BPSD

(Behavioural and Psychological Symptoms of Dementia)

Moving towards a better approach

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Geriatrician and Palliative Care Physician
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genesis oncology trust


Begin each day
with a grateful heart

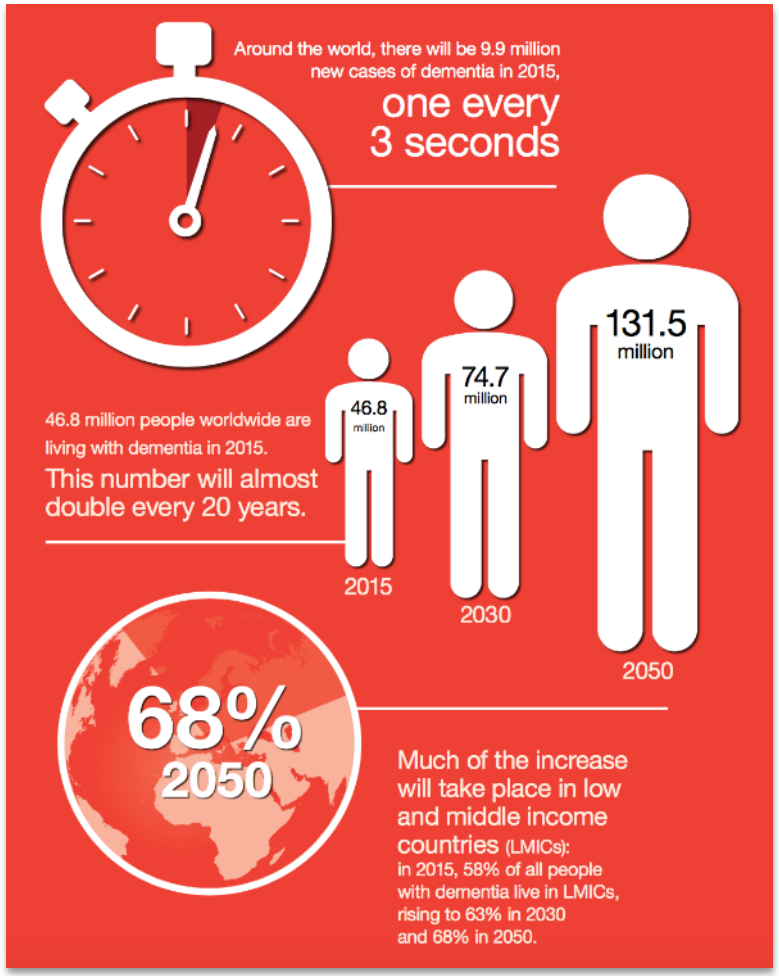
Outline for this morning

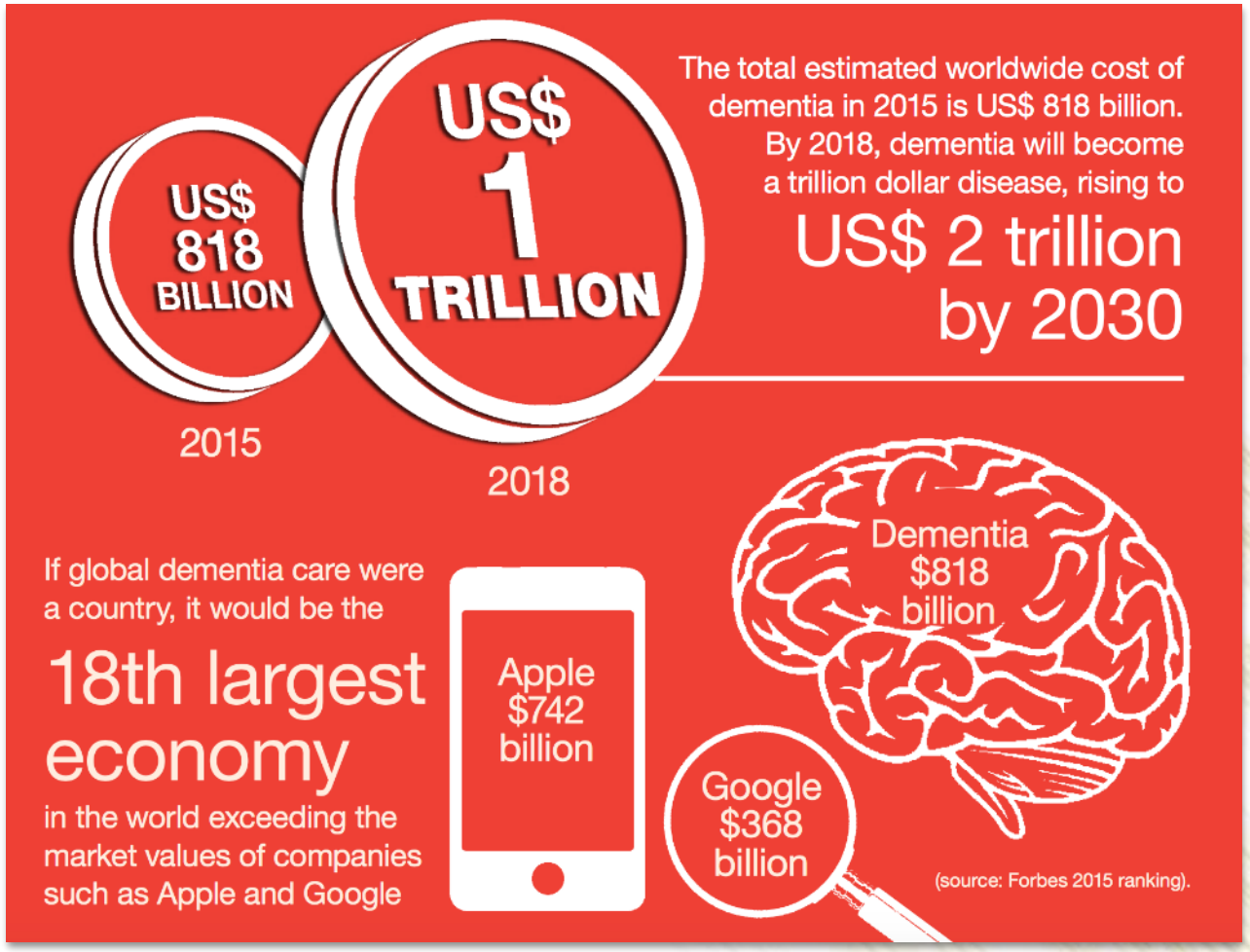
- Overview
- The deficits of dementia
- What is BPSD
- The parameters of BPSD
- Pharmacotherapeutic rationale and limitations
- Time to examine our paradigm of care?
- Nonpharmacological strategies
- The way forward

Areas of less focus this morning

- Assessment
  - Complex and difficult area
  - Non-formulaic in nature though many such resources exist
  - Not sure that even we (MHSOP) do it all that well
- Individual treatments/approaches
  - Not really available or implemented on a wide scale though pockets of excellence do exist

A pressing global scenario





World Alzheimer Report 2015: The Global Impact of Dementia

The situation in New Zealand

Chart c: Prevalence projections by ethnicity, 2016 to 2038

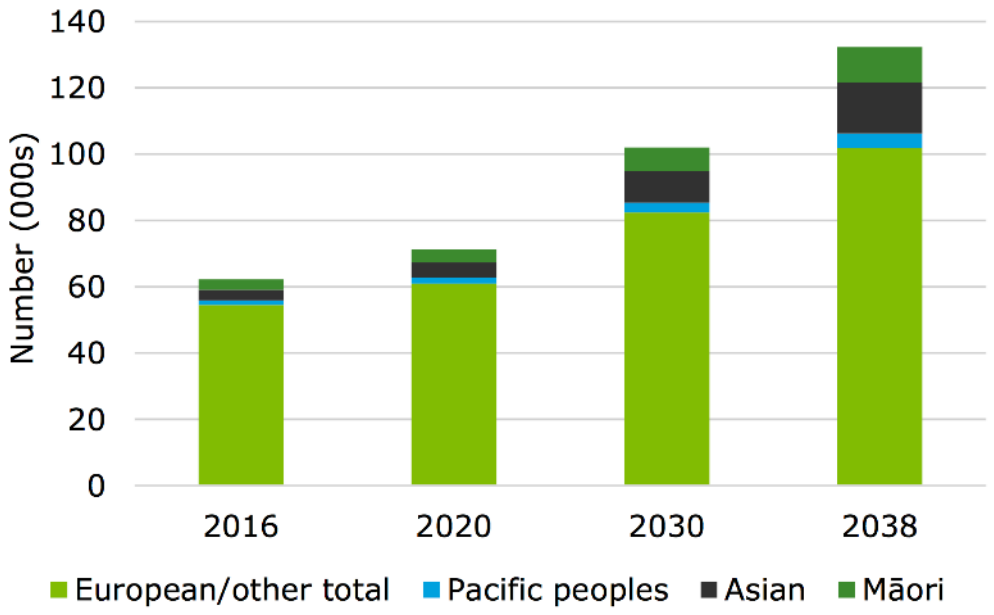
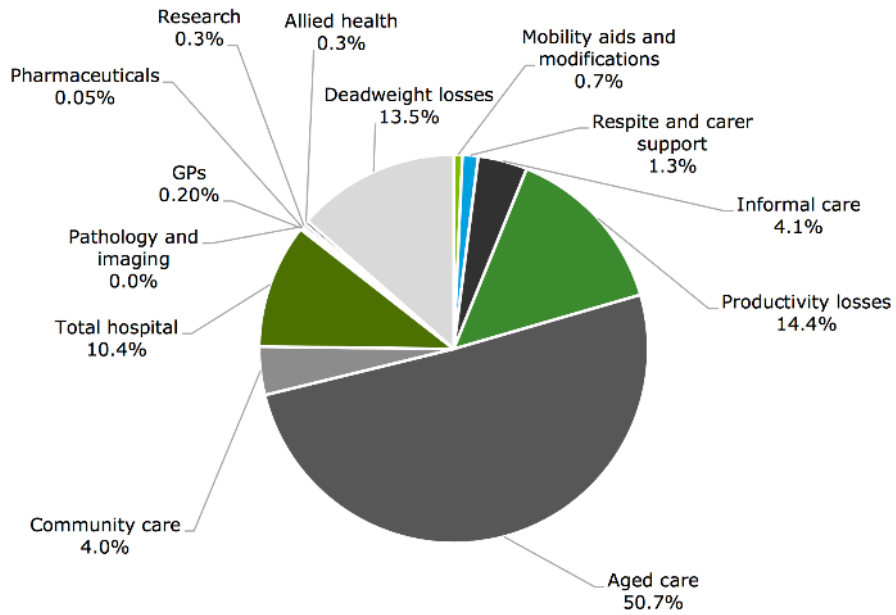


Chart d: Economic costs associated with dementia in New Zealand, 2016



Our view of dementia is one of losses

Neuropsychological

Amnesia
- Immediate, recall
- Ribot's law
- Semantic, visuospatial

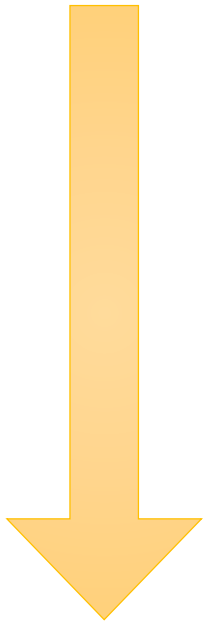
Aphasia
- Word finding, nominal
- Substitutions, semantic paraphrasia
- Comprehension, written language

Apraxia
- Ideomotor, dressing, constructional

Agnosia
- Visual
- Proposagnosia
- Stereognosia

Executive

Cognitive losses



Functional losses

Dementia is more than just loss

Neuropsychological

Amnesia
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Executive

Behavioural

Apathy
Psychomotor agitation/retardation
Verbal and Physical aggression
Wandering and pacing
Sleep disturbance
Eating
Sexual and elimination
Personality changes

Perceptual

Misidentification
Hallucinations
Delusions

Mood

Depression and Anxiety

Definition of BPSD

Behavioural and psychological symptoms of dementia (BPSD) are defined as signs and symptoms of disturbed perception, thought content, mood or behaviour

They include agitation, depression, apathy, repetitive questioning, psychosis, aggression, sleep problems, wandering, and a variety of social inappropriate behaviours

One or more symptom will affect nearly all people with dementia over the course of their illness

