

# UCDAVIS HEALTH

Wisconsin Alheimers Institute

2025

What are we going to do  
with Grandma Tina?:  
Assessment and  
management of responsive  
behaviors in dementia

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## Topics covered

- What prevents families and people with dementia from “living well”?
  - Behavioral and psychological symptoms are among the most difficult aspects of living with dementia
  - Resources are not coordinated
  - Lack of personalization and precision of current dementia care
  - Workforce largely without specialized training
  
- The DICE Approach
  - The use of medications in the approach
  - Mention of brexpiprazole

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- Grandma Tina is a 76 year old woman with moderate dementia who lives with her daughter Athena, her son in law and grandchildren.
- Athena has hired a caregiver Jane for when the family goes to work and school.
- Athena calls Tina’s primary doctor leaving the following message
  - **“My mother is getting agitated with her caregiver. The caregiver is about to quit. Can you prescribe something to calm my mother down?”**



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# Dementia and BPSD

- Devastating syndrome affecting 5 million people in US, 16 million by 2050
- **Non-cognitive behavioral and psychological symptoms of dementia (BPSD)** are universal (>98%)
  - Can occur at any disease stage
  - Occur with every type of dementia
  - Often dominate the disease course
  - Associated with poor outcomes
  - Role of the family caregiver is critical

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

Kales, Gitlin, Lyketsos  
British Medical Journal  
2015

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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

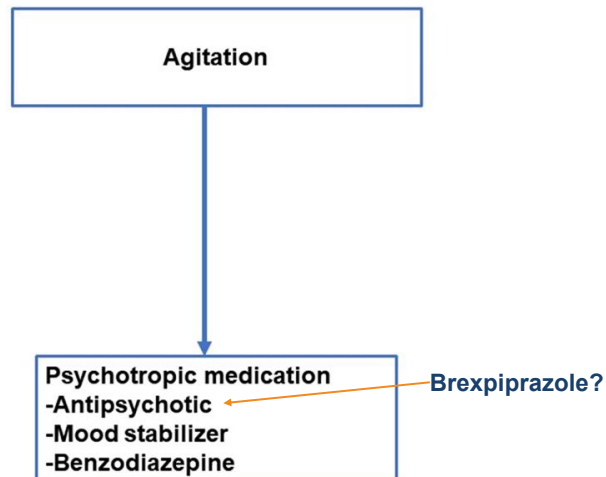
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## Dementia Care for BPSD: Big problem #2

- 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



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## Dementia Care: Big problem #3

- Medications not very effective (1950's treatment for 21<sup>st</sup> 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

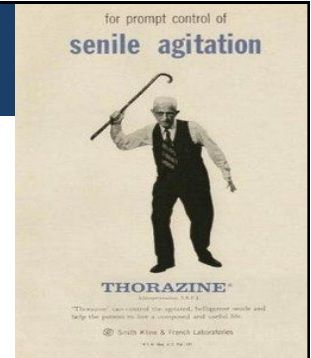


Table 3. Adjusted Mortality Risk Differences in Death Rates During the 180-Day Observation Period Between Medication Users and Antidepressant Users<sup>a</sup>

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

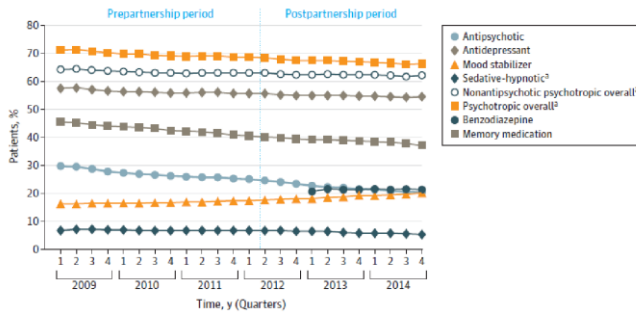
Maust DT, Kim HM, Seyfried LS, Chiang C, Kavanagh J, Schneider LS, Kales HC. Antipsychotics, other psychotropics, and the risk of death in patients with dementia: number needed to harm. JAMA Psychiatry. 2015



## 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?

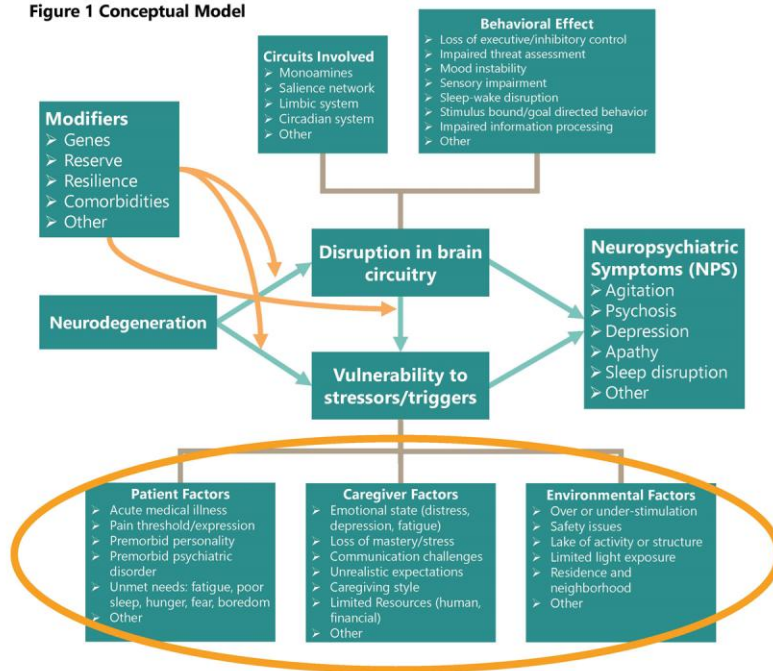
Figure 2. Percentage of Long-Stay Nursing Home Residents With Dementia Prescribed an Antipsychotic or Other Psychotropic Medication



