PROGRAM FOR POSITIVE AGING

IMPROVING LATER-LIFE MENTAL HEALTH AND DEMENTIA CARE

How do we move evidence-informed assessment and management of behavioral symptoms into the real world?: *The DICE Approach*

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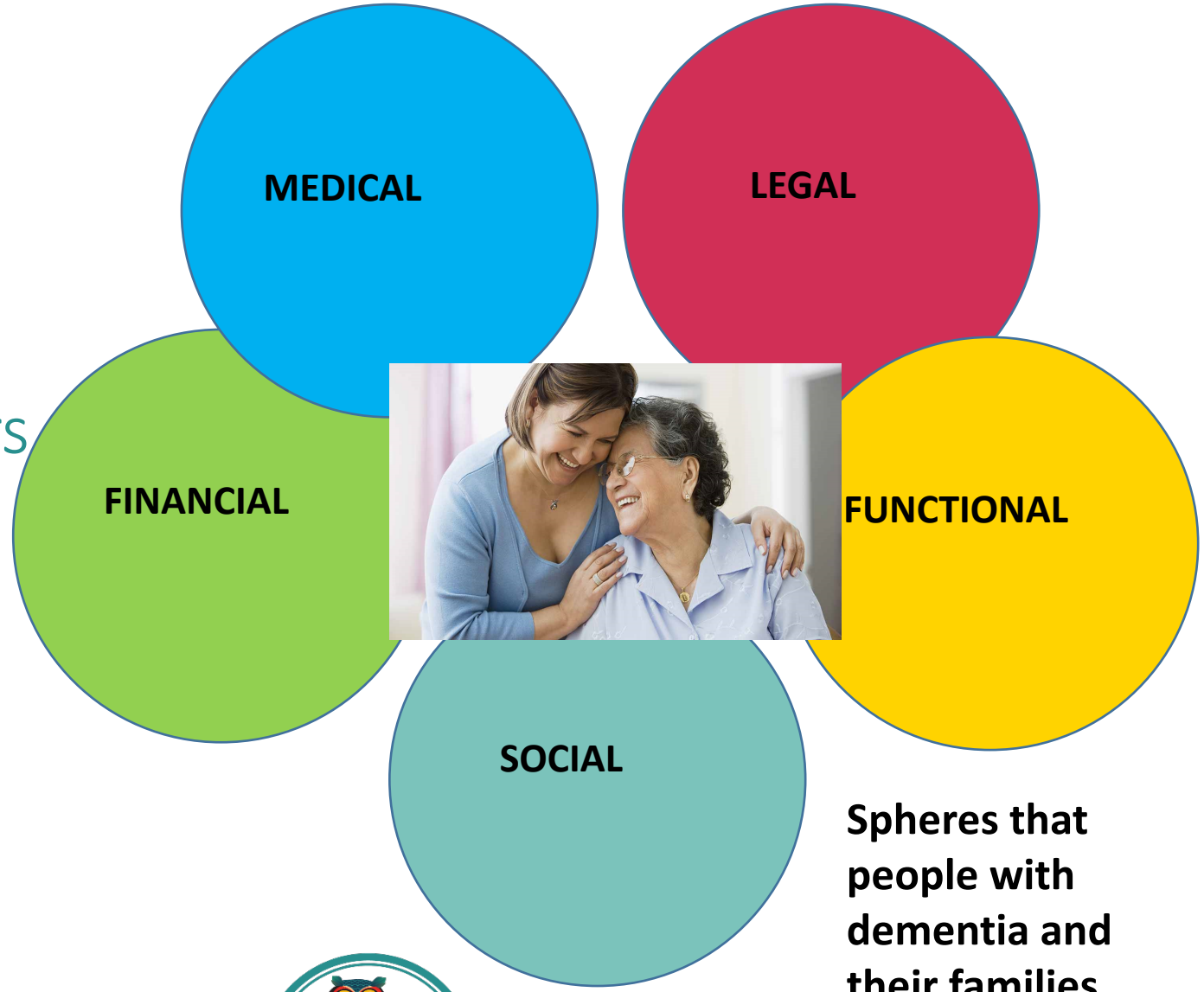
Currently, the **5 million** people with dementia and their **15 million** family caregivers often find themselves navigating without resources or training



Spheres that people with dementia and their families must navigate

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Dementia behaviors (BPSD) and their consequences

