UCDAVIS HEALTH

Assessment and Management of Behavioral and Psychological Symptoms of Dementia

Helen C. Kales MD

Chair of Psychiatry and Behavioral Sciences

Joe P. Tupin Endowed Professor

University of California Davis

Topics covered

- What prevents families and people with dementia from “living well”?
  - Four big problems
- The DICE Approach
- New NIA Funded Study in CPN!

Dementia and BPSD

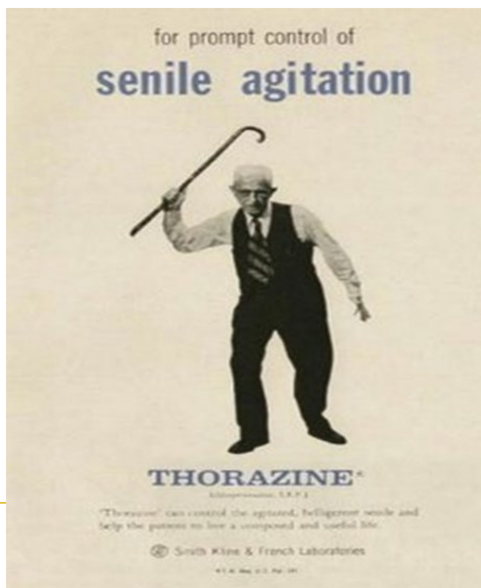
- Devastating syndrome affecting 5 million people in US, 16 million by 2050
- **Non-cognitive behavioral and psychological symptoms of dementia (BPSD)** are universal (>98%)
  - Can occur at any disease stage
  - Occur with every type of dementia
  - Often dominate the disease course
  - Associated with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

Dementia Care for BPSD: Four big problems

- 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=Behaviors remain the day to day focus of management, the medications we use to treat them are not very effective and the focus is on sedation**

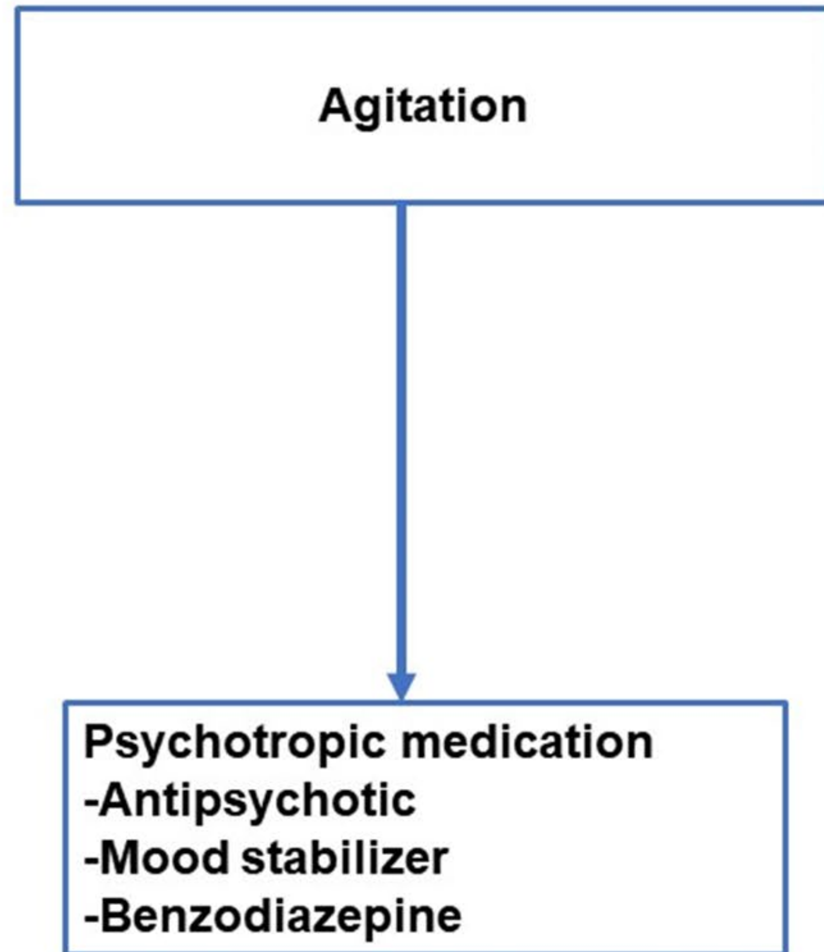


Maust, Kales et al JAMA Psychiatry 2015

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)

