PROGRAM FOR POSITIVE AGING

IMPROVING LATER-LIFE MENTAL HEALTH AND DEMENTIA CARE

Nonpharmaceutical Management of Behavioral Issues in Older Adults

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Agenda

- Behavioral and psychological symptoms of dementia
- Causes
- Consequences
- Current Real-World Treatments
- Nonpharmacologic Strategies
- Potential Ways Forward
  - The DICE Approach™
  - WeCareAdvisor™

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Gemma

- 85-year old woman who emigrated from Italy fifty years ago. Now living in an assisted living facility
- Generally good-natured, but gets agitated in the early afternoon, asking staff to "go home" or saying that she "has to get to church"
- Staff tries to "reason" with her and tells her to "calm down", but Gemma continues to escalate, following staff in her wheelchair, repeatedly asking them to go home or be taken to church
- Because Gemma interferes with their work flow and "won't listen to reason", staff will administer a "prn" dose of an antipsychotic

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Dementia and BPSD

- Devastating syndrome affecting 5 million people in US, 16 million by 2050
- Cognitive impairment is the clinical hallmark
- **However, non-cognitive behavioral and psychological symptoms of dementia (BPSD)** are universal (>98%)
  - often dominate the disease course
- BPSD associated with **poor outcomes**
  - earlier nursing home placement, hospitalizations, caregiver burden and lost income

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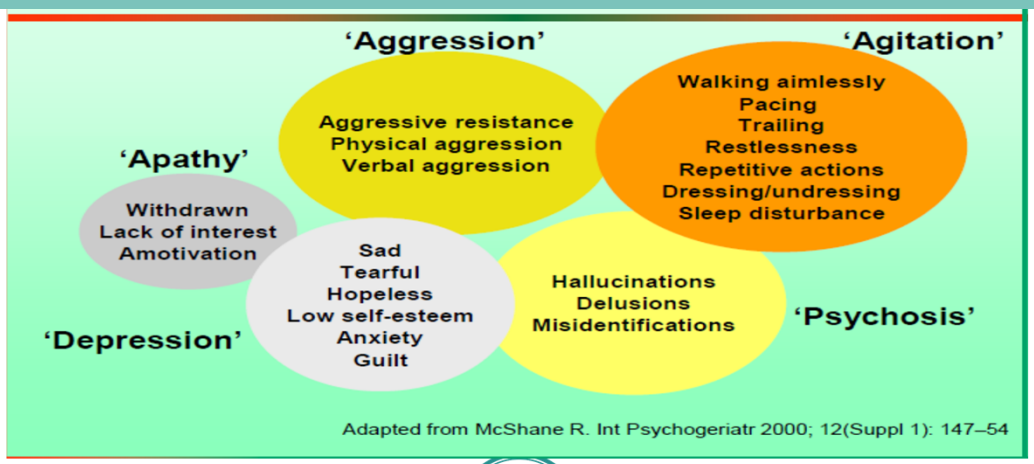
What are the Behaviors?



Rabheru, 2004; McShane, International Psychogeriatrics, 2000

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Other problematic behaviors

- Rejection of care
- Arguing
- Repetitive verbalizations/questioning
- Wandering
- Hoarding/rummaging
- "Inappropriate" behaviors (screaming, spitting, sexual behaviors)
- Sleep problems (day-night reversal)

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The critical role of the family caregiver

- 15 million family caregivers of people with dementia in the US
- Assesses and reports on symptoms, carries out recommendations, evaluates their effects
- Managing BPSD is one of the most challenging aspects of dementia care
- Caregivers of people with BPSD
  - more distressed and depressed than those not managing behaviors
  - does caregiver distress drive outcomes?

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Formal caregivers and health care professionals

- Direct care workers
  - Majority of those in paid long term dementia care
  - Often little specific training focus on dementia care
  - High turnover (contributed to by difficult jobs, inadequate training)
- Professionals
  - Too few geriatricians/geriatric psychiatrists
  - Less than 1% of RNs, PAs or Pharmacists identify themselves as specializing in geriatrics
  - Only 4% of social workers have formal certification in geriatric social work

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The critical role of formal caregivers and non-physician health care professionals in managing BPSD

- Close observation of BPSD and their context
- Interventions with the person with dementia and family caregivers including optimizing physical health and function
- Linking the person with dementia and family caregivers with resources
- Helping to solve family conflicts over care
- Finding STRENGTHS