Maust, Kales et al  
JAMA Internal Med  
2018



Figure 1 Conceptual Model



Kales, Gitlin,  
Lyketsos  
JAMDA 2019

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### Study of mirtazapine for agitated behaviours in dementia (SYMBAD): a randomised, double-blind, placebo-controlled trial

Sube Banerjee, Juliet High, Susan Stirling, Lee Shegstone, Ann Marie Swart, Tanya Telling, Catherine Henderson, Clive Ballard, Peter Benham, Alistair Burns, Nicolas Farina, Chris Fox, Paul Francis, Robert Howard, Martin Knapp, Iracema Lerol, Gill Livingston, Ramin Mirjoroshan, Shirley Nureck, John O'Brien, Annabel Price, Alan J Thomas, Najj Tabet

www.thelancet.com Vol 398 October 23, 2021

Overall, this study adds to the evidence base that shows pharmacological interventions for agitation in dementia are limited in their effectiveness<sup>17,28</sup> and associated with risk of harm. An important limitation in trials of drug and non-drug interventions for agitation is that the causes of agitation are heterogeneous and multifactorial. The syndrome might be caused by any combination of reasons as varied as: unmet needs (eg, hunger, thirst, pain), medical episodes (eg, infections, hypothyroidism), prescribed medication (eg, anticholinergics, steroids), and the environment (overstimulation or understimulation), as well as the illness causing dementia. Even with initial investigation of the causes of the agitation and treatment with non-drug management as in this trial, any one-size-fits-all intervention (whether a drug or non-drug intervention) for a heterogeneous syndrome such as agitation will have a high likelihood of failure due to lack of specificity. The fundamental presumption that there is a single neurobiological basis for agitation and therefore a specific drug that will target it, even in people with narrowly defined Alzheimer's disease or those with closely defined symptom clusters, seems particularly weak. Drugs for which a signal of effect has been found, such as risperidone and citalopram, appear to have achieved those effects through general sedative side-effects, which also drive much of the harm from such medication in the frail population with dementia.

hallucinations or delusions. Use of non-pharmacological interventions that investigate cause and provide a tailored response as a first-line treatment for agitation in dementia, such as the DICE approach (Describe the problem, Investigate the cause, Create a plan, Evaluate its effectiveness), is recommended as best practice.<sup>19</sup>

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## Brexpiprazole

- 2023 US FDA approval brexpiprazole for **agitation in dementia**; first antipsychotic to be approved for this indication.
- Controversy:
  - 1) brexpiprazole studies used an expanded definition of agitation based upon Cohen-Mansfield criteria (never meant to be used in drug trials); in 2<sup>nd</sup> trial, aggression also required
  - 2) bulk of the study population from sites outside of the US and largely white
  - 3) results of the US populations studied indicates they were primarily negative.
- Prior studies in risperidone and aripiprazole indicated greater efficacy for agitation (using more restricted agitation criteria), but did not receive FDA indication due to the conclusion at the time that agitation was a vague syndrome.
- Agitation is a heterogeneous condition: direct brain pathways leading to behavioral expression in some, or indirect pathways in others (possibly the majority; such as pain, infection, lack of sleep, etc). Reflexive treatment with any medication for this “indication” without assessment of underlying causes is concerning.
- Mortality with brexpiprazole is an open question

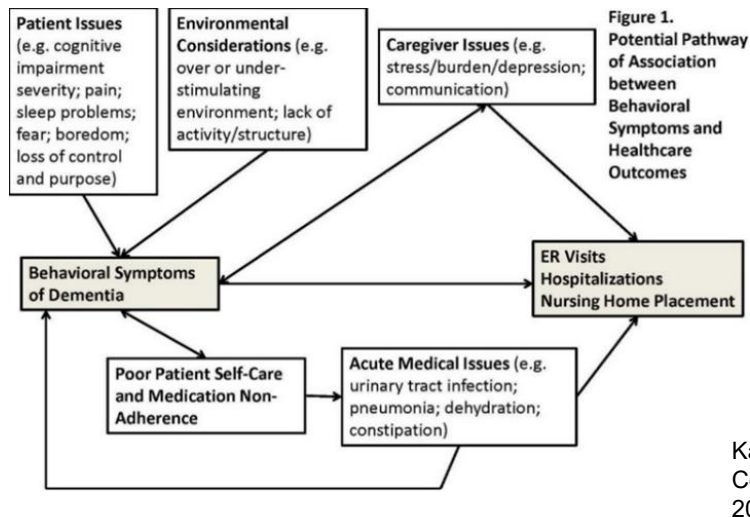
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## Treatment of Agitation