- Depression
- Anxiety
- Apathy
- Psychosis
- Agitation
- Aggression
- And many more

- Greater functional impairment
- Worsened quality of life
- Excess morbidity and hospitalizations
- Earlier nursing home placement
- Major source of caregiver burden and reduced caregiver income
- $10,000/year additional care costs
- Shorter time to severe dementia
- Accelerated mortality

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Dementia Care for BPSD: Big problem #1

- **Big problem #1=Inability to access relevant resources precisely when needed**
  - Few specialists, concentrated in academic centers
  - Primary care physicians with too little training
  - Dementia is more than a “medical” illness, there are multiple other spheres it impacts (legal, financial, functional, social)
  - Resources are available but can be hard for caregivers to find and access

Lack of resources impacts on family caregivers and people with dementia

Caregiver themselves:

- Stress
- Burden
- Depression
- Burnout
- Lost income

To the person with dementia:

- Unoptimized health and function
- Limited social engagement
- Lack of tailored activities

Within the dyad:

- Lack of understanding about dementia (“he’s doing this on purpose”)
- Poor communication (yelling, negative communications)
- Expecting too much for the person’s dementia stage

Dementia Care for BPSD: Big problem #2

- Personalized medicine=treatment focusing on patients based upon their individual clinical characterization
- Precision medicine=focus on identifying which treatment approaches will be effective for which patients

- **Big problem #2=Current dementia care is neither personalized nor precise**
  - Given the lack of a cure for dementia, the current focus is on day to day management
  - Much of that management is focused on the ubiquitous and extremely challenging behaviors that accompany dementia
  - Current real-world care (community or NH) for behaviors is largely centered on medicating/sedating people with dementia

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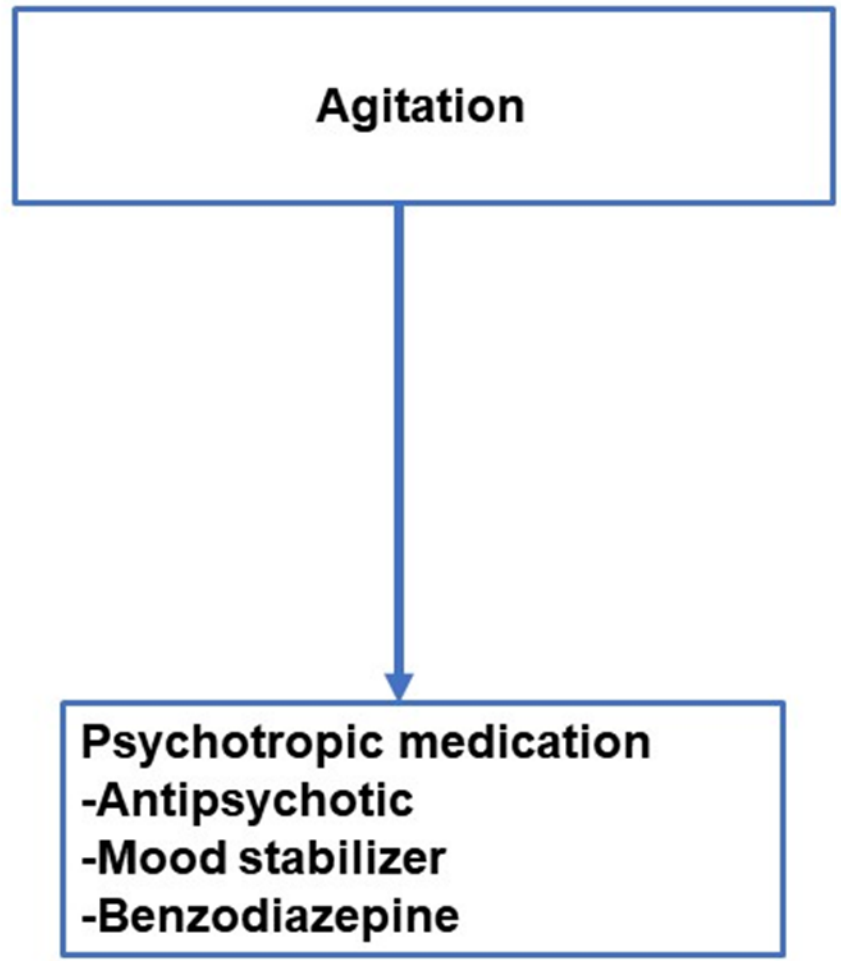
Current Real-World “Assessment” of Behavioral and Psychological Symptoms of Dementia