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

Agitation

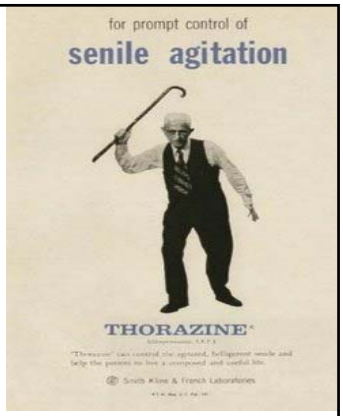
↓

Psychotropic medication
-Antipsychotic
-Mood stabilizer
-Benzodiazepine

Issues with Real-World Treatment

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)



Kales et al, AJP, 2007; Maust et al, JAMA Psychiatry 2015

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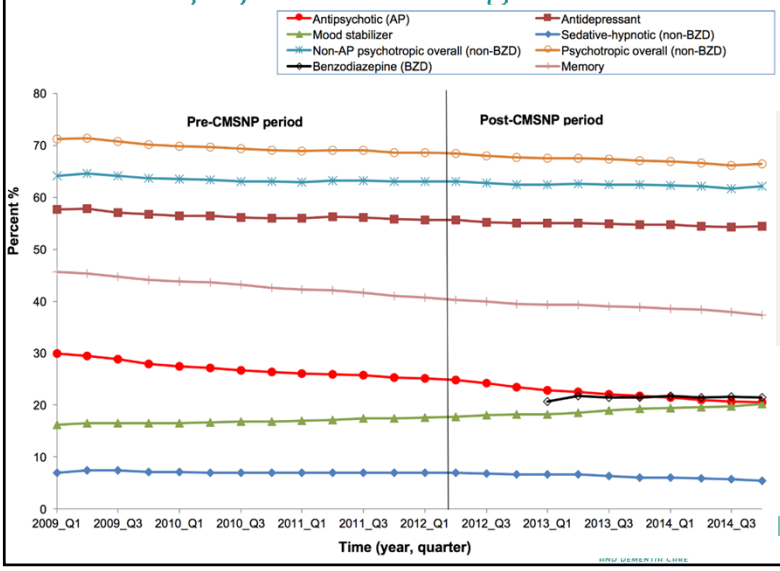
Antipsychotic use HAS declined—but does that mean that fewer people with dementia are being medicated with psychiatric drugs?

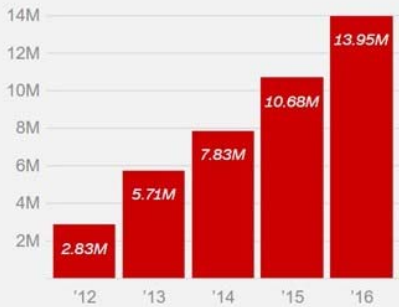


Impact of the CMS National Partnership to Improve Dementia Care on Use of Antipsychotics and Other Psychotropics in Long-Term Care in the U.S.: 2009-2014

Maust, Kim, Chiang, Kales, In Submission

Nuedexta's rapid growth in nursing homes

The number of Nuedexta pills dispensed to long-term care facilities jumped nearly 400% in four years.



http://www.cnn.com/2017/10/12/health/nuedexta-nursing-homes-invs/index.html

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Backdrop of Complexity

- **No one size fits all solutions**, whether pharmacological or nonpharmacologic
- Need to consider underlying brain disease that cause neuropsychiatric symptoms (NPS) or which make the person with dementia vulnerable to NPS
  - what other factors may be required to trigger symptoms