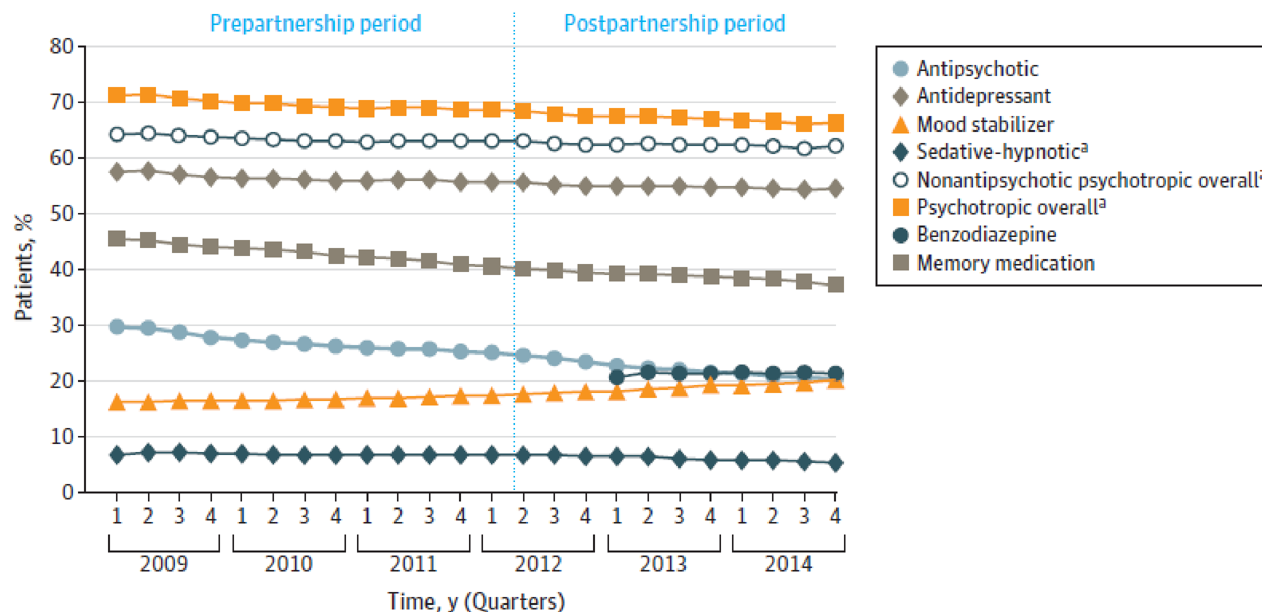
Current Real-World "Assessment" of Behavioral and Psychological Symptoms of Dementia



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?

