES



STRATEGY AND TACTICS

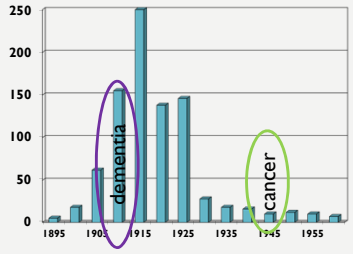
"Strategy without tactics is the slowest route to victory.

Tactics without strategy is the noise before defeat."

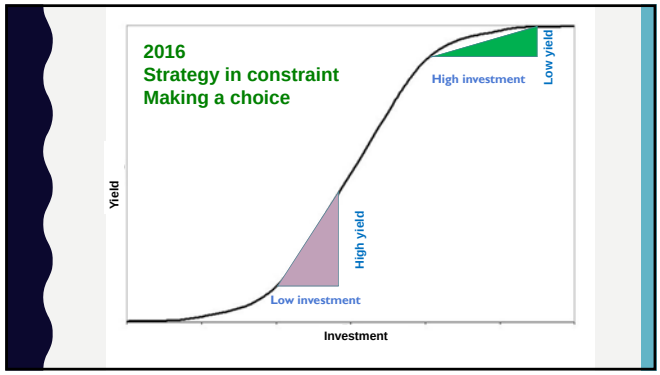
Sun Tzu
544-498BC
The Art of War

FINAL THOUGHTS

US AUTO INDUSTRY LIFE CYCLE (NUMBER OF FIRMS): 1885-1961



Klepper S (2002), *Industrial & Corporate Change*, August 2002, p. 654.



STRATEGIES FOR SUCCESS

1. **Developmental stage**
   - dementia is still in the early stages of development
   - evidence base relatively sparse and equivocal, but the stakes and value are very high indeed
   - need to understand where we are and work on rapid evidence generation, evaluation and translation
2. **Complexity**
   - dementia is more complex a challenge than previous successful health challenges
   - complex narrative more difficult to write and to tell
   - need to understand the new rules and work on multiple fronts at once
3. **Interventions**
   - at the stage of a "hundred flowers" blooming, need to move to consolidation
   - slow translation into policy and practice – need clarity and bravery to accelerate process
4. **Willingness to pay**
   - proportionality – do we need the same level of evidence for singing in care homes as for chemotherapy?
   - funders need to make decisions in uncertainly – need to balance increased uncertainty (in clinical/cost effectiveness) with the potential for higher yield (in health improvement)

"ALICE LAUGHED. 'THERE'S NO USE TRYING,' SHE SAID. 'ONE CAN'T BELIEVE IMPOSSIBLE THINGS.'

'I DARESAY YOU HAVEN'T HAD MUCH PRACTICE,' SAID THE QUEEN. 'WHEN I WAS YOUR AGE, I ALWAYS DID IT FOR HALF-AN-HOUR A DAY. WHY, SOMETIMES I'VE BELIEVED AS MANY AS SIX IMPOSSIBLE THINGS BEFORE BREAKFAST'.

THANK YOU!