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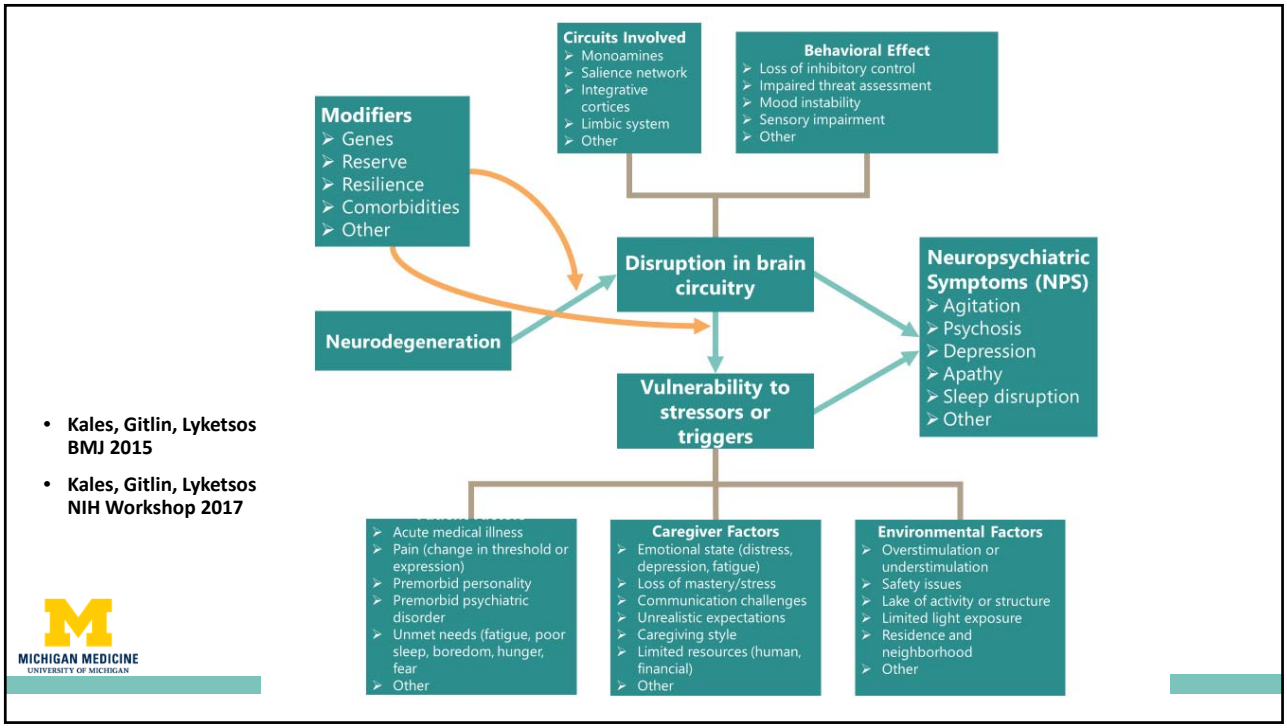

- **Kales, Gitlin, Lyketsos BMJ 2015**
- **Kales, Gitlin, Lyketsos NIH Workshop 2017**

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Consequences of behaviors

- Greater ADL impairment[1]
- Worse quality of life[2]
- Excess morbidity and hospitalizations
- Earlier nursing home placement[3,4]
- Major source of caregiver burden[5] and reduced caregiver income
- $10,000/year additional care costs[6]
- Shorter time to severe dementia[7]
- Accelerated mortality[8]

[1]Lyketsos et al, 1997; [2]Gonzales-Salvador et al, 1999; [3]Steele et al, 1990; [4]Kales et al, 2005; [5]Lyketsos et al, 1999; [6]Murman et al, 2002; [7]Rabins et al, 2012; [8]Peters et al, 2017

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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?

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

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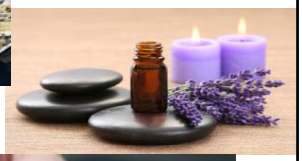
Intervention target: person with dementia

- Inconsistent support for overall efficacy in behaviors
  - Reminiscence
  - Validation
  - Simulated presence
  - Aromatherapy
  - Snoezelen
  - Cognitive rehabilitation
  - Acupuncture
  - Light therapy



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Gitlin, Kales, Lyketsos, JAMA, 2012
Kales, Gitlin, Lyketsos, BMJ

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Environmental Approaches

- Reduction of clutter, use of color contrasts, signage
- Growing evidence for role of the environment in preventing and reducing behaviors, but few randomized clinical trials (RCTs)
- Strategies often used in combination

Kales, Gitlin, Lyketsos, BMJ, 2015

A bright yellow "anti-slip tape" can highlight the threshold to avoid trips.