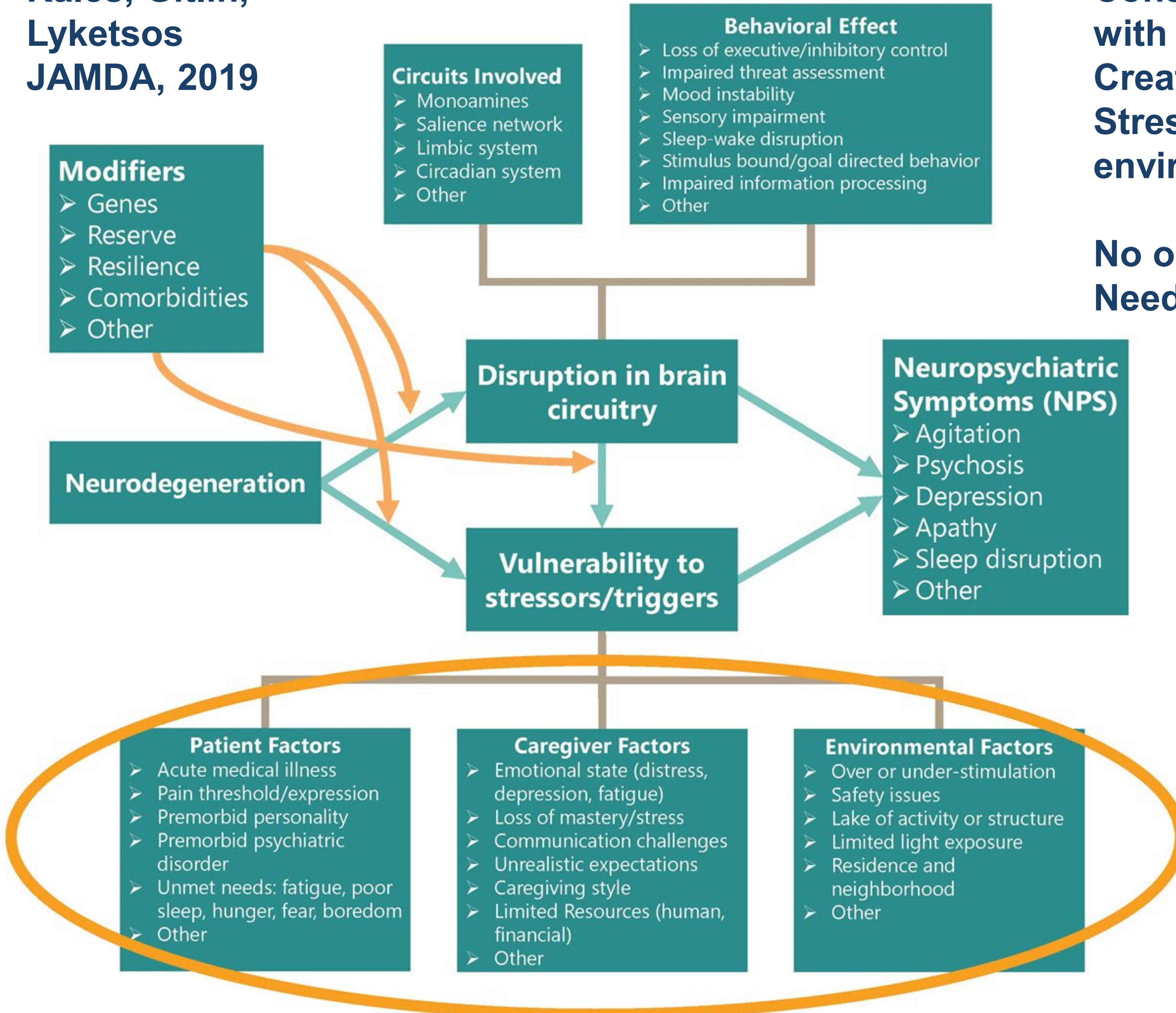
Figure 2. Percentage of Long-Stay Nursing Home Residents With Dementia Prescribed an Antipsychotic or Other Psychotropic Medication



Maust, Kales et al JAMA Internal Med 2018

UCDAVIS HEALTH

Kales, Gitlin, Lyketsos JAMDA, 2019



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

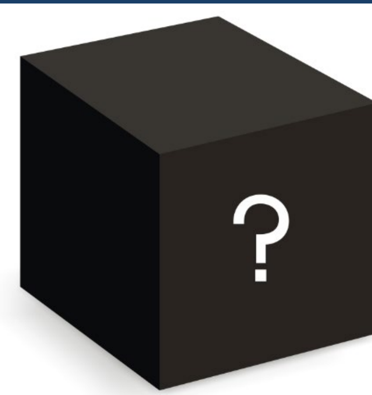
No one-size-fits all solution
Need for personalization and precision

Consequences of the COVID-19 Pandemic in PLWD and Their Caregivers

- Disruption of regular clinical services
- Increased anxiety due to being in a high-risk group
- Disruption in social routine
- Social Isolation
- Loss of outlets and activities (e.g. respite; daycare; senior centers; church)
- Losses among peer group due to virus

M.