Finkel S, et al. *Int Psychogeriatr* 1996

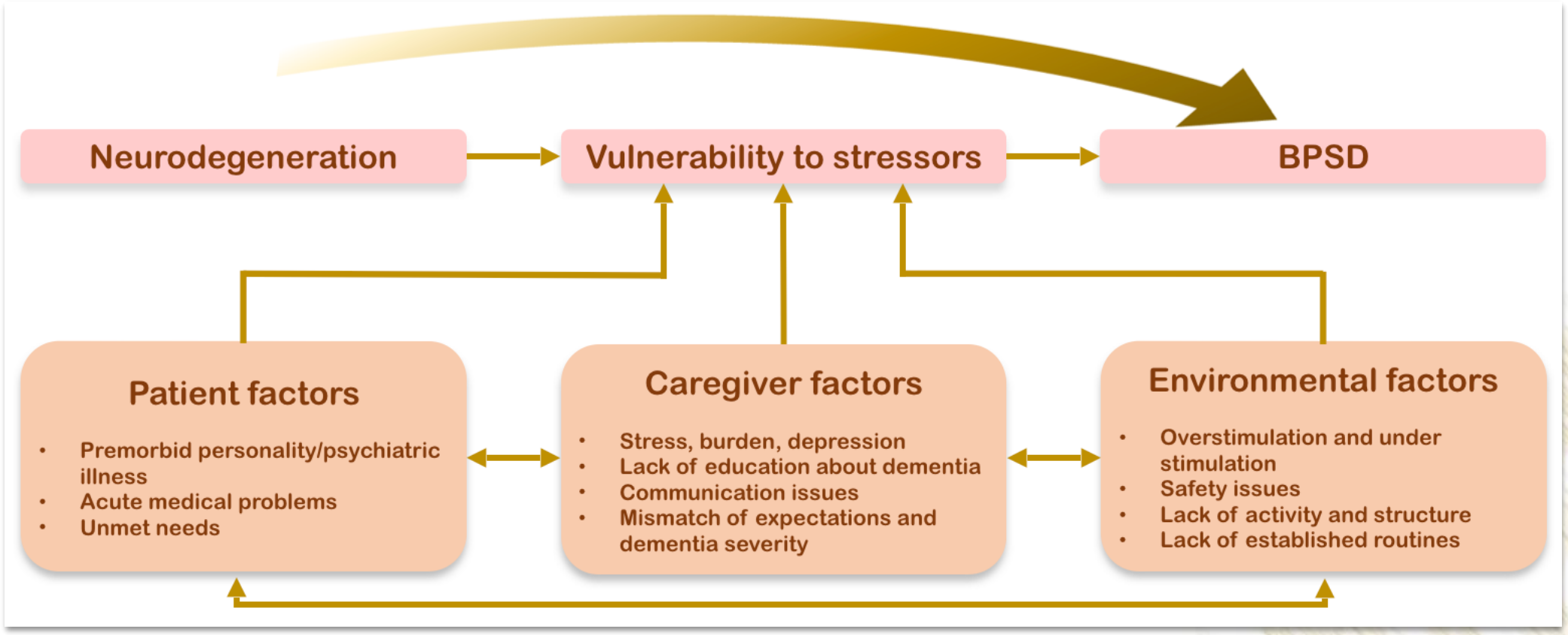
The direct impacts of BPSD

- Impact on carer: **burnout**
  - Due to fundamental changes in relationship
  - Carer response can influence BPSD
  - Even with support, 2/3 indicate unmet needs
  - Stress and depression, loss of income, reduced QoL

- Impact on the patient: **distress**
  - Functional disability
  - Most important reason for premature institutionalisation
  - Restraint use
  - Increased hospitalisations
  - Acceleration of cognitive decline and increased mortality

Aguero-Torres H, et al. *J Clin Epidemiol* 200; Feast A, et al. *B J Psych* 2016; De Vugt ME, et al. *Int J Geriatr Psychiatry* 2004; Peeters JM, et al. *BMC Nursing* 2010; Moniz-Cook E, et al. *Cochrane Syst Res Rev* 2012; Van Den Wijngaart MA, et al. *Aging Ment Health* 2007; Testad I, et al. *Int J Geriatr Psychiatry* 2005; Wancata J, et al. *Int J Psychiatry Med* 2003; Selbaek G, et al. *Am J Geriatr Psychiatry* 2008; Tun SM, et al. *Am J Geriatr Psychiatry* 2007; Emmanuel JE, et al. *Am J Geriatc Psychiatry* 2011; Rabins P, et al. *Alzheimers Dement* 2011; Rosdinom R, et al. *Prev Med* 2013

Factors associated with BPSD



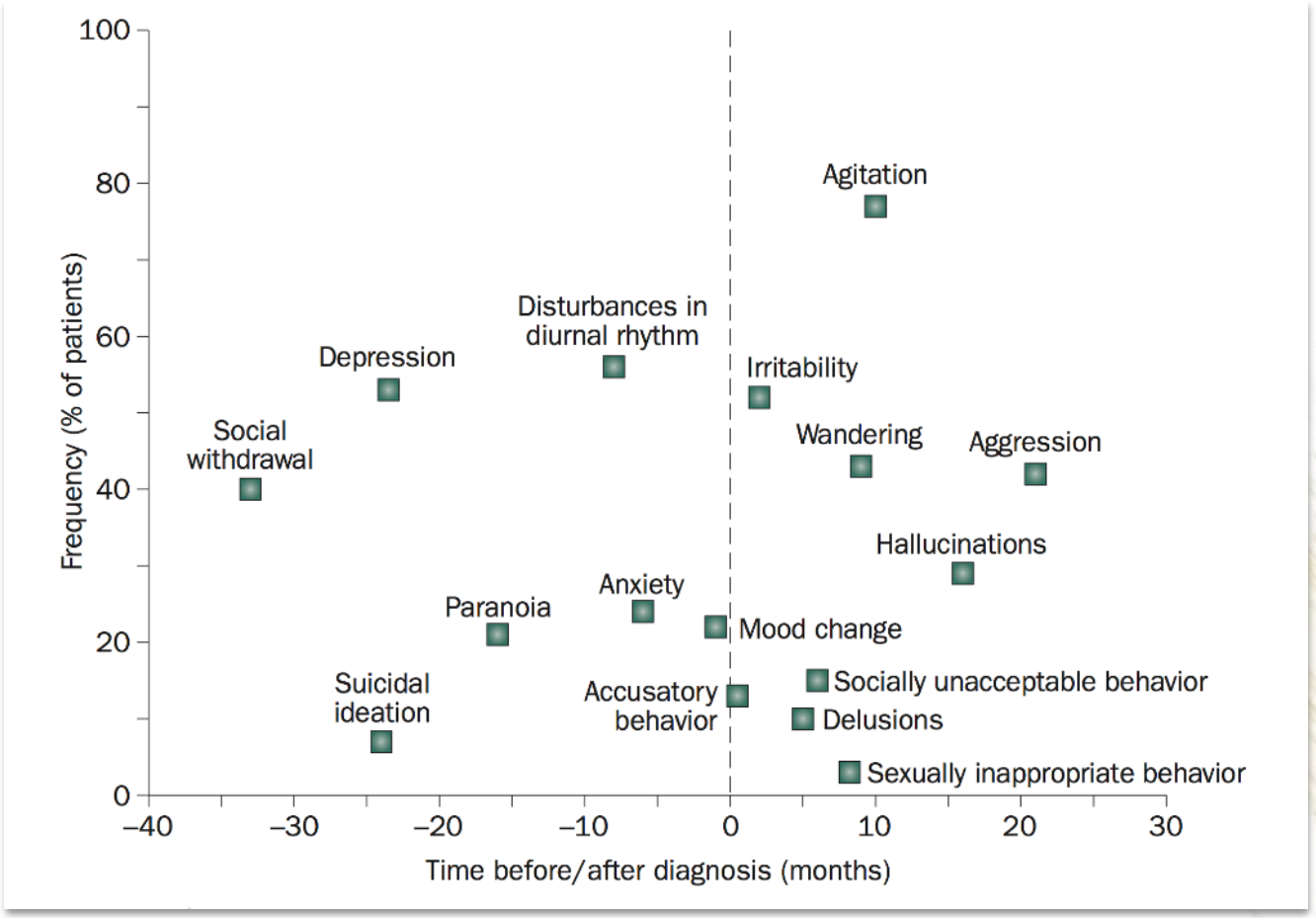
Kales HC, et al. *BMJ* 2015

The prevalence of BPSD

- Fluctuating course as opposed to cognitive symptoms
  - Even in early stages, BPSD can occur in 35-85%
- Prevalence in community-dwelling 56-98% c.f. ARC 90-97%
  - Wide discrepancy due to methodological biases
- Loosely associated with the type of dementia
  - AD: irritability
  - VaD: depression and anxiety, apathy, sleep disturbance
  - FTD: disinhibition, wandering, socially inappropriate
  - LBD: hallucinations

Ballard C. *Curr Opinion Psychiatry* 2009
Steinberg M, et al. *Int J Geriatr Psychiatry* 2008
Frisoni GB, et al. *Dement Geriatr Other Disord* 1999

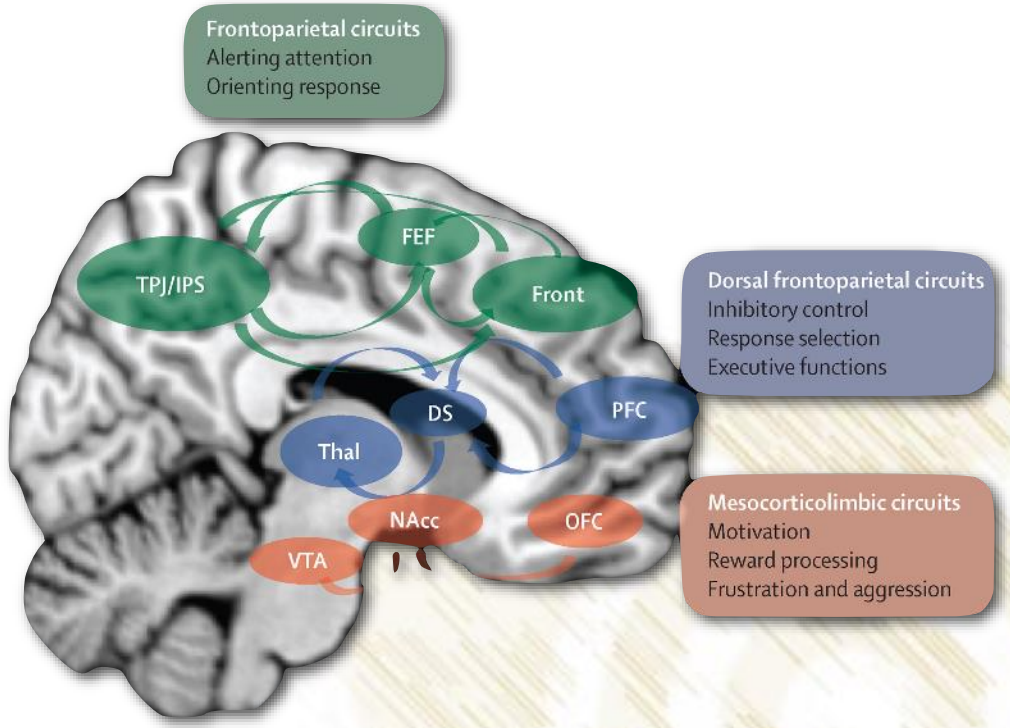
Natural history - incidence



Ballard CG, et al. *Nature Rev Neurol* 2009

Do BPSD symptoms cluster?