Intervention target: caregiver

- Problem-solving with the caregiver to identify modifiable causes of behaviors
- Often also include interventions targeted at the person with dementia (e.g. activities) and environment

Belle et al, Ann Int Med, 2006; Nichols et al, Arch Int Med, 2011

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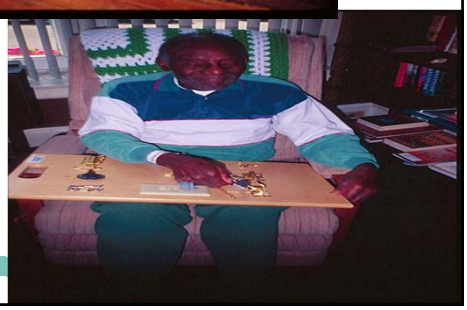
Laura Gitlin's work

- Tailored Activity Program (TAP):
  - 8-12 home/telephone sessions by occupational therapists; caregiver training including customized activity
  - Significant reductions in problem behaviors (p=0.004) including agitation (p=0.14) and decrease in caregiver "hours on duty" (p=0.001)



Gitlin et al, Am J Geriatr Psychiatry, 2008

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Project ACT

- N=272 patients
- 11 home/telephone sessions over 4-months by health professionals
- Identification of potential triggers of problem behaviors
  - Communication
  - Environment
  - Patient undiagnosed medical condition
- Caregiver training to modify triggers and reduce caregiver upset
- Medical testing for undiagnosed illnesses

Gitlin, et al, JAGS, 2010

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Project ACT

Table 2. Prevalence of Caregivers Targeting the Problem Behavior as Most Upsetting (N = 239)

Problem Behavior	Caregivers, n (%)
Refusing help or resisting care	35 (15.4)
Repetitive questioning	25 (10.5)
Argumentative	20 (8.4)
Wakes up at night	19 (7.9)
Toileting problems	19 (7.9)
Aggressive verbally	19 (7.9)
Wandering or tries to leave home	17 (7.1)
Inappropriate behaviors (destroys property, loud in public, blames others)	14 (5.9)
Upset or agitated	12 (5.0)
Safety concerns (leaves stove on, unlocks doors, overdoses on medications)	12 (5.0)
Delusions	12 (5.0)
Screaming or crying	10 (4.2)
Shadowing	10 (4.2)
Harmful to self	9 (3.8)
Worried, anxious, fearful	9 (3.8)
Other (inability to communicate, affective stance, nonresponsive)	8 (3.3)
Aggressive physically	7 (2.9)
Hallucinations	7 (2.9)
Rummaging or hoarding	6 (2.5)
Restlessness	5 (2.1)

Gitlin et al, JAGS, 2010

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Project ACT

- At 16 weeks:
  - Improvement in 67.5% of intervention dyads vs. 45.8% of control dyads (p=0.002)
  - Reduced caregiver upset (p=0.028)
  - Enhanced confidence in managing behaviors (p=0.011)
  - Improved caregiver well-being (p=0.001)
  - Improvement in ability to keep patient at home (p=0.001)
- Similar outcomes at 24 weeks

Gitlin et al, JAGS, 2010

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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

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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How do we improve the assessment and management of BPSD in the real world?

- 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

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Kales, Gitlin, Lyketsos JAGS 2014

Use The DICE Approach

Describe

- Caregiver **describes** problematic behavior
  - Context (who, what, when and where)
  - Social and physical environment
  - Patient perspective
  - Degree of distress to patient and caregiver

Investigate

- Provider **investigates** possible causes of problem behavior
  - Patient
    - Medication side effects
    - Pain
    - Functional limitations
    - Medical conditions
    - Psychiatric comorbidity
    - Severity of cognitive impairment, executive dysfunction
    - Poor sleep hygiene
    - Sensory changes
    - Fear, sense of loss of control, boredom
  - Caregiver effects/expectations
  - Social and physical environment
  - Cultural factors

Create

- Provider, caregiver and team **collaborate to create** and implement treatment plan
  - Respond to physical problems
  - Strategize behavioral interventions
    - Providing caregiver education and support
    - Enhancing communication with the patient
    - Creating meaningful activities for the patient
    - Simplifying tasks
    - Ensuring the environment is safe
    - Increasing or decreasing stimulation in the environment

Evaluate

- Provider **evaluates** whether "CREATE" interventions have been implemented by caregiver and are safe and effective

Consideration of Psychotropic Use (Acuity/Safety)

Kales et al, JAGS, 2014

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****: Gemma is getting "agitated" after lunch*
- Learn to "play it back like a scene from a movie"

WHO?
WHEN?
WHERE?
WHAT?