Big Problem #4



- **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

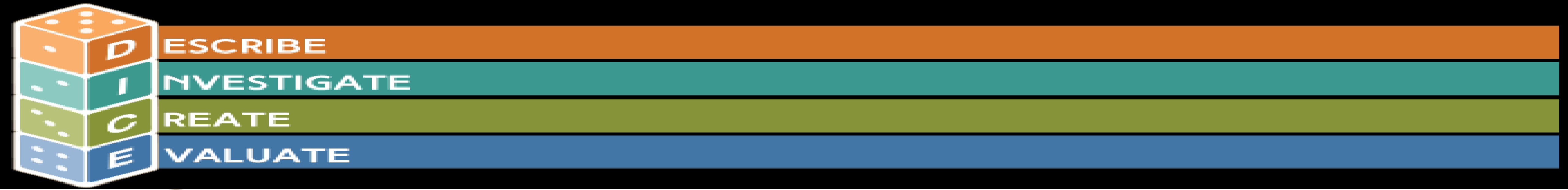
- **Brodaty Meta-analysis**

OR

CHOLINESTERASE INHIBITORS

Brodaty et al, Am J Psychiatry, 2012

UCDAVIS HEALTH



- **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, Gitlin, Lyketsos
Journal of the American Geriatrics Society
2014

Frank

- Frank is a 78 year old man with moderate dementia living at home with his 75 year old wife Dot
    - **“My husband Frank has been getting really agitated in the past week, can you prescribe something to calm him down?”**

DESCRIBE the problem behavior

Frank:

- Staring into space
- Holding left upper chest
- “I already ate”
- “Leave me alone”
- Gets angry: “what are you trying to do”
- Gets physical: “I’m leaving!”

Frank’s wife Dot:

- Approaches in haste; seems overburdened, already on edge
- Confrontational: “you haven’t touched your lunch” “No you haven’t!”
- Disparaging: “what is the matter with you!?”

Environment

- Sitting in front of TV with blanket and tray
- Room somewhat dark

PD-DOC

Describe

Date 1-24-2018

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

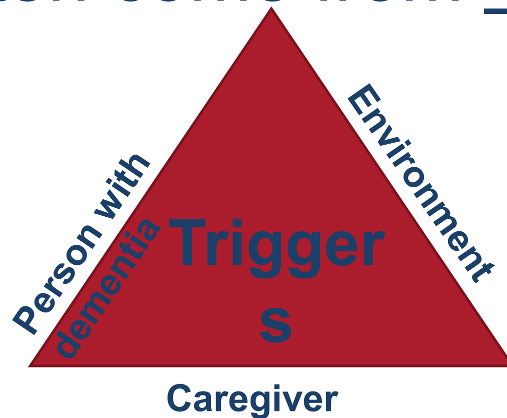
4 =very severe and/or daily

APATHY OR INDIFFERENCE

his and 7.1 7.2 7.3

INVESTIGATE

- Another “left out” step
- This step is led by the clues from DESCRIBE
- Play “detective” to search for underlying causes/triggers of behavioral symptoms
- Triggers often come from $\geq$1 of three categories



Patient Factors

Problem	What you might notice
Pain	• Holding or rubbing part of body • Fast breathing • Groaning or moaning • Tension • Pushing away when touched
Constipation	• Pain and difficulty opening bowels • Hard poo • Pain on touching stomach
UTI (Urinary Tract Infection)	• Burning pain on passing urine • Urinating more frequently • Cloudy or different smelling urine
Recent changes in medication	• Dose changes in long-standing medications • New medications causing behavioral changes (e.g. Benadryl, Ditropan)

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

UCDAVIS HEALTH

INVESTIGATE underlying causes

Frank:

- No psychiatric history
- Holding his left upper chest; assess for pain
- Ditropan for incontinence; anticholinergic effect? (confusion)
- Type II Diabetes; are blood sugars under control?
- Is safety at risk?