- Neuropathophysiological correlates
  - Fronto-subcortical circuits: impulse control
  - Cortico-cortical circuits: emotion and cognition
- BPSD symptoms that cluster
  - Psychosis: delusions and hallucinations
  - Affective: depression and anxiety
  - Aberrant motor: agitation, aggression, irritability
- BPSD symptoms that don't cluster
  - Sleep disturbance
  - Eating disturbance
  - Apathy



Spaletta G, eta l. *Am J Geriatr Psychiatry* 2008; Rockwood K, et al. *Int J Geriatr Psychiatry* 2014; Marra C, et al. *Dement Geriatr Cogn Dis* 2007; Nyatsanza S, et al. *J Neuro Neurosurg Psychiatry* 2003; Staekenborg SS, et al. *J Neuro Neurosurg Psychiatry* 2010; Petrovic M, et al. *Acta Clin Belg* 2007

Natural history - persistence

Table 2 Results of 13 studies reporting at least two behavioural and psychotic symptoms of dementia

Symptoms	Number of studies	Baseline prevalence (%) 11 studies	Persistence (%)[a] 10 studies	Incidence (%)[b] 9 studies
Affective	12	High	Moderate	Moderate
Depression	12	High (8–57%)	Moderate (16–70)	Moderate (10–73)
Anxiety	8	High (17–52%)	Moderate (17–52)	Moderate (12–38)
Apathy	4	High (19–51)	High (20–55)	High (27–64)
Psychosis	13	Low	Moderate	Moderate
Delusions	10	Moderate (9–40)	Low (0–82)	Moderate (5–84)
Hallucinations	11	Low (0–18)	Low (0–52)	Low (4–45)
Hyperactivity	12	High	High	High
Irritability	9	High (6–57)	Moderate (12–80)	High (10–69)
Agitation	7	High (18–87)	Moderate (21–77)	High (19–80)
Wandering	1	NR	High (60)	NR
Elation	4	Low (3–9)	Low (2–39)	Low (4–5)
Sleep problems	7	Moderate (6–11)	Low (10–57)	Low (8–31)

NR, not reported.
a. Percentage of symptoms persistent over 3 months or more.
b. Percentage incidence over 3 months or more.

Van der Linde RM, et al. *B J Psych* 2016; Wetzels R, et al. *Int J Psychogeriatr 2010*

Antipsychotic medication

- Prevalence of use has steadily increased globally
  - European nursing homes: 19-46%
- Typical antipsychotics
  - 2002 Cochrane review of haloperidol vs placebo
- Atypical antipsychotics
  - At best a modest effect and limited to some specific Sx in BPSD spectrum
- CATIE-AD trial
  - 421 with AD randomised to olanzapine, quetiapine, risperidone or placebo
  - No significant difference in 1º outcome of medication discontinuation
  - No significant difference in 2º outcome of CGIC at 12 weeks
  - Significantly more EPSE and sedation with risperidone and olazapine

Mann E, et al. *BMC Geriatr* 2009; Lonergan E, et al. *Cochrane Syst Rev* 2002; Schneider LS, eta al. *NEJM* 2006

FDA Black Box warning issued in 2005

Risk of Death With Atypical Antipsychotic Drug Treatment for Dementia

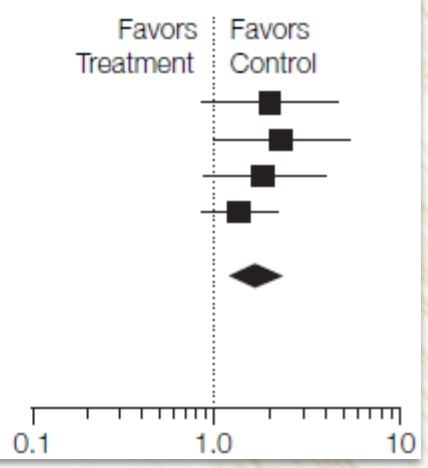
Meta-analysis of Randomized Placebo-Controlled Trials

Lon S. Schneider, MD, MS
Karen S. Dagerman, MS
Philip Insel, MS

Context Atypical antipsychotic medications are widely used to treat delusions, aggression, and agitation in people with Alzheimer disease and other dementia; however, concerns have arisen about the increased risk for cerebrovascular adverse events, rapid cognitive decline, and mortality with their use.

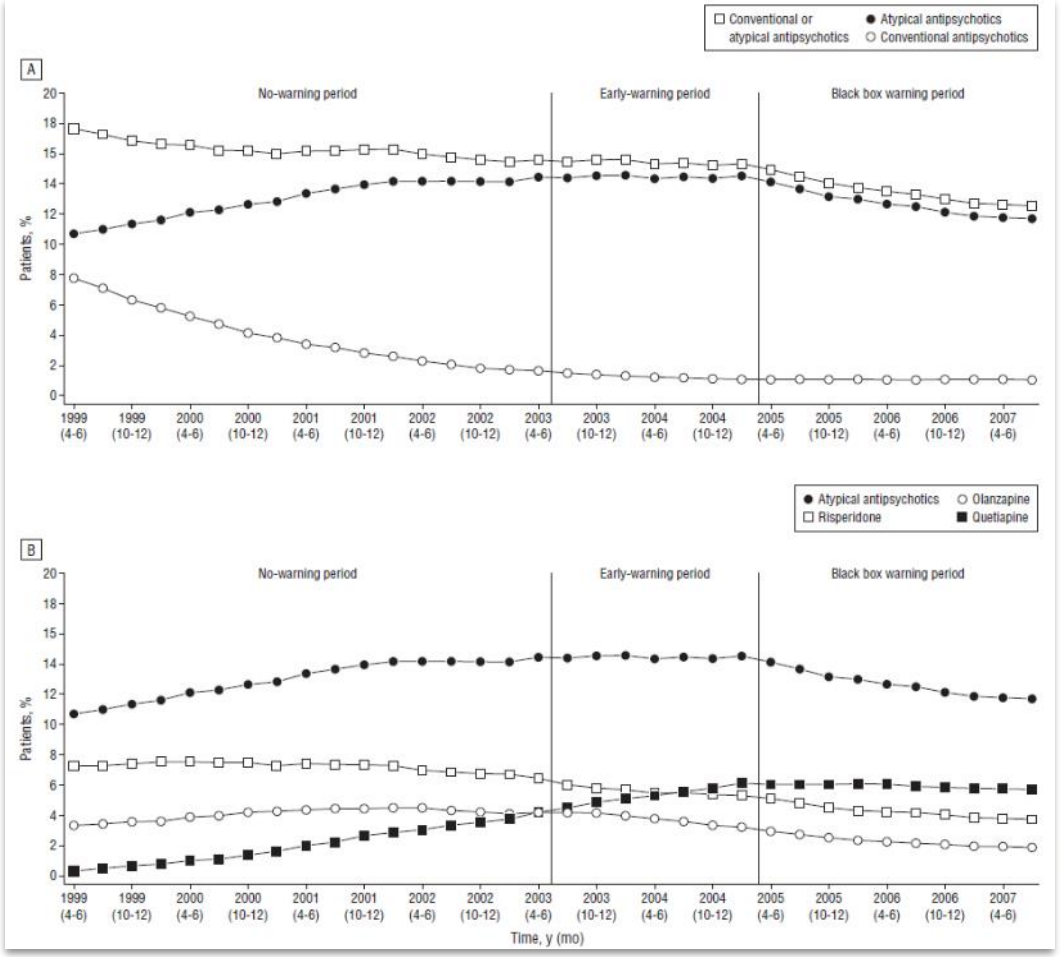
Drug	Death: Treatment, No. of Events/ Total No.	Death: Placebo, No. of Events/ Total No.	RR (95% CI) (Random-Effects Model)
Aripiprazole	21/95	6/54	1.99 (0.86-4.62)
Olanzapine	31/217	6/97	2.31 (1.00-5.35)
Quetiapine	21/58	7/36	1.86 (0.88-3.93)
Risperidone	45/201	22/133	1.35 (0.85-2.14)
Overall	118/571	41/320	1.65 (1.19-2.29)

Test for Heterogeneity $\chi^2_3 = 1.63$, $I^2 = 0\%$ ($P = .65$)
Test for Overall Effect $z = 3.01$ ($P = .003$)



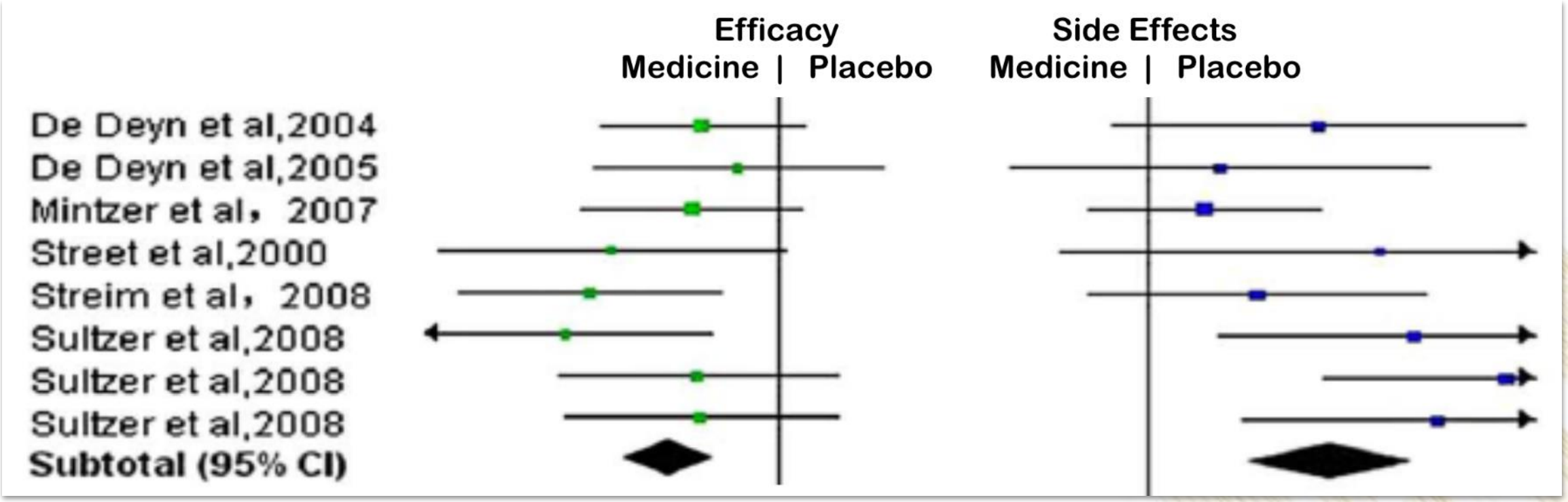
Schneider LS, et al. *JAMA* 2005

How the FDA has influenced practice



Kales HC, et al. *Arch Gen Psychiatry* 2007

Antipsychotic update



Wang J, et al. *J Neurol Neurosurg Psychiatry* 2015

The very real harms of antipsychotics

- Only 10% of psychotropic use in BPSD is fully appropriate
- Multitude of additional harms have since emerged
  - Stroke, falls, fractures, DVT/PE, cognitive decline
- Clinical use extends much longer than intended
  - 60% receive antipsychotics > 6 months
  - 18% started antipsychotics showed improvement while 49% deteriorated

Van der SpeK K, et al. *BMC Psychiatry* 2013; Banerjee S. *Dept Health* 2009; Liperoti R, et al. *J Clin Psychiatry* 2009; Azermai M, et al. *Int Psychogeriatr* 2011; Barnes TR, et al. *Br J Psychiatry* 2012; Kleiger BC, et al. *Int Psychogeriatr* 2009

Barriers to stopping antipsychotics

- 13.8% nurses and 12.2% GPs showed willingness to discontinue with a shared willingness of 4.2%
- Greater willingness when:
  - Older resident
  - More physically dependent
  - Resident in ward with controlled access
- Lesser willingness when:
  - Previously failed discontinuation
  - Risk of causing harm to themselves or others
  - Nurses working longer on the ward with lower education