- Agitation is an extremely heterogeneous syndrome (wandering, fidgeting, hoarding, yelling, etc)
- Behaviors are often a communication of a problem (e.g. infection, pain, issues with a caregiver)
- Use of medications is often more related to degree of caregiver distress than to severity of behavioral symptoms
- “Treating” a communication to effectively silence it misses 2 opportunities
  - Treating underlying modifiable causes
  - Use of more person-centered strategies

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## What outcomes result from BPSD?



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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: Lack of training 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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## Family Caregiver Interventions: Meta-analysis

- Brodaty meta-analysis of 23 RCTs with family caregivers; outcomes related to frequency/severity of behaviors and caregiver well-being
  - effect size (magnitude of treatment effect) is LARGER for family caregiver interventions for behaviors in dementia than for antipsychotics OR for cognitive enhancers for cognitive symptoms



>



OR

CHOLINESTERASE  
INHIBITORS

Brodaty et al, Am J Psychiatry, 2012

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## Non-pharmacologic approaches: best evidence

- Behavioral, environmental, and caregiver supportive interventions that have a growing evidence base
- Most significant evidence base for family caregiver interventions that train caregivers to:
  - Use problem-solving skills to manage behaviors
  - Increase tailored activity for the person with dementia
  - Enhance communication in the dyad
  - Reduce environmental complexity
  - Simplify tasks for the person with dementia



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- **Big problem #1=Inability to access relevant resources precisely when needed**
- **Big problem #2=Current dementia care is neither personalized nor precise**
- **Big problem #3: Lack of training among caregivers (or providers) on how to use proven non-pharmacological strategies to manage behavioral symptoms and therefore medications remain the real-world treatment**

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

With innovation, “packaging” and technology

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## The DICE Approach

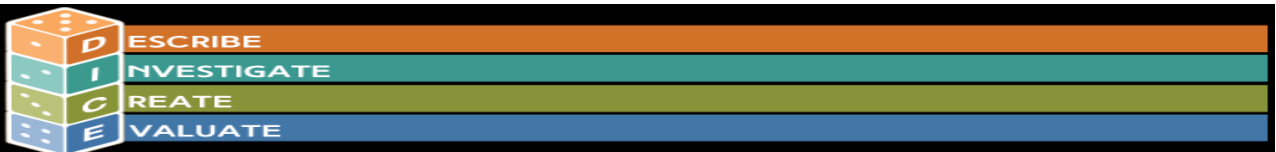
- Michigan Program for Positive Aging organized and funded a 2011 meeting of national experts across disciplines
  - Consider possible etiologies
  - Include caregiver in process
  - Integrate pharmacologic and non-pharmacologic
  - Build in flexibility to use in various care settings
  - Goal to avoid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



Kales, Gitlin, Lyketsos JAGS 2014



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- **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

Kales et al, JAGS, 2014

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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

## DESCRIBE

- Full and accurate description of the behavior
- Critical step often left out
  - Do we treat “shortness of breath” with antibiotics without history, physical or labs?
- Full description leads to underlying cause possibilities
- **Clinical scenario:** “Grandma Tina gets so agitated with her caregiver”
- Learn to “play it back like a scene from a movie”

**WHO?**  
**WHEN?**  
**WHERE?**  
**WHAT?**

## Play it back like a scene from a movie!



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### **DESCRIBE the problem behavior**

#### **Grandma Tina:**

- In bed in the morning (9 AM); eyes closed
- Possibly surprised by Jane entering/disoriented
- Gets angry: “leave me alone!” “don’t you touch me!”
- Gets physical throwing pillow and hitting Jane

#### **Jane the Caregiver:**

- Approaches in haste; seems overburdened, already on edge
- No introduction to tasks; multiple steps and tasks listed
- Confrontational and possibly disparaging: “your bed is wet!” “stop it and calm down”

#### **Environment**

- Light in room may not be optimal to cue waking up and morning routine
- Is there any morning routine/structure?