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DESCRIBE the problem behavior

Gemma:

- Asking to "go home" or saying "I have to get to church"
- Typically starts in the late afternoon
- Will begin to follow staff in her wheelchair

Assisted Living Staff:

- Try to "reason" with her and "give her reality"
  - "This is NOT your home"
  - "You live here in the facility now"
  - "We are not going to church"
- Staff feel that Gemma's behavior is interfering with their workflow

Environment

- Group activities are going on in the afternoon, Gemma does not seem to enjoy these and will try to leave the group

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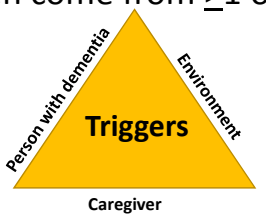
INVESTIGATE

- 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 ≥1 of three categories



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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

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Environmental Factors

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INVESTIGATE underlying causes

Gemma:

- No prior psychiatric history, although family states that when Gemma got anxious she would be very "action-oriented" (cleaning, cooking)
- Gemma was a regular church-goer all her life, attending Catholic mass daily
- She also ran an Italian family restaurant for years and loves to cook and talk about food
- She loves Italian music from the 1940's (but calls "American" music "noise")
- Used to say that many "American activities" are a "waste of time" ("Why they exercise? They should do work instead.")

Staff:

- Did not know much of Gemma's history
- Couldn't understand why she couldn't see "that they were busy"
- Frustrated that she won't participate in group activities like music and exercise group, "Why won't she go along with the program?"

Environment

- Daily groups are a mismatch for her interests and preferences

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CREATE-Six general strategies

- Manage any physical problems

- Provide family/staff education/support

- Improve communication

- Create meaningful and tailored activities

- Simplify tasks

- Ensure the environment is safe

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Create/implement collaborative treatment plan

Gemma:

- Rule out acute medical issues

Staff:

- Educate staff about BPSD and "broken brain"
- Reinforce communication strategies that are more effective (e.g. reasoning is not working)
- Taking some time to brainstorm tailored activities will save time in the long run
- Redirect calmly and with humor, occasionally incorporate Gemma in the staff routine as time/work permit

Environment

- Create routines and activity for Gemma that are safe, not overstimulating and meaningful/tailored to her interests, start them BEFORE she usually gets agitated
- Consider activities incorporating Italian food/music or religious practices
- Allow to wander safely

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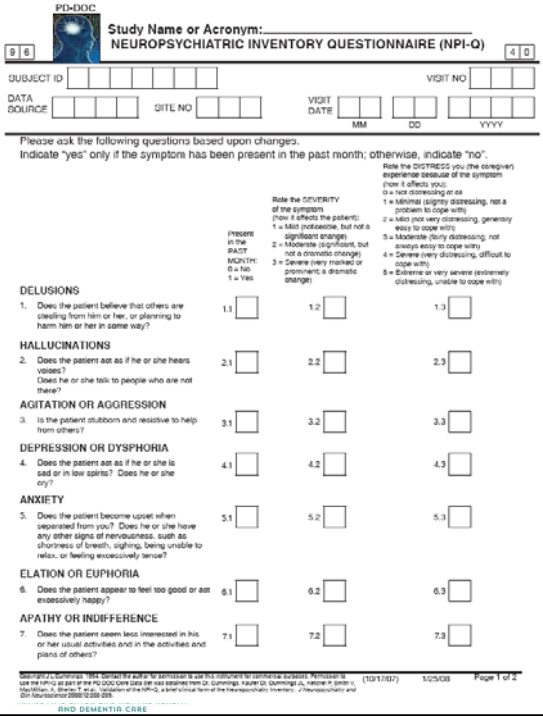
Don't forget to evaluate!

Best way to tell if something is working may be to do a formal assessment at baseline and after a trial of an intervention

NPI Q is a nice tool to measure symptoms and caregiver distress



PD•DOC

Study Name or Acronym:

NEUROPSYCHIATRIC INVENTORY QUESTIONNAIRE (NPI-Q)

9 6 4 0

SUBJECT ID | VISIT NO | DATA SOURCE | SITE NO | VISIT DATE MM DD YYYY

Please ask the following questions based upon changes.
Indicate "yes" only if the symptom has been present in the past month; otherwise, indicate "no".