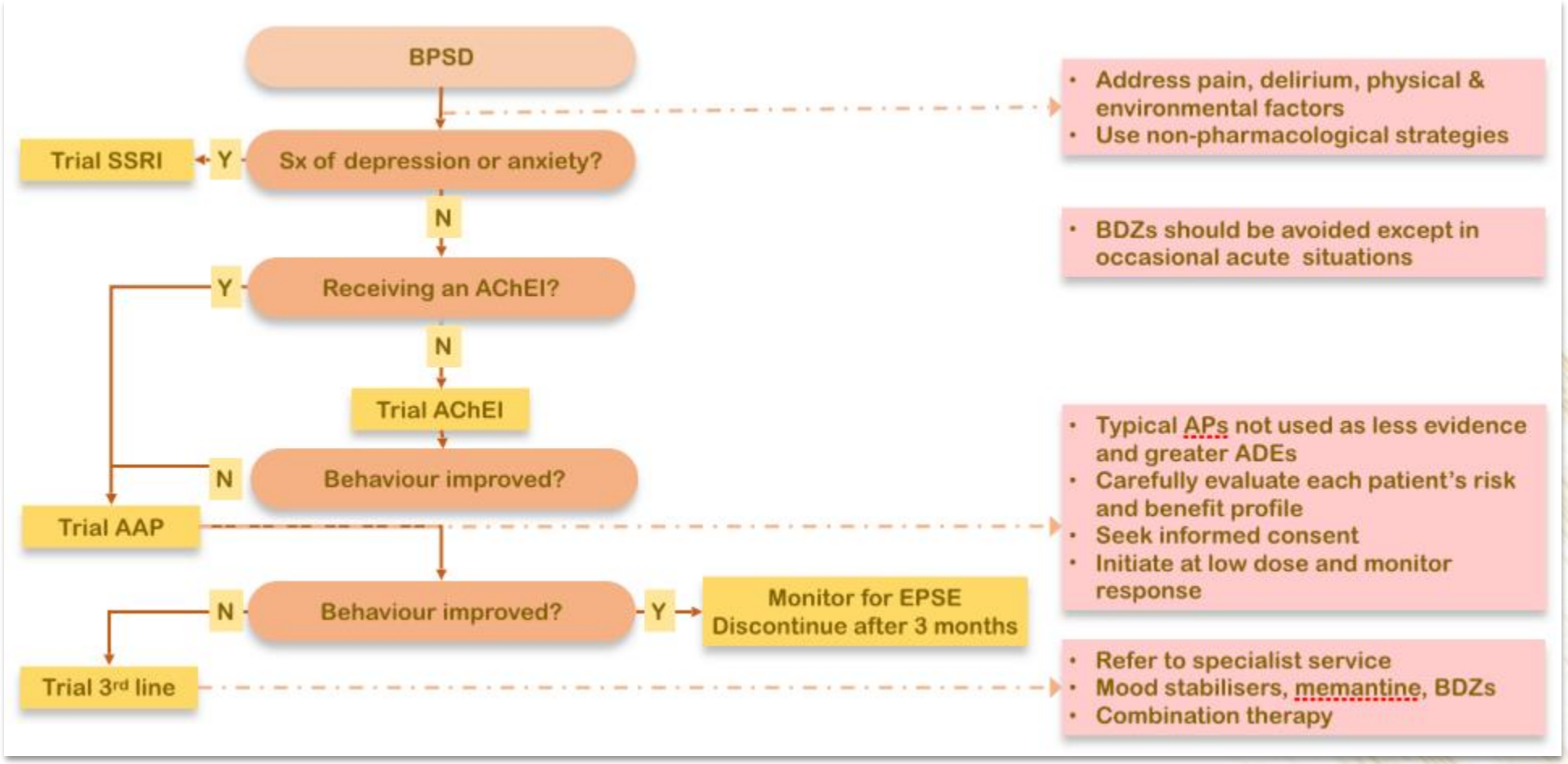
Azermai M, et al. *Aging Mental Health* 2014

Other pharmacotherapy

- Acetyl Cholinesterase Inhibitors
  - Modest effect in a broad spectrum of symptoms in AD
  - Should be initiated before other psychotropics
- Antidepressants
  - SSRIs effective in mood symptoms though may also help with agitation
  - Effective and well tolerated alternative to antipsychotics
  - Citalopram seems to have a particular role n FTD
- Memantine
  - NMDA receptor antagonist
  - Improves irritability in moderate to severe dementia when used in combination with AChE-I

Gauthier , et al. *Int Psychogeriatr* 2010

Typical pharmacological approach



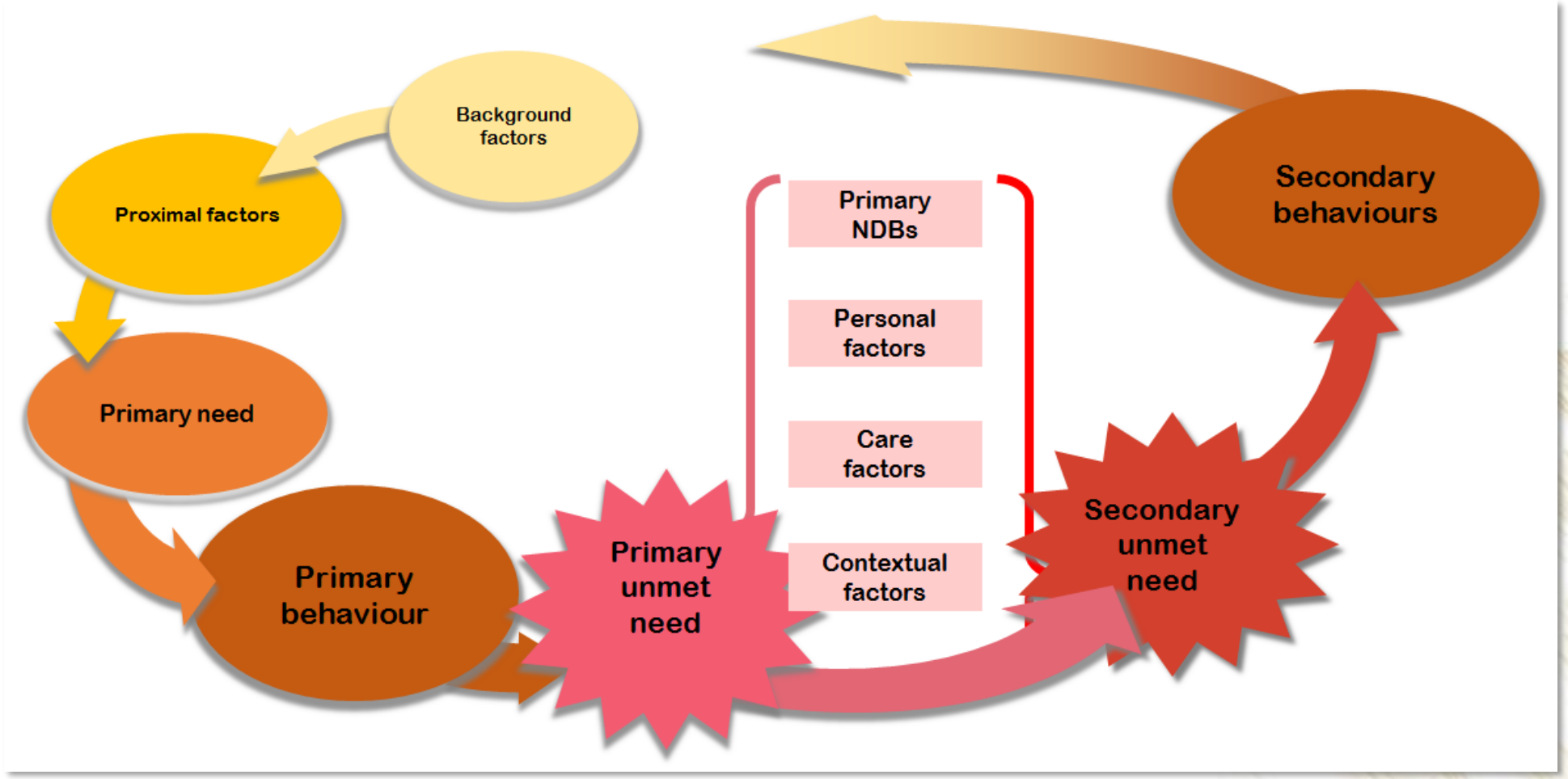
Sink KM, et al. *JAMA* 2005

Pathologising behaviour

- **Dementia continues to be framed biomedical**
  - All behaviours are viewed through the lens of disease
  - 28.6% of elderly people without dementia have neuropsychological symptoms
  - 'Dysfunctional' behaviours judged from a normative perspective
  - Psychological approaches are then utilised to manage behaviour
  - The aim is to manage or extinguish such behaviours
- **An alternative point of view may be more constructive**
  - All behaviours are driven by a need (particularly unmet needs)
  - They are meaningful forms of communication that are codified
  - The aim is to understand the behaviour

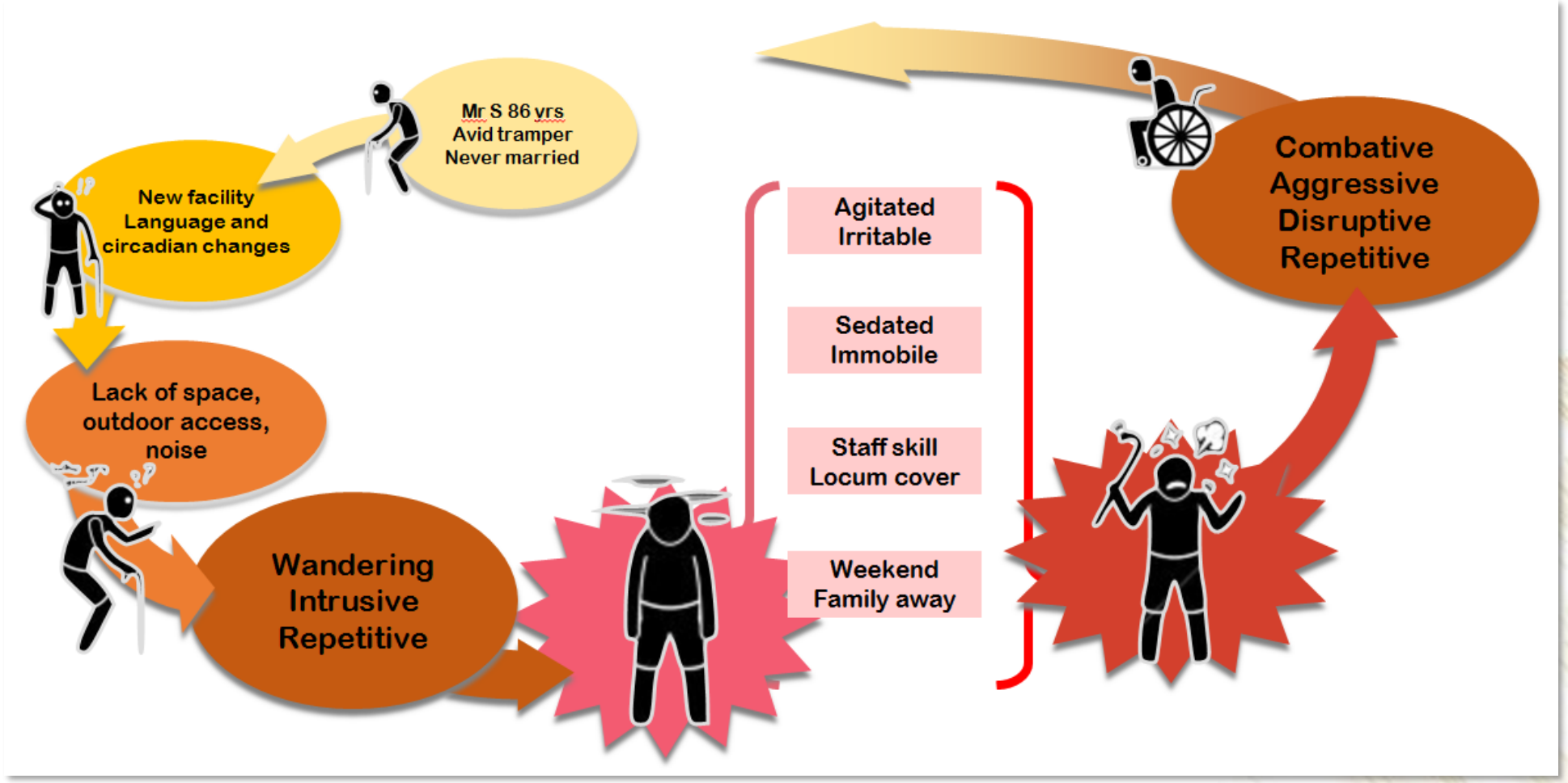
Algase DL, et al. *Am J Alzheim Dis Other Dement* 1996; Colling K, et al. *J Gerontol Nurs* 2002; Cravello L, et al. *Int Psychogeriatr 2011;* Dupuis SL, et al. *J Aging Stud* 2012

Unmet needs…(NDBs)