Dementia Care: Big problem #3

- Medications not very effective (1950's treatment for 21st century patients)
- In most cases, medications do not treat the underlying problem, but cover it over (e.g. sedate)
- Medications are associated with significant side effects including mortality
- Efforts by national policy bodies to limit use of one medication (e.g. antipsychotics) drive up use of others (e.g. anticonvulsants)
- Behavioral and environmental treatment strategies if selected appropriately (precision medicine) are more effective

Table 3. Adjusted Mortality Risk Differences in Death Rates During the 180-Day Observation Period Between Medication Users and Antidepressant Users[a]

Medication	Risk Difference, % (95% CI)	NNH (95% CI)
Antidepressant	[Reference]	NA
Haloperidol	12.3 (8.6-16.0)[b]	8 (6-12)
Olanzapine	7.0 (4.2-9.8)[b]	14 (10-24)
Quetiapine	3.2 (1.6-4.9)[b]	31 (21-62)
Risperidone	6.1 (4.1-8.2)[b]	16 (12-25)
Valproic acid	5.1 (1.8-8.4)[b]	20 (12-56)

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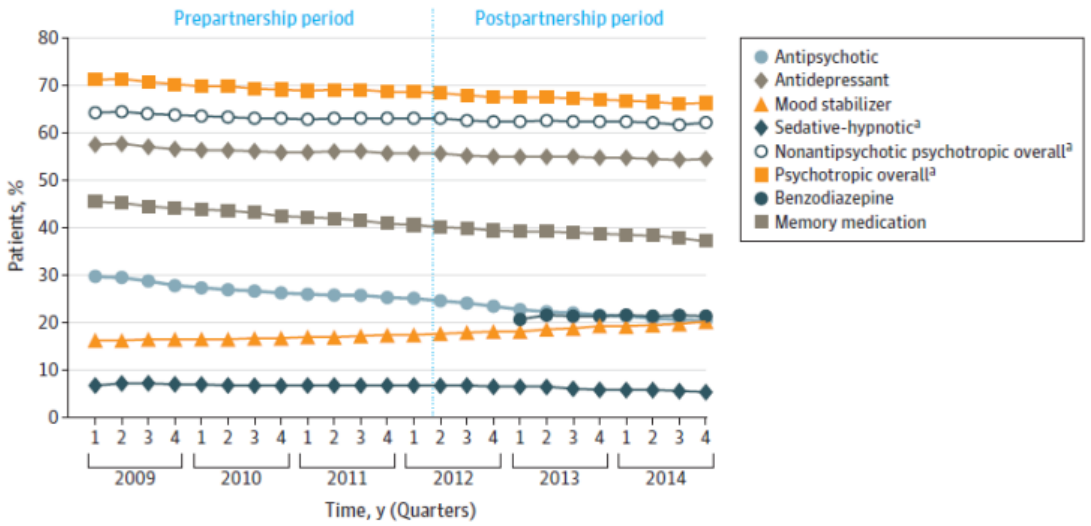
Antipsychotic use HAS declined—but does that mean that fewer people with dementia are being medicated with psychiatric drugs?

- Programs such as CMS' National Partnership have driven down nursing home AP use
- Unintended consequences?: Shift to other psychotropics with less evidence of benefit and similar risks?

Figure 2. Percentage of Long-Stay Nursing Home Residents With Dementia Prescribed an Antipsychotic or Other Psychotropic Medication