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## Patient Factors

Problem	What you might notice
Pain	<ul style="list-style-type: none"> <li>• Holding or rubbing part of body</li> <li>• Fast breathing</li> <li>• Groaning or moaning</li> <li>• Tension</li> <li>• Pushing away when touched</li> </ul>
Constipation	<ul style="list-style-type: none"> <li>• Pain and difficulty opening bowels</li> <li>• Hard poo</li> <li>• Pain on touching stomach</li> </ul>
UTI (Urinary Tract Infection)	<ul style="list-style-type: none"> <li>• Burning pain on passing urine</li> <li>• Urinating more frequently</li> <li>• Cloudy or different smelling urine</li> </ul>
Recent changes in medication	<ul style="list-style-type: none"> <li>• Dose changes in long-standing medications</li> <li>• New medications causing behavioral changes (e.g. Benadryl, Ditropan)</li> </ul>

## Caregiver Factors

- “Doing this on purpose”
- Reacting harshly
- Offering too many choices
- Expecting more than possible
- Feeling stressed, anxious, depressed
- Family, facility or cultural expectations



## Environmental Factors

## INVESTIGATE underlying causes

### Grandma Tina:

- History of bipolar disorder; on low-dose lithium
- Ditropan for incontinence; anticholinergic effect? (confusion)
- History of UTIs
- Type II Diabetes; are blood sugars under control?
- Is safety at risk?

### Jane the caregiver:

- Communication is not optimal (rushing, negative tone, critical, confrontational)
- Lack of education about dementia stages (multistep commands)
- Does she view behavior as volitional?
- What other responsibilities?
- Is safety at risk?

### Environment

- Morning light to cue for waking up
- Lack of structure/cuing for activities

# CREATE-Six general strategies

- Manage any physical problems uncovered



- Create meaningful and tailored activities



- Provide family/staff education/support



- Simplify tasks



- Improve communication



- Ensure the environment is safe



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## Create/implement collaborative treatment plan

### Grandma Tina:

- Consider replacing Ditropan with a more bladder-selective agent
- Check urine; lithium level, BUN/Creatinine, TSH
- Low blood sugars pre-breakfast could be triggering irritability

### Jane the caregiver:

- Psychoeducation on dementia stages, BPSD and simplifying communications
- Offer choices but limited
- Change tone "playing the role" (replacing negative, critical, confrontational tone) including identifying herself
- "Set the stage" for morning routine with communication and kindness; avoid physicality if this seems to increase aggression
- Make sure Jane feels safe and has resources to contact if she does not

### Environment

- Increase the amount of natural light in the room for cueing
- Create structure and cueing for Grandma Tina around morning routine

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## Rewind using DICE!



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### Evaluate the interventions

#### Grandma Tina:

- Did a new bladder medication impact behavior?
- Did stabilizing
- If an antibiotic
- Did adjusting

#### EVALUATE

Date February 10,  
2025

**Behavioral severity/frequency:** Rate the severity and frequency of the behavior from 0 to 4. If the severity and frequency are different, pick the higher score (e.g. a behavior that is daily but mild should be scored as a 4)

- 0 =none and/or never
- 1 =mild and/or occasionally
- 2 =moderate and/or sometimes
- 3 =severe and/or frequently
- 4 =very severe and/or daily



SD with

#### Jane the caregiver:

- Was Jane able to complete her education?
- Was Jane able to complete her education?  
• Tone; avc

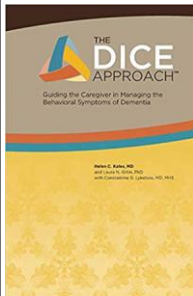
#### Environment:

- What impact did increasing morning light have?
- What new routines were implemented and what impact did they have?

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## 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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## DICE Website

### The DICE Approach Online Training Program

Are you a caregiver of a person with dementia?

Are you trying to manage behavioral symptoms such as agitation, wandering, aggression, anxiety (and so many others)?

Welcome to your one-stop location for evidence-informed training for assessing and managing the behavioral symptoms of dementia!

Years of research, hands-on experience and feedback are the foundation of this customized video training program and detailed manual to provide caregivers the education, expertise, confidence and strategies needed to better assess and manage the behavioral symptoms that so frequently accompany dementia.

LEARN MORE



<p>DEMENTIA OVERVIEW</p> <p>▶ PLAY VIDEO</p>	<p>DEMENTIA OVERVIEW</p> <p>▶ PLAY VIDEO</p>	<p>DESCRIBE (Step 1 of the DICE approach)</p> <p>▶ PLAY VIDEO</p>
<p>MODULE 3</p> <p>INVESTIGATE (Step 2 of the DICE approach)</p>	<p>MODULE 4</p> <p>CREATE (Step 3 of the DICE approach)</p>	<p>MODULE 3</p> <p>INVESTIGATE (Step 2 of the DICE approach)</p>

### Describe: First step in DICE

It is **CRUCIAL** to **DESCRIBE** the problem behavior thoroughly and clearly



### eSimulation Videos

Ready to take the next step? Test your skills with e-simulation

Home/Family Caregiver

Professional Caregiver



▶ PLAY VIDEO

▶ PLAY VIDEO

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## Regular Research Article

## Moving Evidence-Informed Assessment and Management of Behavioral and Psychological Symptoms of Dementia into the Real World: Training Family and Staff Caregivers in the DICE Approach

Helen C. Kales, MD, Vincent Kern, BA, H. Myra Kim, ScD,  
Mary C. Blazek, MD MEd

## ARTICLE INFO

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## Key Words:

Dementia  
BPSD  
caregiving

## ABSTRACT


**Objective:** To investigate the impact of a one-day training program on caregivers' confidence and knowledge in managing aspects of dementia care. **Design:** One-day caregiver training program featuring: 1) an interactive, multi-media format; 2) a companion manual; and 3) a "brain-storming" session at the end of the day that utilized attendees' real-world cases where the use of the DICE (Describe, Investigate, Create, and Evaluate) approach was illustrated "live." **Setting:** Three different geographical sites in Michigan. **Participants:** Family ( $n=40$ ) and professional (paid;  $n=140$ ) caregivers (total  $n=180$ ) for people with dementia. **Measures:** Pre- and post self-ratings related to confidence in aspects of dementia care management before and directly after the training. **Results:** Comparing self-ratings pre- and post-training, more than 50% of family caregivers showed improvement in confidence post-training on 11 of 12 items with significant improvement in 4 items. Among professionals, more than 50% of caregivers showed improved confidence on 3 of 12 items, with 4 items showing significant improvement. Family caregivers were significantly more likely than professionals to show improved confidence on 6 of 12 items. **Conclusions:** 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

## Geriatric Nursing

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## Featured Article

## Training dementia care professionals to help caregivers improve the management of behavioral and psychological symptoms of dementia using the DICE Approach: A pilot study

Tammi Albrecht DNP<sup>a</sup>, Molly Schroeder CSW<sup>a</sup>,  
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### THE DICE APPROACH™

- **PACE -- Washtenaw County (Program All-Inclusive Care for the Elderly):** PACE is using The DICE Approach online training for each of its 70-plus employees of all roles not only to implement the strategy for caregivers but also so all employees (even transportation specialists) who make contact with patients "speak the language" of DICE to provide better care and interactions. PACE is also adopting The DICE Approach "Case Study Review" into its patient review strategy.
- **University of Wisconsin:** Training Physicians and Social Workers on The DICE Approach utilizing the web-based modules across the state as part of two grants to improve caregiving and reduce stress on caregivers. Over 120 professionals have/will receive the training and work with home caregivers to apply The DICE Approach.
- **John Muir/Alzheimer's Disease Center UCD Walnut Creek:** 35 professionals – a mix of clinicians and physicians have completed The DICE Approach web-based training and attended virtual case-review workshops provided by the DICE Team.