Kovach C, et al. *Nurs Schol* 2005

…are all too common

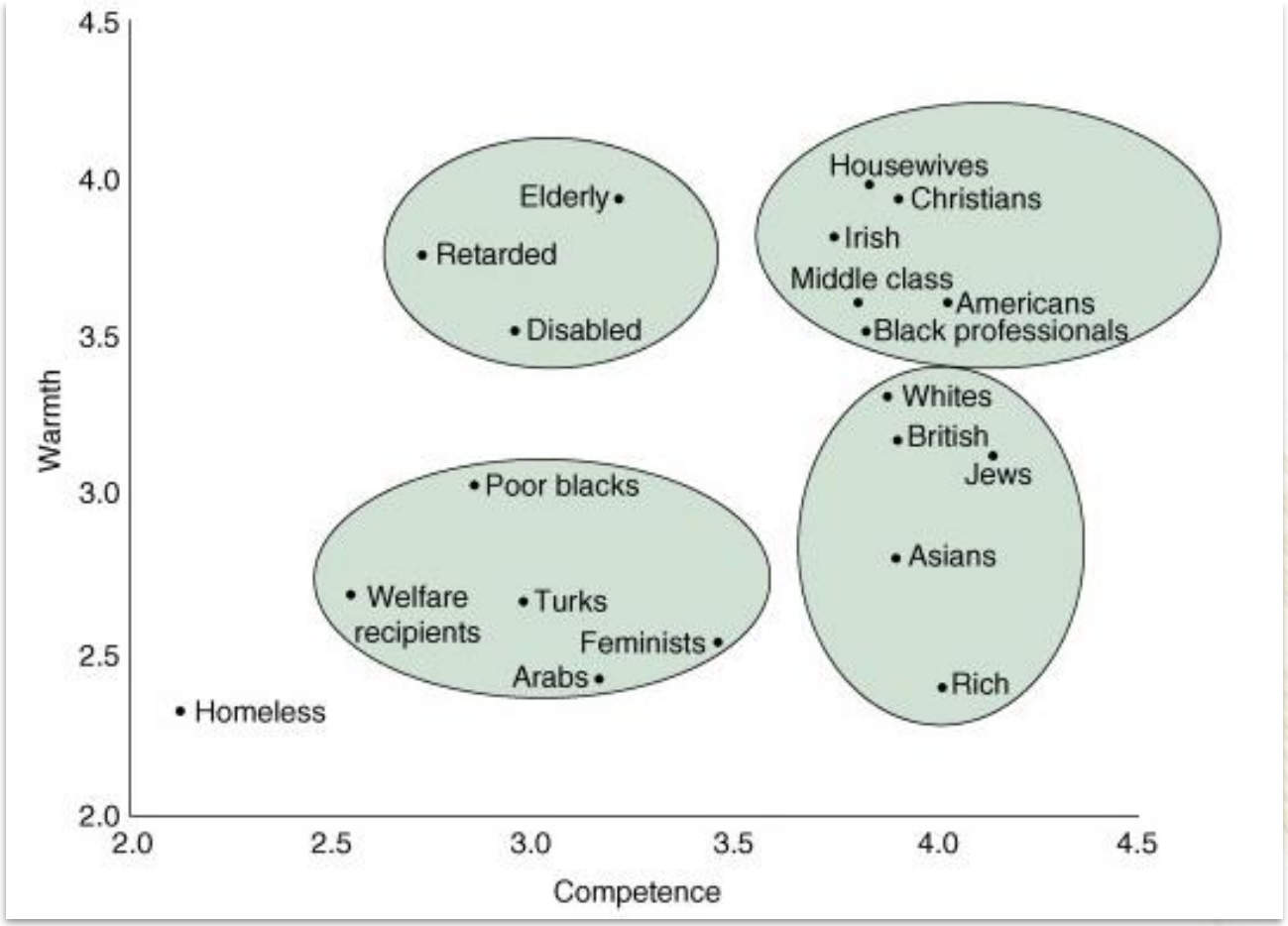


Kovach C, et al. *Nurs Schol* 2005

Ageism-Stigma-Disability

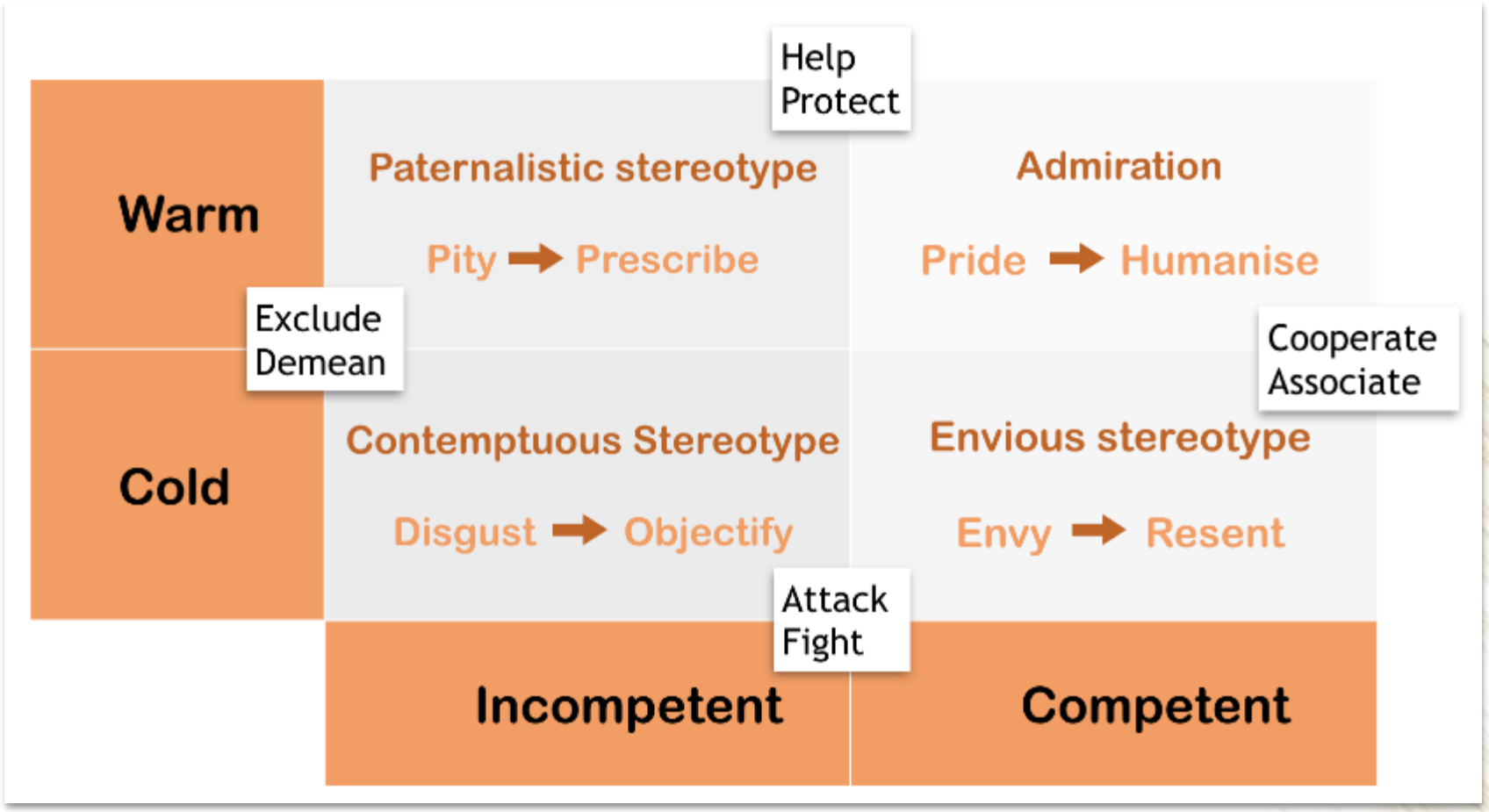
- Ageism
  - Silently pervasive in western cultures
  - Has received very little attention
  - Unique as directed against the future self
  - Only social liberty becoming further disenfranchised
- Stigma
  - Stereotypes + prejudice + discrimination
- Disability
  - UN Convention on the Rights of Persons with Disabilities (CRPD) 2006
  - Viewing dementia as a disability ***not*** a disease

Stereotype content model



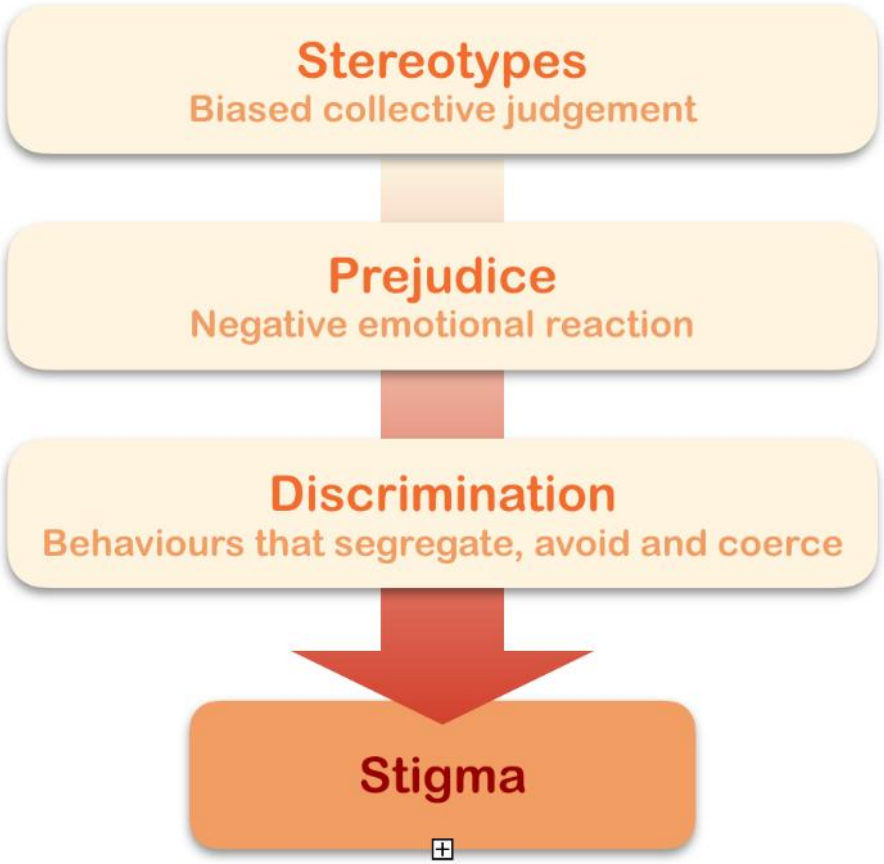
Fiske S, et al. *J Personality Soc Psychol.* 2002

Society pities the elderly



Fiske S, et al. *J Personality Soc Psychol.* 2002

The pervasive stigma of dementia



Self stigmatisation

- Most feared diagnosis (cf cancer and mental health)
- Late presentation thru concealment and minimisation

Caregiver stigmatisation

- Undervalue and appreciation of burden

Public stigmatisation

- Reaction of lay people; media representation; political lobbying
- Presumptive negative quality of life assessments
- Segregation and institutionalisation

Secondary stigmatisation

- Undervalue of staff working in dementia

Professional stigmatisation

- Avoidance of diagnostic disclosure; therapeutic nihilism
- Prognostic pessimism

Policy, service & structural stigmatisation

- Inequity in service resourcing, availability and prioritisation

Benbow SM, et al. *Neurodegen Dis Manage* 2012

Stigma in the words we use…

…impacts the care we give

"That's such an important thing, for people to realise that lots of times, you know we've always been labeled as being violent or reacting inappropriately, but if people were to think deeper than that, and see deeper than that, lots of times we're reacting to something, there's a trigger…Because they often joke about it, I'm going to be labeled as sexually inappropriate when I get into long term care because I can't stand the heat and they're all so warm. I'm going to be in there and my children already know I'm going to remove my clothing because I'm hot. And I will be labeled as sexually inappropriate, but it will be the heat"