Maust, Kales et al
JAMA Internal Med
2018

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BMJ Conceptual Model

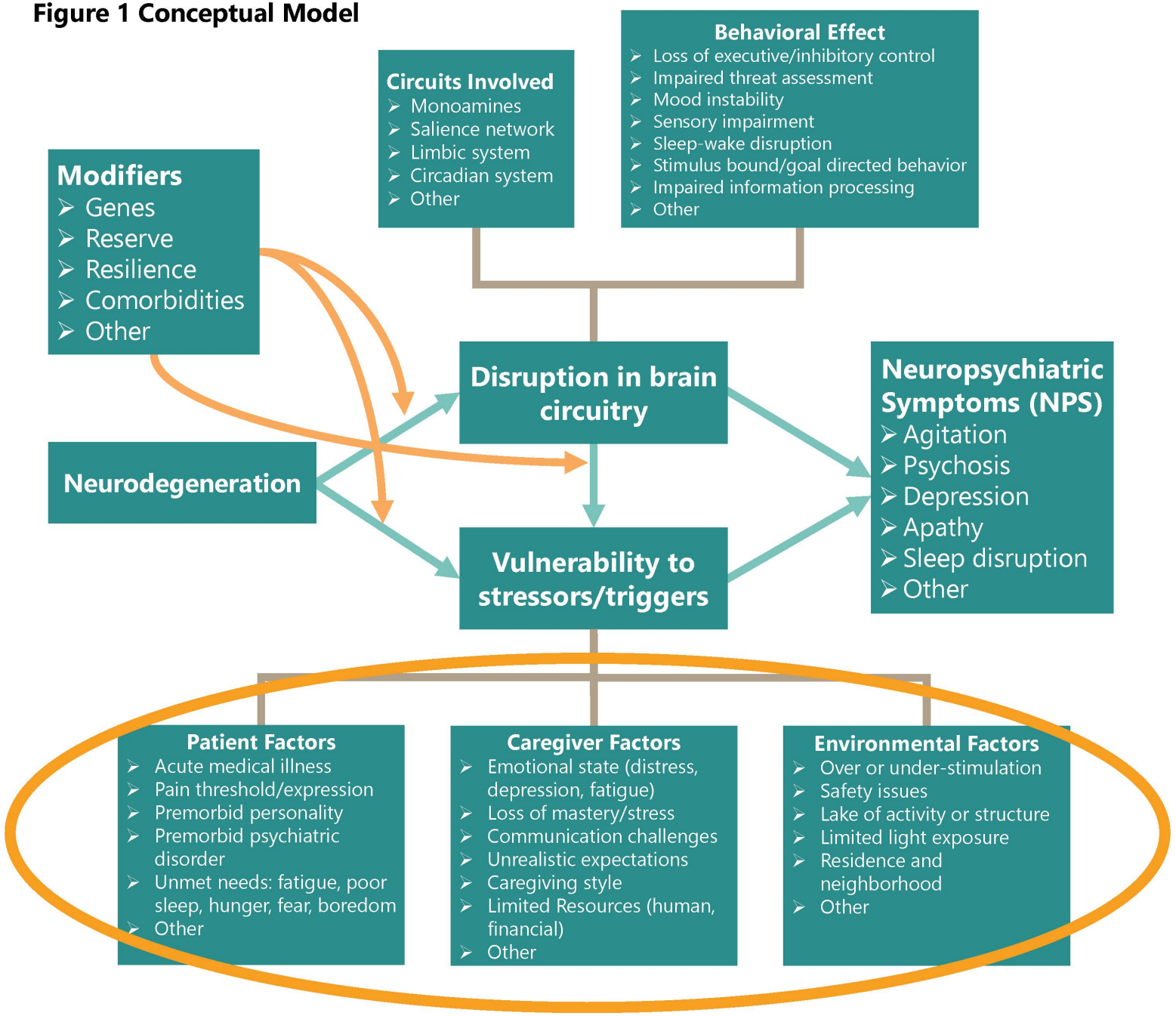
- Consequence of neurodegeneration associated with dementia
- Creates an increased vulnerability to stressors
- Stressors include patient, caregiver and environmental factors