Dot:

- Communication is not optimal (negative tone, critical, confrontational)
- Could she be depressed? Lack of sleep?
- Lack of education about dementia stages (multistep commands)
- Is she the sole caregiver? Any respite? What other responsibilities?
- Is safety at risk?

Environment

- Lack of structure/cuing for activities
- Tripping hazards
- Lack of light

CREATE-Six general strategies

- Manage any physical problem uncovered

- Provide family/staff education/support

- Improve communication

- Create meaningful and tailored activities

- Simplify tasks

- Ensure the environment is safe

CREATE/implement collaborative treatment plan

Frank:

- Consider replacing Ditropan with a more bladder-selective agent
- Low blood sugars pre-meal could be triggering irritability; schedule snack if lunch is late

Dot:

- Psychoeducation on dementia stages and simplifying communications
- Offer choices but limited
- Change tone "playing the role" (replacing negative, critical, confrontational tone)
- "Set the stage" for activities with communication
- Get respite for "fresh arms"
- Make sure Dot feels safe and has resources to contact if she does not

Environment

- Create routines and activity for Frank around mealtimes or taking medications
- Increase the amount of natural light in the room for cuing
- Avoid sitting Frank in front of the TV if this is not of interest (may overstimulate)
- Create activities tailored to his interest/abilities, e.g. help with meal prep
- Remove tripping hazards

Evaluate the interventions

Frank:
- Did a new bladder medication impact behavior?
- Did stabilizing blood sugars impact behavior?

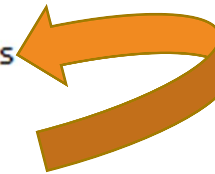
EVALUATE

Dot:
- Was Dot able communicatio
  - Tone; avoic role, settin
- Has Dot been professional)?

Date 1-24-2018

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



Environment:
- What new routines were implemented and what impact?
- What new activities were created and what impact?
- What impact did increasing light have?

Patient Issues (e.g. cognitive impairment severity; pain; sleep problems; fear; boredom; loss of control and purpose)

Environmental Considerations (e.g. over or under-stimulating environment; lack of activity/structure)

Caregiver Issues (e.g. stress/burden/depression; communication)

Behavioral Symptoms of Dementia

ER Visits
Hospitalizations
Nursing Home Placement

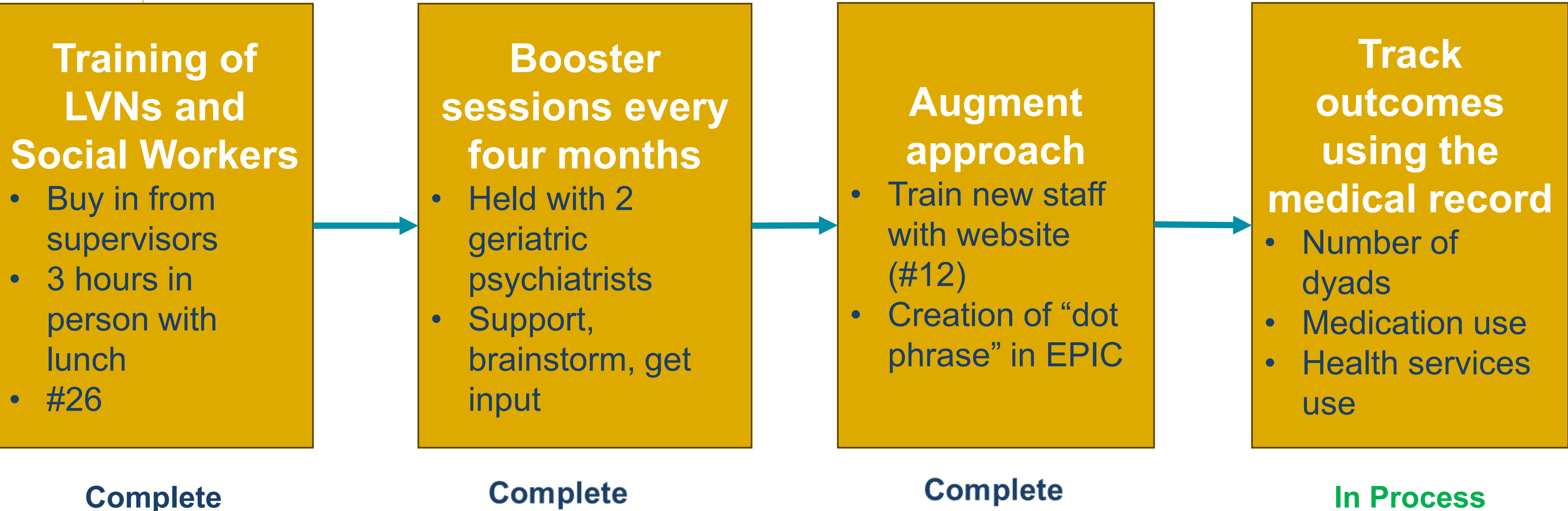
Poor Patient Self-Care and Medication Non-Adherence