Mitchell G, et al. *Murray Alzheim Res Educ Prog* 2006

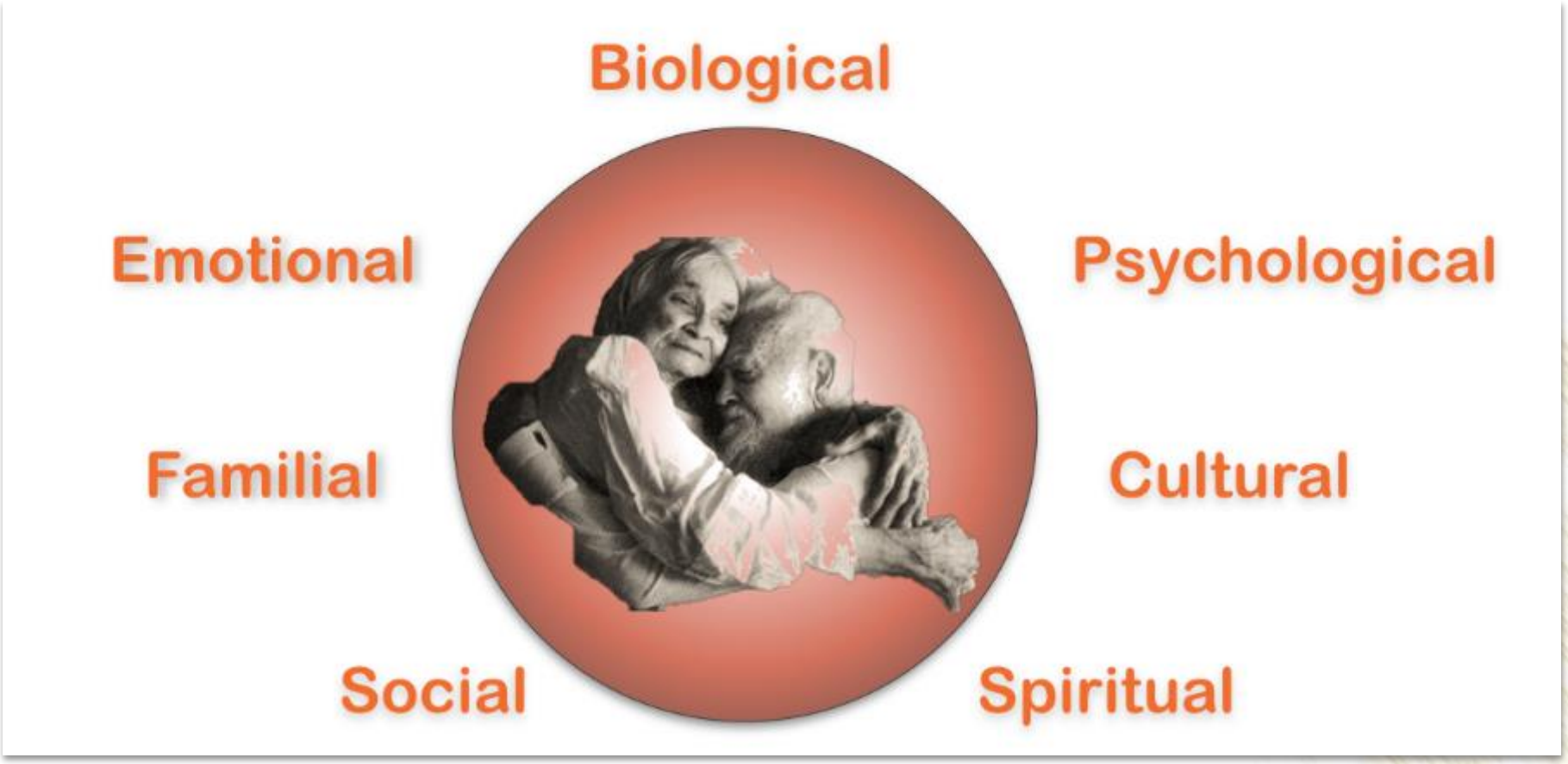
Adopting a more neutral terminology

- **Describe the behaviour in preference to labelling**
  - *"Frequently seen walking past the nursing station in the afternoon"*
  - *vs*
  - *"Wandering"*
- **Avoid attributing blame or motivation**
  - *"Behaviour that challenges"*
  - *vs*
  - *"Challenging behaviours"*
- **Non-judgemental**
  - *"Impaired capacity to accept help with showering"*
  - *vs*
  - *"Resistant to cares"*

The disability challenge

- **Dementia is a disability**
  - Cognitive and psychological deficits
  - Functional impairments
  - Social limitations
- **Disability is defined by society**
  - Thresholds of tolerance
  - Levels of accommodation
- **Reattribution leads to reintegration**
  - Shifting blame from the person
  - Citizenship reaffirmed

Return to a holistic approach

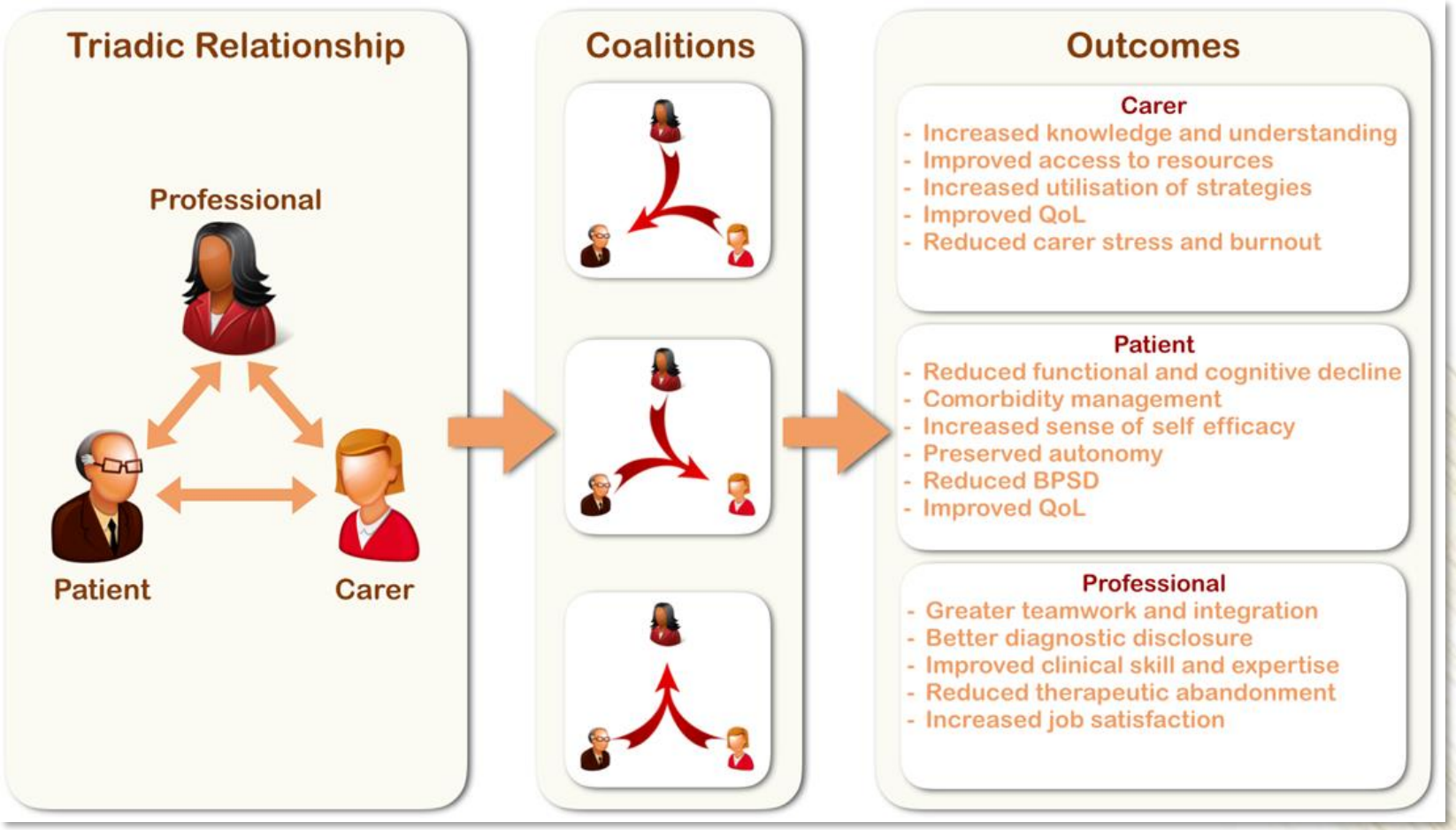


Person centred care in dementia

- Personhood has to be preserved in dementia
  - Loss of ethical imperative reduces care to mechanics
  - Meaningless life = meaningless care
- Kitwood's equation D = NI + PH + B + MSP
  - See the person, not the disease
  - Creating a positive care environment
- Little clinical progress in the following two decades
  - Lack of consensus and empirical evidence
  - Fails to fully capture the interdependencies of relationships

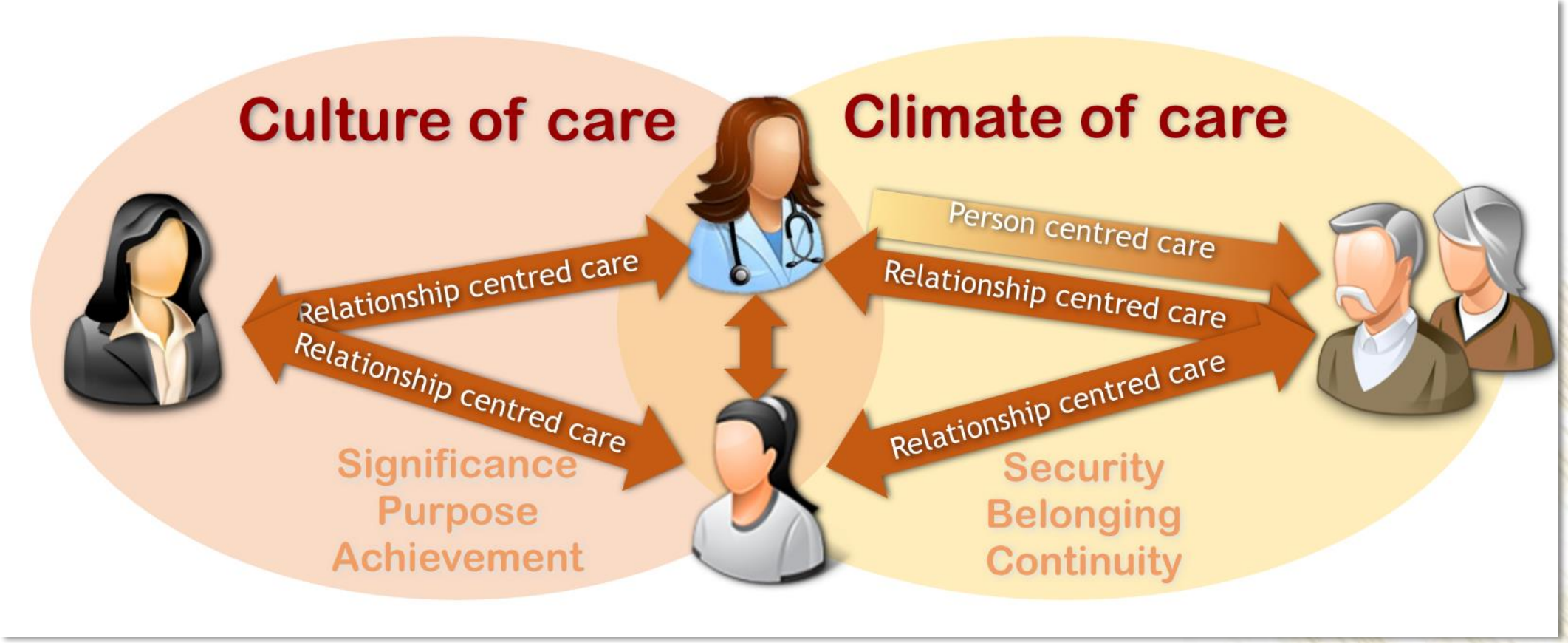
Kitwood T, *Open University Press* 1997; Adams T, et al. Dementia 2005

Dementia care triads



Fortinsky RH, et al. *Aging Ment Health* 2001; Adams T. *Dementia* 2005

Reconfiguring the directions of care



Nolan MR, et al. *J Clin Nurs* 2004

The SENSES Framework

"If employees are abandoned and abused, probably clients will be too. If employees are supported and encouraged they will take their sense of well-being into their day-to-day work too"