- No one-size-fits all solution
- Need for personalization and precision

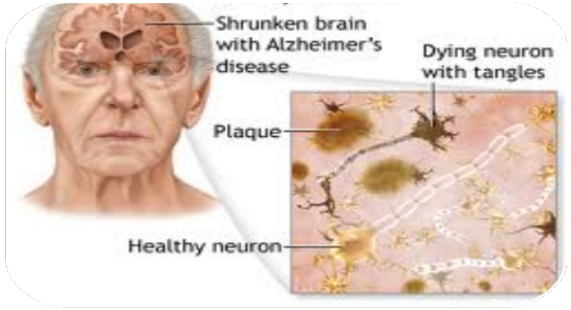
Kales, Gitlin, Lyketsos BMJ 2015

NIA/NIMH Panel, 2017

Figure 1 Conceptual Model

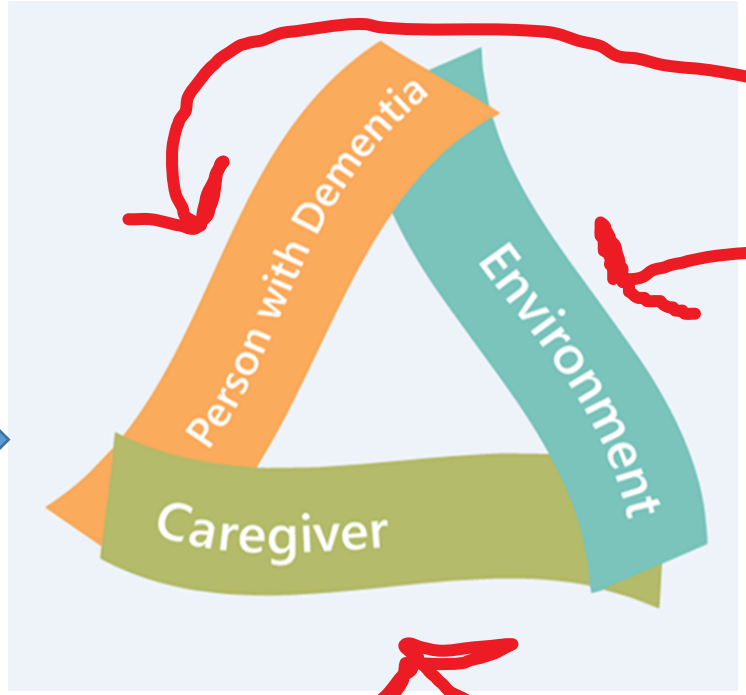


Does how we treat behaviors currently make sense?



Brain disease

Behavior



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Non-pharmacologic treatment

- Numerous expert bodies recommend as first-line
- May be better stated as **"ecobiopsychosocial"** interventions
- Largely NOT been translated to real-world care and clinical settings
  - Lack of scalable training programs for caregivers and providers
  - Time required
  - Lack of guidelines-what strategy to use and when?
  - So many interventions (e.g. acupuncture, music therapy, reminiscence)—what works?

- **Big problem #3: L<u>ack of training</u> among caregivers (or providers) on how to use proven non-pharmacological strategies to manage behavioral symptoms**

Molinari et al, 2010;
Cohen-Mansfield et al, 2013

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How can we solve Big Problems #1, 2 and 3?

With innovation, “packaging” and technology

The DICE Approach

- Program for Positive Aging organized and funded a 2011 meeting of national experts across disciplines
  - Consider possible etiologies
  - Include caregiver in process
  - Integrate pharmacologic and non-pharmacologic
  - Build in flexibility to use in various care settings
  - Goal to avoid knee-jerk prescribing without assessment of underlying causes

Kales, Gitlin, Lyketsos JAGS 2014

  - ***We need to better PACKAGE non-pharmacologic approaches**

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DESCRIBE

INVESTIGATE

CREATE

EVALUATE

- **Describe** a behavior that challenges; who, what, where, when, and how the behavior occurs
- **Investigate** thinking like a detective and explore the person with dementia, the caregivers, and environment for possible clues to triggers underlying possible causes of behavior
- **Create** a prescription in collaboration with your team to help prevent and manage behaviors
- **Evaluate** and review prescription effectiveness, and modify or restart the process as needed

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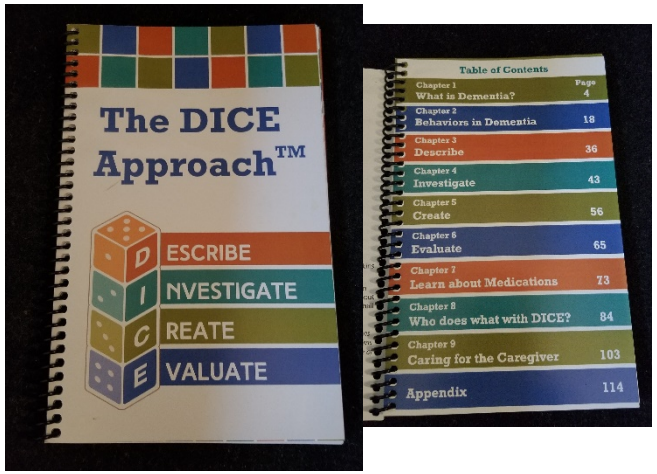
How Does DICE Differ from Other Approaches Out There?