Acute Medical Issues (e.g. urinary tract infection; pneumonia; dehydration; constipation)

Figure 1. Potential Pathway of Association between Behavioral Sympto He es

YOU using the DICE Approach!

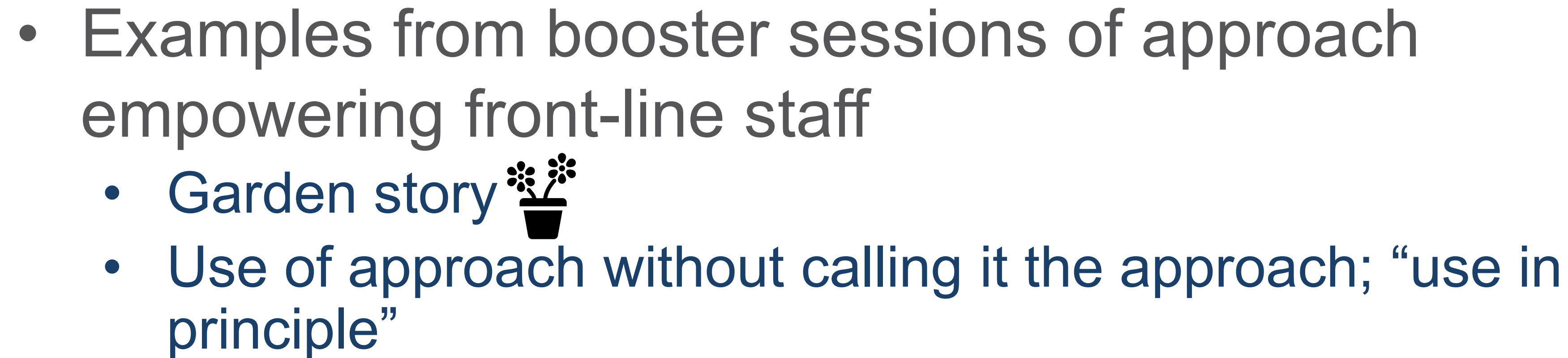
IMPACT Pilot Grant



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)
  - Recent RIF
  - Initial buy-in and staff time has become more difficult
- Staff input to tweak approach
  - Creation of dot phrase
  - Disuse of dot phrase
  - Revamp of worksheet
  - Fear of taking "ownership" of BPSD; don't want to be "in it" alone

Lessons learned so far



- Examples from booster sessions of approach empowering front-line staff
    - Garden story
    - Use of approach without calling it the approach; “use in principle”

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

- Helen C. Kales MD
- Joe P. Tupin Professor and Chair,

Department of Psychiatry and Behavioral Sciences

- University of California Davis
- hckales@ucdavis.edu