Tim Kitwood

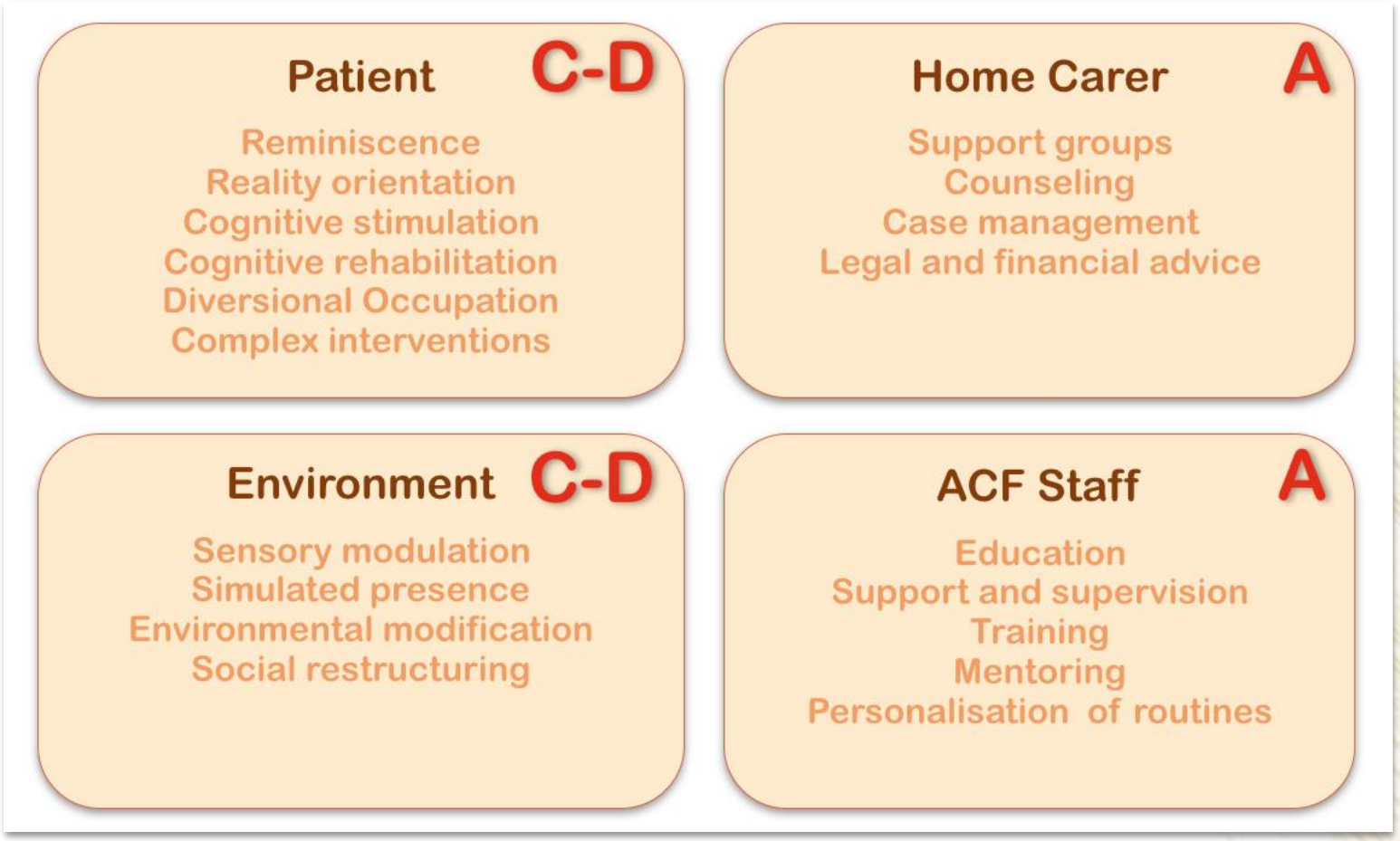
Nolan MR, et al. *J Clin Nurs* 2004

Fundamental challenge

Why is it that people who are the most vulnerable and least able to adapt are required to change their behaviours so as to better fit into societal norms and expectations?

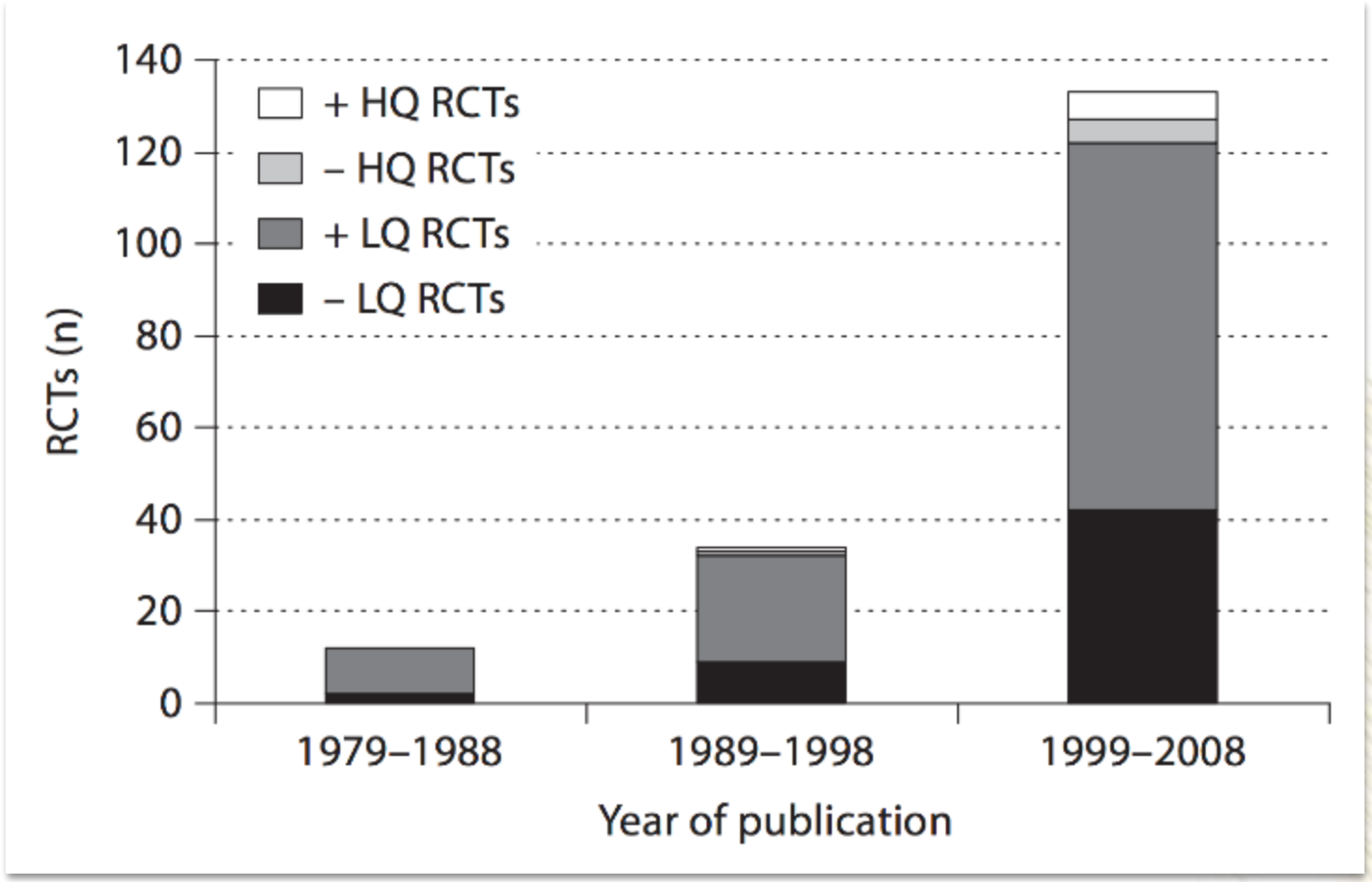
Shouldn’t the work of adapting and changing behaviours come from those who are actually able to do so in order to meet the needs of the most vulnerable?

Nonpharmacological interventions



Olazaran J, et al. *Dement Geriatr Cog Disord* 2010

Quantitative research is improving



Olazaran J, et al. *Dement Geriatr Cog Disord* 2010

Steps for implementing strategies

1. Examine and reframe our attitudes
2. Support staff education and training
3. Facilitate family involvement
4. Establish individual ways of ‘connecting’
5. Focus on remaining strengths
6. Encourage meaningful contribution
7. Support and accommodate disabilities
8. Adapt the social context and environment

Nonpharmacological frustrations

- Recommended as first line treatment in all guidelines
  - Individual interventions not generally supported
  - Acknowledges the low quality of evidence
  - Lack of agreement between guidelines regarding specific options
- Despite these recommendations and the overall supportive evidence, many of these interventions have not translated into real world clinical practice and become standard care

Azermai M, et al. *Ageing Res Rev* 2012; Molinari V, et al. *J Gerontol B* 2010

What is standard care?

- Filtering behaviours through the lens of pathology
  - All behaviour seen as arising from dementia
- Assigning a special moral status
  - Assumed lack of insight thus absolved personal responsibility
- Assigning meaning to the behaviour
  - Masked to a varying degree by dementia
- Characterising which behaviours were challenging
  - Intentional, unpredictable, persistent, threatening or inappropriate
- Reacting through crisis management
  - Clinical threshold of awareness misses opportunity gaining meaning from usual ways of behaving
  - Predominance of generic responses such as distraction or redirection

Dupuis SL, et al. *J Aging Stud* 2012

Barriers to implementation

- Lack of staff education and training opportunities
- Resistance to change because of institutionalised attitudes
- Inadequate staffing levels or lack of organisational and peer support
- High staff turnovers leading to inconsistent care practices
- Insufficient time and financial resources
- Lack of authority to change practice

Cohen-Mansfield J, et al. *Int Psychogeriatr* 2013

A plethora of interventions

Standard therapies
- Dementia day care
- Cognitive rehabilitation
- Cognitive stimulation
- Reality orientation
- Sensory enrichment
- Simulated presence
- Validation therapy
- Reminiscence therapy
- Personalised recreation
- Life review
- Functional analysis of bathing
- Individual exercise therapies
- Group exercise therapies

Environmental
- Environmental manipulation
- Specialised behaviour management units
- Reduced stimulation unit
- Design of internal corridors
- Blinds and cloth barriers to cover doors/windows
- Outdoor spaces
- Gardening therapy
- Design of walking path
- Signposting
- To dimensional grid pattern by doorway
- Mural painted over doors
- Removing mirrors
- Nine types of visual barriers
- Dementia designed environment
- Doors un/locked for standard periods
- Group living
- Low density family like units

Complementary therapies
- Aromatherapy
- Stimulating and sedative music
- Preferred music during bathing
- Quiet music at mealtimes
- Individual music therapy programme
- Sound therapy (white and pink noise)
- Reading sessions
- Audiobook sessions
- Puzzle play
- Aquatic therapy
- Dance therapy
- Therapeutic touch; Expressive touch
- Language-relevant focused therapy
- TENS stimulation
- Acupuncture
- Trancranial magnetic stimulation
- Bright light therapy
- Pet therapy
- Rocking chair therapy
- Therapeutic recreational activities

Staff education & training
- Behaviour management techniques
- Emotion orientated care
- Mentor programmes
- Care management
- Mindfulness based stress reduction
- Behaviour intervention training
- Supportive psychotherapy
- Social skills training
- Interdisciplinary care planning
- Montesorri training
- Integrity to promote care training
- Individual professional supervision
- Manual guided course for nurse aides