	Present in the PAST MONTH: 0 = No 1 = Yes	Rate the SEVERITY of the symptom (how it affects the patient): 1 = Mild (noticeable, but not a significant change) 2 = Moderate (significant, but not a dramatic change) 3 = Severe (very marked or prominent; a dramatic change)	Rate the DISTRESS you (the caregiver) experience because of the symptom (how it affects you): 0 = Not distressing at all 1 = Minimal (slightly distressing, not a problem to cope with) 2 = Mild (not very distressing, generally easy to cope with) 3 = Moderate (fairly distressing, not always easy to cope with) 4 = Severe (very distressing, difficult to cope with) 5 = Extreme or very severe (extremely distressing, unable to cope with)
DELUSIONS			
1. Does the patient believe that others are stealing from him or her, or planning to harm him or her in some way?	1.1	1.2	1.3
HALLUCINATIONS			
2. Does the patient act as if he or she hears voices? Does he or she talk to people who are not there?	2.1	2.2	2.3
AGITATION OR AGGRESSION			
3. Is the patient stubborn and resistive to help from others?	3.1	3.2	3.3
DEPRESSION OR DYSPHORIA			
4. Does the patient act as if he or she is sad or in low spirits? Does he or she cry?	4.1	4.2	4.3
ANXIETY			
5. Does the patient become upset when separated from you? Does he or she have any other signs of nervousness, such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?	5.1	5.2	5.3
ELATION OR EUPHORIA			
6. Does the patient appear to feel too good or act excessively happy?	6.1	6.2	6.3
APATHY OR INDIFFERENCE			
7. Does the patient seem less interested in his or her usual activities and in the activities and plans of others?	7.1	7.2	7.3

Copyright J. Cummings, 1994. Contact the author for permission to use this instrument for commercial purposes. Permission to use the NPI-Q as part of the PD DOC Core Data Set was granted from Dr. Cummings. Kaufer DI, Cummings JL, Ketchel P, Smith V, MacMillan A, Shelley T, et al. Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. J Neuropsychiatry and Clin Neurosci 2000;12:233-239.

(10/17/07) 1/25/08 Page 1 of 2

AND DEMENTIA CARE

Evaluate the interventions

Gemma:

- Evaluate effect of non-pharmacologic strategies

Staff:

- What approaches did staff try? Were there any that they were resistant to? If so, why?
- What worked?
- What didn't?
- Were there any unintended consequences or "side effects" noted?

Environment:

- What changes were made? Were new routines instituted? Any issues with that?

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DICE caregiver training in Michigan and Wisconsin

- Funding through Michigan Health Endowment Fund and Medicaid Match, and the Administration for Community Living
- Over 150 caregivers trained so far
- Creation of a sustainable training website

MICHIGAN HEALTH ENDOWMENT FUND

ACL
Administration for Community Living




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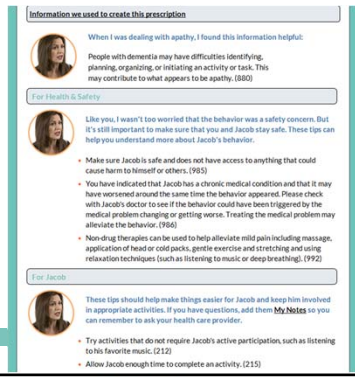
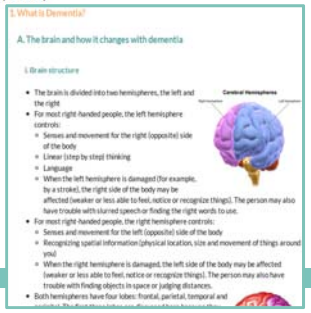
- Peer navigator
- DICE approach
  - WeCareAdvisor Prescription
- Caregiver Survival Guide
- Daily messaging

Here's what it's like to use the DICE process...

1. Describe - First choose a behavior that's challenging for you or Jacob. Then answer a few questions to describe the behavior. These questions help WeCareAdvisor choose the best tips for your situation.
2. Investigate - Next, you get to "play detective" and think about what might be contributing to Jacob's behavior. You'll answer questions to identify and rule out possible triggers for the behavior.
3. Create - Then, WeCareAdvisor will give you a behavior prescription with tips to help prevent and manage the behavior. The tips are based on your answers and are specific to your situation.
4. Evaluate - After a week, WeCareAdvisor will ask you how things are going and whether the tips were helpful. If things haven't improved, you can get new tips to try.