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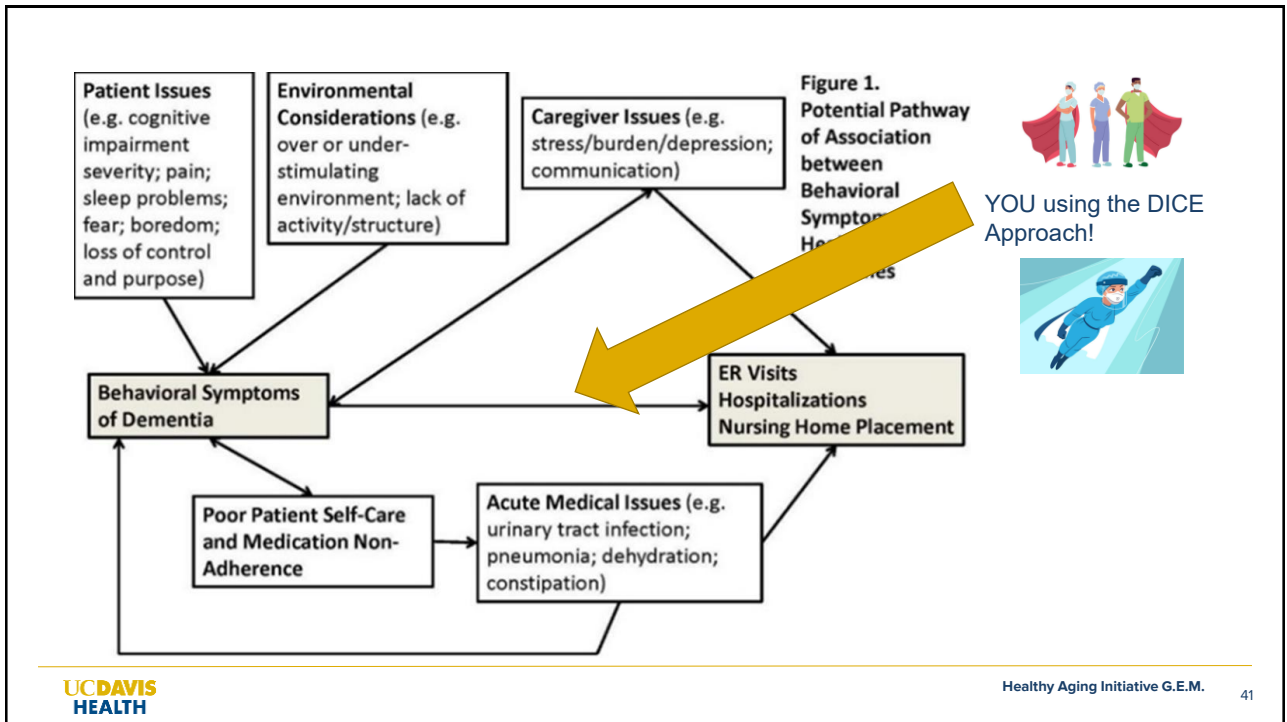
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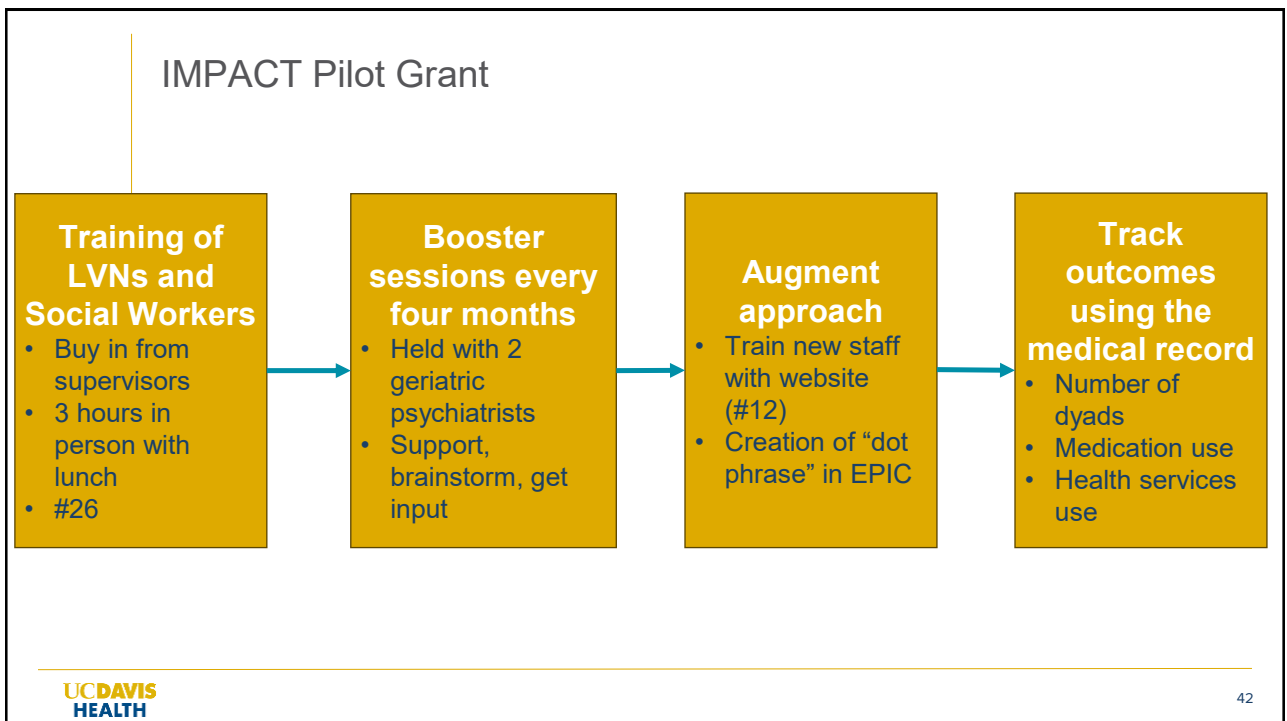
## THE DICE APPROACH™

- **The DICE Approach for Caregivers in the Home:** With little marketing and promotion since it's launch in July 2020, the online web-based training is providing critical education and a stress-reducing approach for over caregivers around the country who have subscribed to the training.
  - Made FREE for use in March 2024 and subscriptions have climbed to almost 6000
- **The DICE Approach in National Assisted Living Company: Ascension Living**
  - 2600 sites of care in 20 states
  - Putting DICE approach training into LMS
- **The DICE Approach International**
  - Brazil
  - Ghana

Can we deliver the DICE Approach by training front-line health care staff?  
Current IMPACT Pilot



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## Lessons learned so far

- Real-world/pragmatic vs. pure research study
  - Structure of IMPACT pilots
  - Multiple reorganizations of staff for dementia care
  - Turnover of staff (#12 new and #7 who left)
  - Reduction in Force
  - Initial buy-in and staff time became more challenging
- Staff input to tweak approach
  - Creation of dot phrase
  - Revamp of worksheet
  - Fear of taking “ownership” of BPSD; don’t want to be “in it” alone
- Examples from booster sessions of approach empowering front-line staff
  - Garden story
  - Use of approach without calling it the approach; “use in principle”

## Preliminary Results

N=1157 patients with dementia

Historical controls (comparison of patients to their own pre-intervention)

- ❖ Use of sedating psychotropics (antipsychotics and benzodiazepines) significantly reduced from 29.4% to 25.5% ( $p < 0.05$ )
- ❖ Slight increase in use of antidepressants 46.1% to 47.3% (NS)
- ❖ Decrease in inpatient hospitalizations

# Can we deliver the DICE Approach without training? Current NIA R01

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Prior NIA R01 with Laura Gitlin PhD (2012-2016)  
Creation of the WeCareAdvisor App