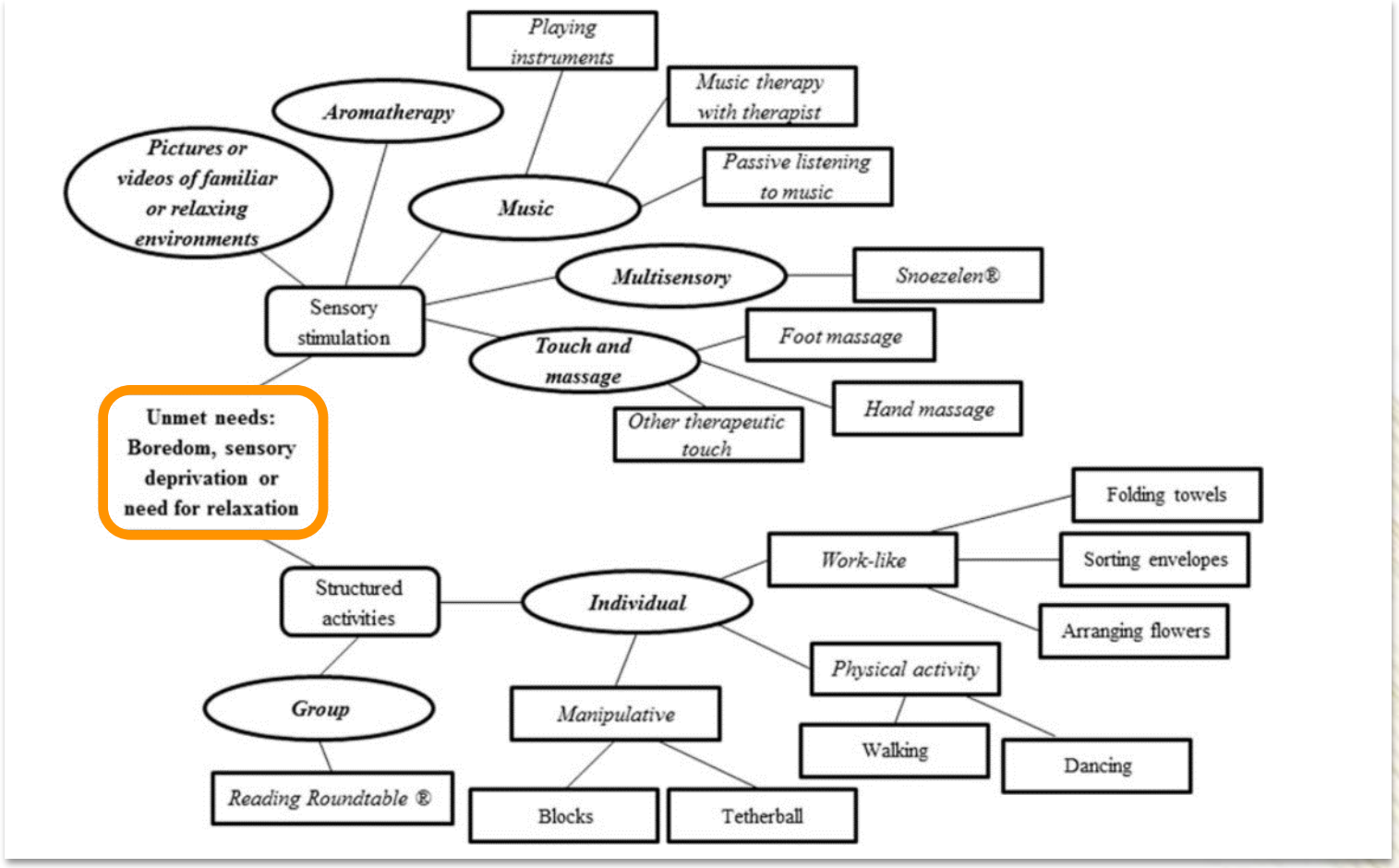
Brief psychotherapy
- Cognitive behavioural therapy
- Progressive muscle relaxation
- Interpersonal therapy
- Family counselling sessions
- Fading cue and spaced retrieval
- Behavioural reinforcement
- Non-contingent reinforcement
- Restore-empower-mobilise intervention
- Reinforcement of quiet behaviour
- Group CBT
- Anxiety management
- Applied behaviour analysis
- Time-out
- Anger management
- Self monitoring by patient

Carer focussed
- CG education
- CG support
- Case management
- Respite care
- Multicomponent
- Family support
- CG training in behaviour management
- CG awareness and problem solving
- Manual guided group intervention
- Psychoeducational group programmes
- CG groups
- Integrated family support programme
- Family therapy
- Specialist “admiral” nurse service

Multicomponent therapies
- Snoezelen therapy
- Individual coaching
- General activity sessions
- Therapist assisted multi-sensory stimulation
- Sensory integration therapy
- Unstructured group work
- DAISY intervention
- ADLs interventions
- Way-finding interventions
- Stimulation-retreat programme
- Abilities focussed programme of morning activities
- Group activities
- Classroom therapy
- Orientation training
- Family support
- Self maintenance therapy
- Habit training for ADLs
- Pleasant event training
- Problem solving training
- Functional assessment of disruptive vocalisations
- Functional analysis based on superstitions
- Psychomotor activation programme
- Small group activities
- Volunteer led interventions
- Quiet week intervention
- Intergenerational activities
- Enforced social activity with nurses
- Montesorri activities
- Specialised care planning
- Group music therapy
- Singing groups
- Therapist led ADL planning therapy

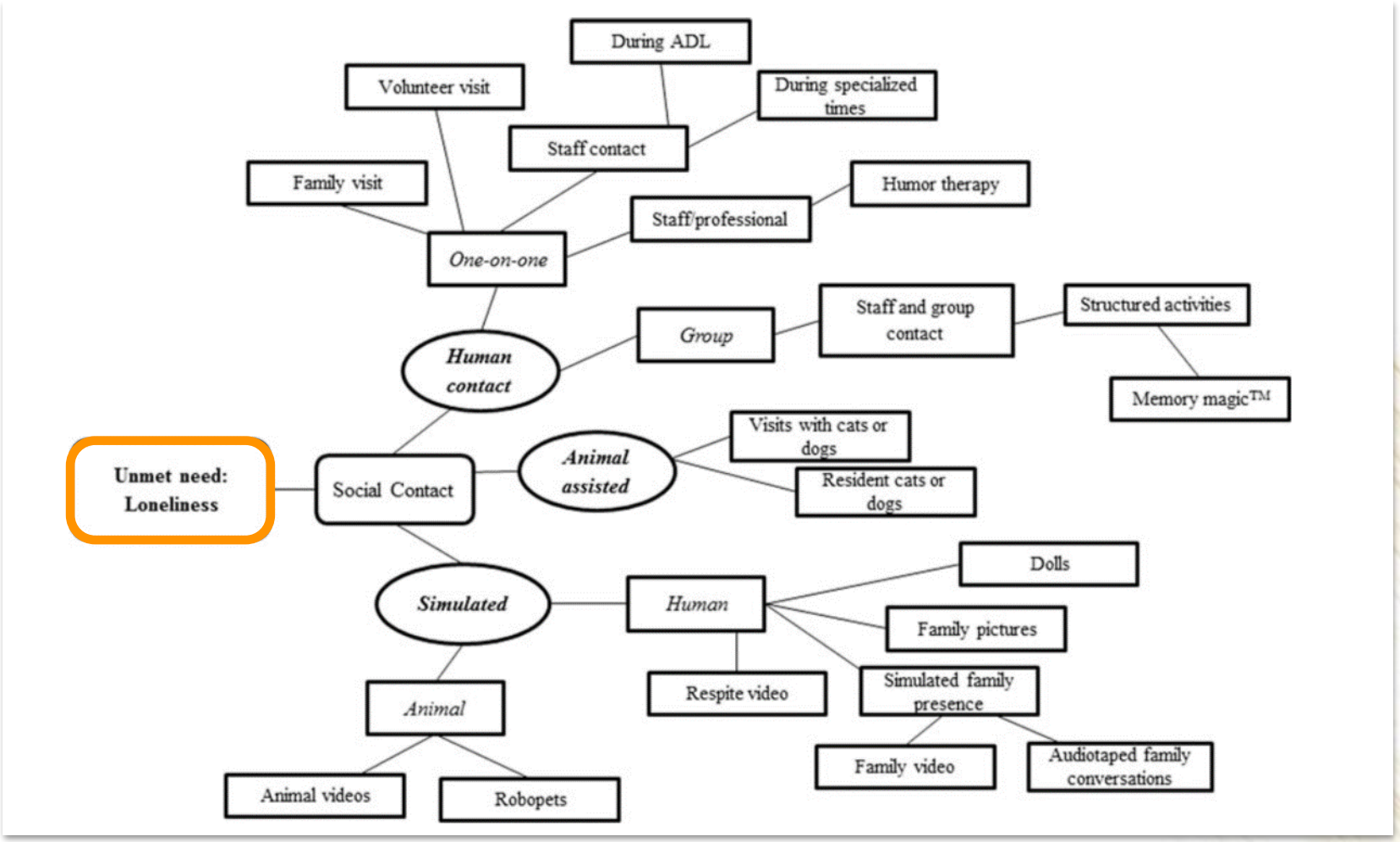
Too many to list

Unmet need: boredom



Cohen-Mansfield J. *Curr Treat Options Dement* 2013

Unmet need: loneliness



Cohen-Mansfield J. *Curr Treat Options Dement* 2013

A matter of being sensible

Potential durability of response

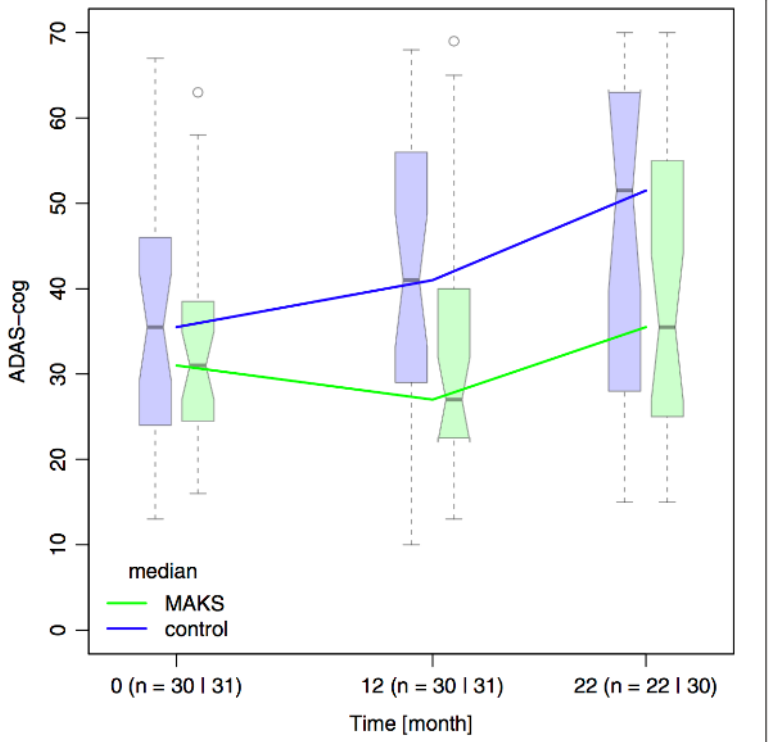


Figure 3 Median ADAS-cog values over time. Median ADAS-cog values in the MAKS and control groups over time together with the corresponding notched boxplots. Higher scores indicate greater deficits. Boxplots represent the distribution of raw data values. Non-overlapping notches are a (rough) indicator of significantly different medians [28].

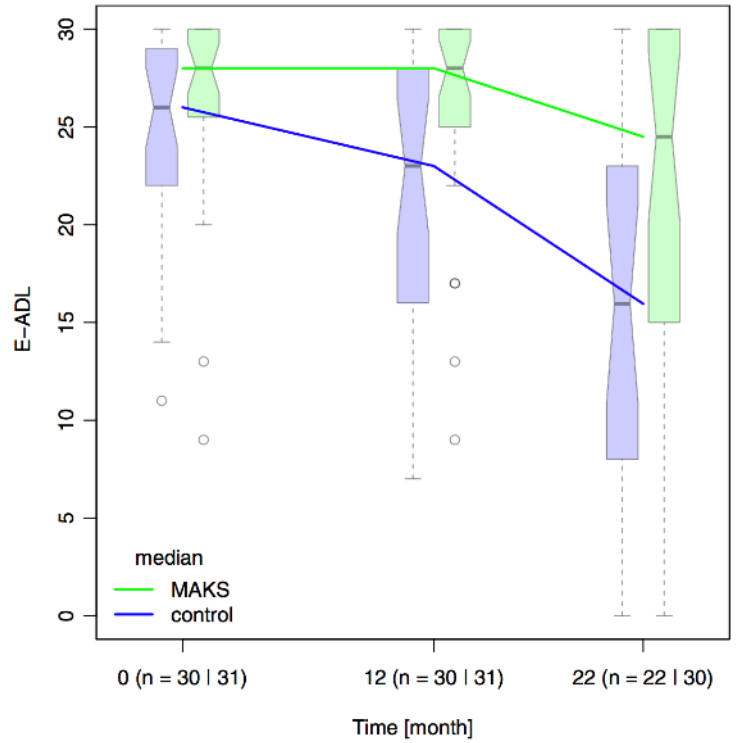


Figure 2 Median E-ADL test values over time. Median E-ADL test values in the groups MAKS and control over time together with the corresponding notched boxplots. Lower scores indicate greater deficits. Boxplots represent the distribution of raw data values. Non-overlapping notches are a (rough) indicator of significantly different medians [see 28].

Luttenberger K, et al. *BMC Neurology* 2012

My (hypothetical) scrap book


Imagine yourself at 80...
...how would you feel?
...what would you still love to do?
...who would still be there to care?
...?

Final thoughts towards a better approach

- We are caring for our future selves when we provide care to people with dementia
- Remember the person is always more important than their illness
- Be kind to yourself

Thank You