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Study objectives

- Primary Aim: to evaluate immediate effects of tool use on
  - **Caregiver distress**
  - **Caregiver confidence**

- Other outcomes:
  - Caregiver: stress level, depression, burden, negative communication, relationship closeness
  - Person with dementia: behavioral symptom frequency and severity

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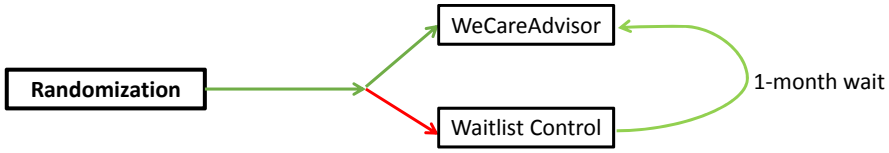
WeCareAdvisor™ Trial Design

- Two-site phase II randomized trial
  - Treatment (n=30 dyads) vs. waitlist control (n=30 dyads)
  - Waitlist control = group of participants included in an outcome study that is assigned to a waiting list and receives intervention after the active treatment group
  - Waitlist control group reassessed after their one month of tool use



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Eligibility and recruitment

- Two sites: Ann Arbor, MI and Baltimore, MD
- Recruitment methods:
  - provider or staff referral
  - on-site by research staff
  - caregiver responding to fliers placed in participating sites
  - participants from previous trials
- Determination of eligibility
  - Step 1- Telephone screen for eligibility criteria
  - Step 2- In person baseline interview including assessment of behavioral symptoms (NPI-Q) and comfort with technology; written consent

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Eligibility criteria

- Primary caregiver for a person diagnosed with dementia (clinical diagnosis or MMSE <24)
- ≥ 21 years old
- Live close by or with the person
- Report managing ≥ 1 behavioral symptoms
- English speaking
- Familiarity with technology (computer, tablet or smartphone)
- EXCLUSION:
  - Caregiver: sensory impairment
  - Person with dementia: imminent placement, terminal illness, or active suicide risk; not on a stable dose of psychotropic for at least 60 days

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WeCareAdvisor Group

- Following randomization, WeCareAdvisor group receives:
  - Ipad and orientation
  - Optional email account set up (if no prior email access)
  - Instruction in use of the tool

- During the one-month of tool use:
  - Weekly check in calls from the study team
    - Trouble shoot any problems with the tool, encourage tool use

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Caregiver and Person with dementia characteristics

- No significant differences between WeCare and Waitlist caregiver groups (n=57) except for caregiver confidence:
  - Significant difference in mean caregiver confidence (0-50) between groups
    - WeCare 35.0±10.0 Waitlist 39.7±6.9 p=0.04
- No significant differences between WeCare and Waitlist person with dementia groups

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Results

- After one month of tool use, WeCare caregivers showed significant:
  - Improvement in caregiver distress
  - Decrease in behavioral frequency
  - Decrease in behavioral severity
  - Decrease in total behavioral score
- After one month, Waitlist caregivers showed a significant decrease in confidence (-6.40±10.30, t=-3.40, p=0.002)

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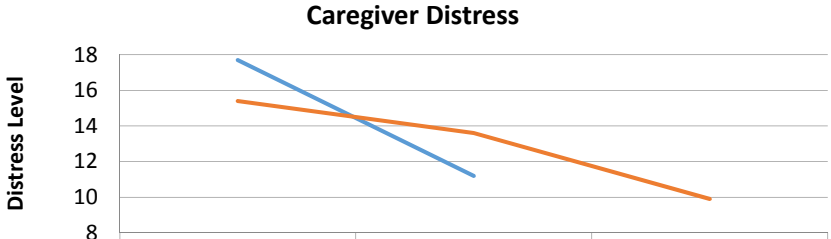
Caregiver outcomes-Distress



	Baseline (T0)	Month 1 (T1)	Month 2 (T2)
WeCare	17.7	11.2	
Waitlist	15.4	13.6	9.9

- Improved distress: WeCare 73.1% vs. Waitlist 46.7% (X^2=6.05, df 2, p=0.04)
- WeCare had significant improvement from T0 to T1, **significantly greater improvement than Waitlist (t=-2.49, p=0.02)**, after receiving the tool, Waitlist also had a significant decline in distress (t=-2.66, p=0.01)

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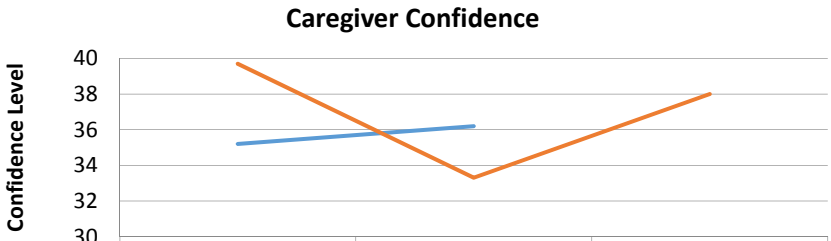
Caregiver outcomes-Confidence