- Approach is algorithmic
  - Simple but elegant
  - Designed to be easy to remember and to help create “good habits”
- Integrates pharmacologic and non-pharmacologic approaches
- Expands the discussion of medications beyond psychiatric medications to other medications (for pain, infection, constipation, etc)
- Strategies are tailored to the PWD, caregiver and environment

We've "Packaged" the Approaches Via DICE, How Do We Deliver Them?



- **Michigan Health Endowment Funding (MHEF)**
- Pilot of DICE Trainings: 1 day; 8 modules with 1.5 hour brainstorming session
  - Creation of DICE manual
  - Michigan-3 trainings (Grand Rapids, Ann Arbor, East Lansing)
    - Mix of family (n=40) and professional (RN, LPN, CNA, PT, RT, SW; n=142) caregivers; a number of the professional caregivers were also family caregivers
    - N=182

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Michigan Training Results	Family Caregivers (n=40)	Professional Caregivers (n=182)
Understand feelings of PWD	1.67 (0.81-3.41) NS	1.46 (0.66-3.35) NS
Understand way the PWD interacts with others and their environment	2.78 (1.30-5.95) **p<0.009**	2.78 (1.18-6.52) **p<0.02**
Use information about past interests	1.67 (0.81-3.41) NS	1.81 (0.80-4.13) NS
Protect the dignity of the PWD	2.13 (0.92-4.92) NS	2.93 (1.11-7.71) **p<0.03**
Deal with behavior of the PWD	5.60 (2.16-14.50) **p<0.0004**	3.92 (1.40-10.98) **p<0.01**
Decide about risk in PWD	2.44 (1.13-5.31) **p<0.03**	1.53 (0.64-3.65) NS
Offer stimulation to the PWD	2.78 (1.30-5.95) **p<0.009**	1.35 (0.57-3.20) NS
Offer choices to the PWD	3.29 (1.41-7.66) **p<0.006**	2.62 (1.03-6.67) **p<0.05**
Engage PWD in creative activities	3.00 (1.35-6.68) **p<0.008**	1.55 (0.63-3.80) NS
Understand the causes of behaviors	4.50 (1.86-10.90) **p<0.0001**	1.95 (0.74-5.18) NS
Understand how to assess and manage BPSD	10.33 (3.16-33.80) **p<0.0001**	4.88 (1.39-17.09) **p<0.02**
Understand PWD, caregiver, environmental factors and BPSD	4.80 (1.83-12.58) **p<0.002**	3.55 (1.24-10.18) **p<0.02**