## Nonpharmacologic Management of Behavioral Symptoms in Dementia

Laura N. Gitlin, PhD  
Helen C. Kales, MD  
Constantine G. Lyketsos, MD, MHS  
JAMA, November 21, 2012—Vol 308, No. 19

Kales et al. *BMC Geriatrics* (2018) 18:113  
https://doi.org/10.1186/s12877-018-0203-8  
BMC Geriatrics

RESEARCH ARTICLE Open Access

### Effect of the WeCareAdvisor™ on family caregiver outcomes in dementia: a pilot randomized controlled trial

Helen C. Kales<sup>1,2\*</sup>, Laura N. Gitlin<sup>1,3,4</sup>, Barbara Stanislawski<sup>1,2</sup>, H. Myra Kim<sup>1</sup>, Katherine Marx<sup>5</sup>, Molly Turmwald<sup>1</sup>, Claire Chang<sup>1,2</sup> and Constantine G. Lyketsos<sup>5</sup>

**A1**

How Can DICE Help with Problem Behaviors?

With a plan for behavior, caregivers create and describe their own behavior plan using behavioral principles to manage the DICE process. This will answer some questions about the behavior plan and help with other, related plan items. How can you answer them for your plan?

When you respond about DICE, a personalized engagement plan is created that supports behavior, and it will show how to begin to do with these items successfully.

How to use DICE to help in dementia care (https://doi.org/10.1186/s12877-018-0203-8). The behavior plan is getting more and more helpful. For more information on DICE, please visit our website at [www.diceapproach.org](http://www.diceapproach.org).

https://doi.org/10.1186/s12877-018-0203-8

1. Describe: First describe behavior that is challenging for you or that you want to change. Then describe the question to describe the behavior. Then describe the behavior plan and how to do it for your situation.
2. Create: Next, you will get the "DICE" plan and what about what might be contributing to your behavior. This will answer some questions about the behavior plan and help with other, related plan items. How can you answer them for your plan?
3. Communicate: Then, the caregiver will get a plan and a behavior plan and will be able to help plan and manage the behavior. The plan is based on your behavior and will be helpful for your situation.
4. Evaluate: After a week, the caregiver will get a new behavior plan and will be able to help plan and manage the behavior. The plan is based on your behavior and will be helpful for your situation.

UCD HEA

**A2**

Aggression

Please describe the current level of pain.

No pain at all | Slight pain | Moderate pain | Severe pain | Very bad pain

**A3**

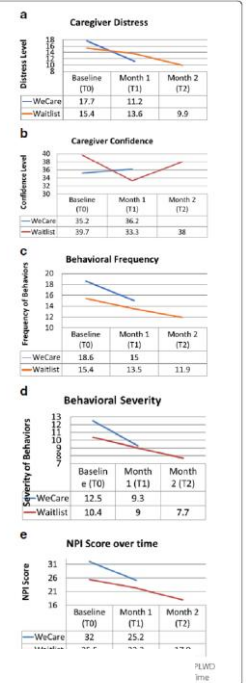
Aggression

Please describe the current level of pain.

No pain at all | Slight pain | Moderate pain | Severe pain | Very bad pain

Items to use can change from a person to a person, but it does change the person's ability to respond to DICE.

- Changes in behavior (eg, aggression, fighting, being too angry or resistant to care, aggression, or hitting or striking out right)
- Worst (changing in depression, withdrawal)
- Not important for helping, annoying, or being mean or aggressive
- Body language like pointing, frowning, rolling or holding the participant of the body
- Repeated vocalizations like shouting, screaming, crying, growling or roaring
- Changes in voice patterns
- Signs or signs that person seems distressed or in pain (behavior)
- Changes in mood or feeling
- Increased blood pressure and pulse
- Swearing
- Pain refusal and loss of appetite



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## Big Problem #3=Lack of training caregivers on how to use non-pharmacologic strategies to manage dementia behaviors

- After using the DICE approach within the WeCareAdvisor (to figure out the underlying causes of behaviors), an individualized “prescription” is created for the caregiver and person with dementia (precision medicine)
- Using a proprietary algorithm, (based on caregiver input during DICE) treatment strategies are selected from over 1000 contained in the tool

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### Information we used to create this prescription



When I was dealing with apathy, I found this information helpful:

People with dementia may have difficulties identifying, planning, organizing, or initiating an activity or task. This may contribute to what appears to be apathy.

### For Health & Safety



Like you, I wasn't too worried that the behavior was a safety concern. But it's still important to make sure that you and Jacob stay safe. These tips can help you understand more about Jacob's behavior.

- Make sure Jacob is safe and does not have access to anything that could cause harm to himself or others.
- You have indicated that Jacob has a chronic medical condition and that it may have worsened around the same time the behavior appeared. Please check with Jacob's doctor to see if the behavior could have been triggered by the medical problem changing or getting worse. Treating the medical problem may alleviate the behavior.
- Non-drug therapies can be used to help alleviate mild pain including massage, application of head or cold packs, gentle exercise and stretching and using relaxation techniques (such as listening to music or deep breathing).