	Baseline (T0)	Month 1 (T1)	Month 2 (T2)
WeCare	35.2	36.2	
Waitlist	39.7	33.3	38

- Maintenance of confidence: WeCare 42.3% vs. Waitlist 26.7% (NS)
- **WeCare had significantly higher change in confidence as compared to Waitlist (t=2.55, p=0.01),** Waitlist had a significant improvement in confidence after 1 month of tool use (t=4.56, p<0.0001)

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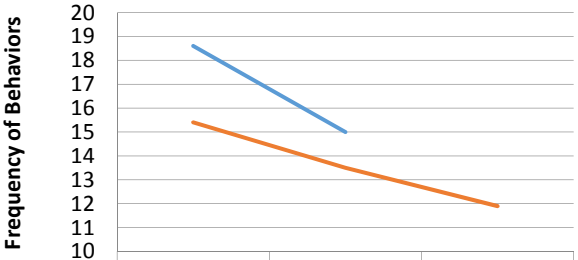
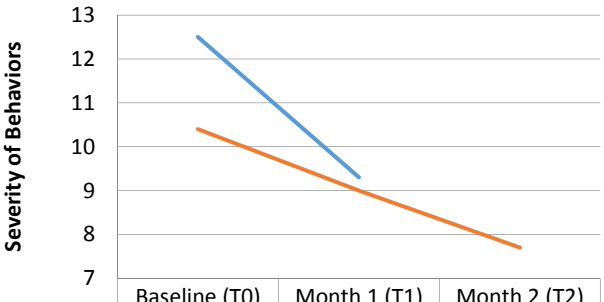
Person with dementia outcomes

Behavioral Frequency



	Baseline (T0)	Month 1 (T1)	Month 2 (T2)
WeCare	18.6	15	
Waitlist	15.4	13.5	11.9

Behavioral Severity



	Baseline (T0)	Month 1 (T1)	Month 2 (T2)
WeCare	12.5	9.3	
Waitlist	10.4	9	7.7

- No significant differences except frequency waitlist T1 vs T2 (0.037), trend for severity waitlist T1 vs. T2 (0.09)

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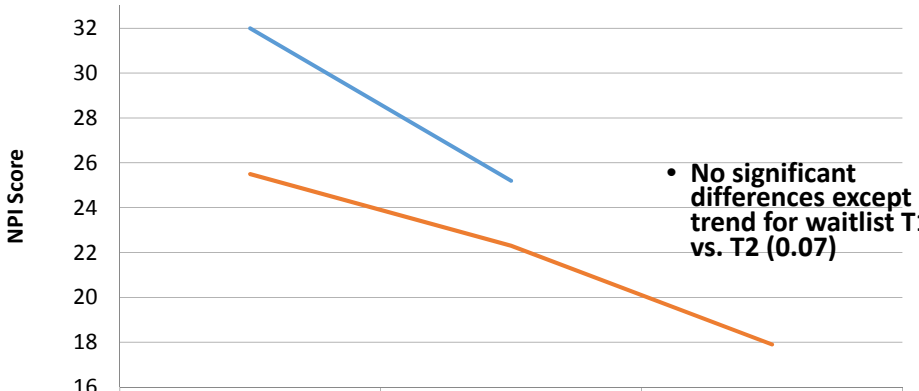
Person with dementia outcomes

NPI Score over time



	Baseline (T0)	Month 1 (T1)	Month 2 (T2)
WeCare	32	25.2	
Waitlist	25.5	22.3	17.9

- **No significant differences except trend for waitlist T1 vs. T2 (0.07)**

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Summary

- Behaviors are universally experienced by people with dementia with a significant negative impact on quality of life, health care outcomes, caregiver stress/burden and health care costs
- We need new models and approaches that consider the full biopsychosocial complexity of BPSD as well as real-world treatment settings
- Few assessment and treatment options for BPSD currently available for formal/informal caregivers and providers
- Approaches like DICE and WeCare can guide them though the clinical reasoning process to identify, monitor, and manage behaviors
  - Increase caregiver self-efficacy
  - Reduce adverse events including ED visits and hospitalizations
  - Improve communication with providers

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