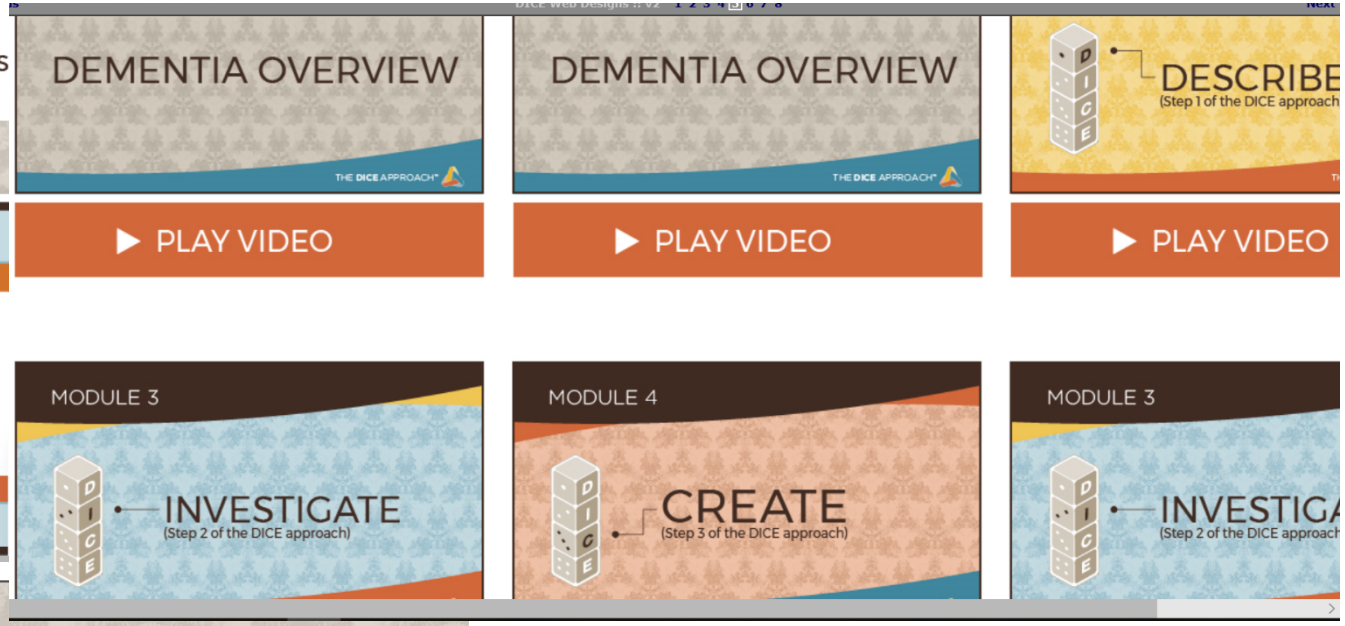
Qualitative Feedback

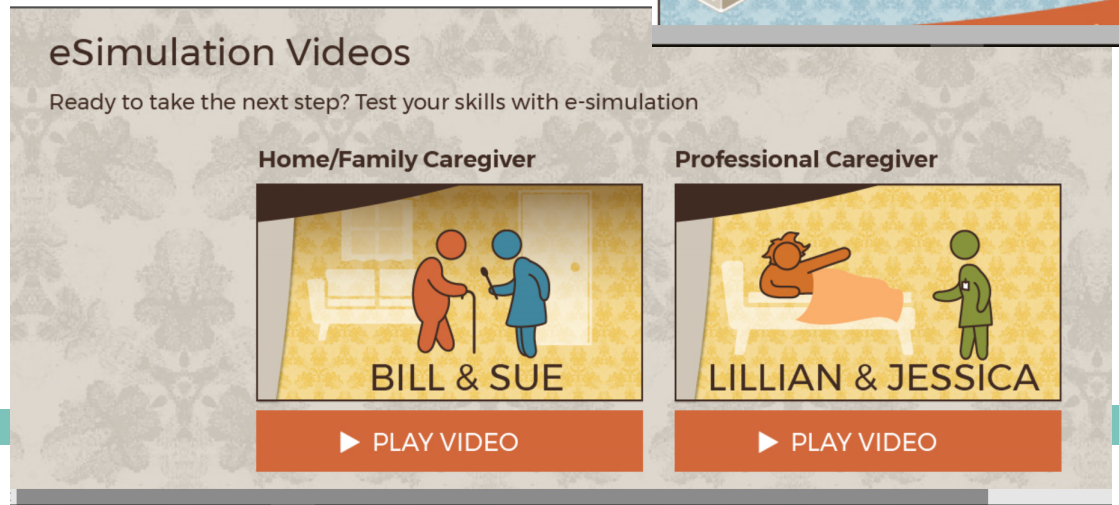
- The whole approach organizes a complicated medical problem - brain disease -into something more manageable. Each aspect of the training was illuminating for me as a caregiver. I have found great comfort today -education really is empowering.
- The DICE approach incorporates front line staff to help describe and investigate and be included in the process.
- I liked the different steps in DICE and how simple the acronym is. I also like how it focuses on the person and how to help them and the caregiver through situations rather than just accept the disease.

DICE Trainings

- Most helpful aspects:
  - Use of workshop materials (case studies, role playing, time to talk to other providers)
  - Combining paid professionals and home/family care givers for interaction and learning
  - Use of simple framework (DICE) that is understandable to all
  - Covering medication issues
  - Handouts to take home

DICE Website—Coming Soon (January 2019)





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Website samples

- https://drive.google.com/drive/folders/1BRjRoD05v-95Q7SgAl_7VA5b1vkQltTL

Summary

- The number of people with dementia and their family caregivers is large and growing every day with the aging of the population
- Living well with dementia is the goal
- Current care systems are inadequate and lead to multiple poor outcomes

- Innovative solutions like the DICE Approach with delivery methods including a manual, training and website can put the key components of good dementia care at the fingertips of the people who need it most