### For Jacob



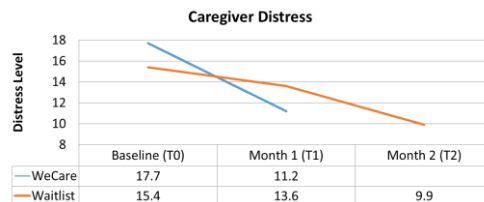
These tips should help make things easier for Jacob and keep him involved in appropriate activities. If you have questions, add them **My Notes** so you can remember to ask your health care provider.

- Try activities that do not require Jacob's active participation, such as listening to his favorite music.
- Allow Jacob enough t..... ..mp

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## Nice. But does it work?

- Randomized controlled trial of the WeCareAdvisor in comparison to wait-list control ([BMC Geriatrics, 2017](#))
- During brief (one-month) use of the tool:
  - Family caregivers had significant reductions on the primary outcome of **DISTRESS**
  - Distress is associated with most of the negative outcomes of dementia caregiving (hospitalizations, NH placement)
  - Trends to decreased dementia behaviors

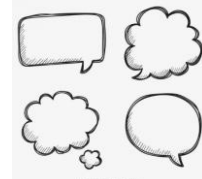


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# Caregiver Feedback

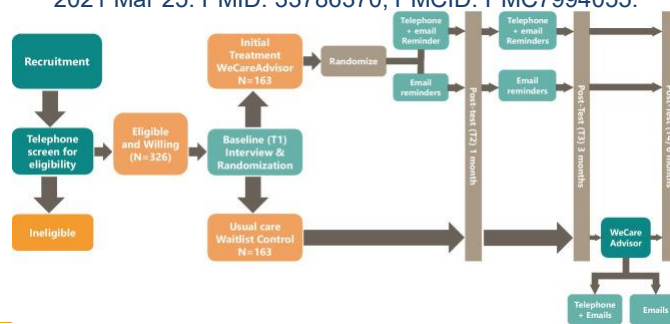


- “Wonderful new tool in my caregiving arsenal”
- “DICE structures my thinking”
- “Survival guide is comprehensive”
- “I shared the tool with my support group and everyone was impressed by the content and ease of use”
- “Love the feeling of support”
- “Ease of use if very nice”
- “Daily tips are awesome”
- “I wish I would have had this a long time ago”
- “I learned a great deal more about dementia and the skills to use in dealing with related behaviors”
- “This week my spouse had a UTI and the WeCareAdvisor helped to trigger in my mind that something was wrong and he should see the doctor”
- “We can go to the doctor, go to support groups, but I see the value of having this daily. This is advice every day”

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## Current R01 with Laura Gitlin (2019-present)

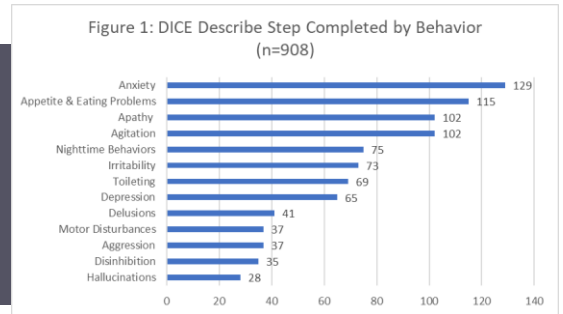
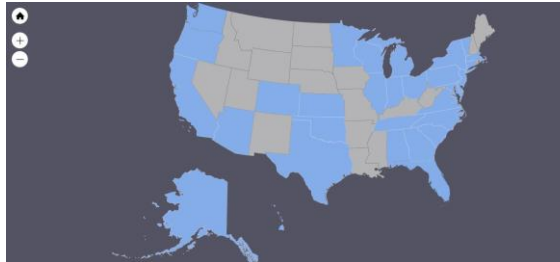
Gitlin LN, Bouranis N, Kern V, Koeuth S, Marx KA, McClure LA, Lyketsos CG, Kales HC. WeCareAdvisor, an Online Platform to Help Family Caregivers Manage Dementia-Related Behavioral Symptoms: an Efficacy Trial in the Time of COVID-19. *J Technol Behav Sci.* 2022;7(1):33-44. doi: 10.1007/s41347-021-00204-8. Epub 2021 Mar 25. PMID: 33786370; PMCID: PMC7994055.



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## National recruitment

- Enrolled 262 participants from 31 states



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## Preliminary results

Caregivers		PLWD	
Mean age	63.8 years	Mean age	75.1 years
Gender	82% female	Gender	57% male
Race	83% white	Race	82% white
Education	92% some college	Education	72% some college
Marital status	82% married	Marital status	71% married
Relationship to PLWD	65% spouse	Dementia severity	
Mean caregiving duration	4.6 years	Mild	35%
		Moderate	57%
		Severe	8%

Significant decrease in the **number of behaviors** and **caregiver distress and upset** with tool use as compared to waitlist control

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## 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 put the key components of good dementia care at the fingertips of the people who need it most
- Such solutions can shift the paradigm from one of sedation to more personalized and precise treatment enhancing quality of life

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<https://diceapproach.com/>