Tailoring, Targeting and Addressing what Matters: Supporting People with Intellectual and Developmental Disabilities who are Living with Dementia

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Consultant to various community-based agencies concerning dementia care;
Inventor of an online program for an intervention (Tailored Activity Program) for which
Johns Hopkins University, Drexel University, and Dr. Gitlin are entitled to fees.
Objectives

- State of dementia care research
- Promising interventions that support quality of life
  - DICE approach (targeted to addressing specific behavioral symptoms)
  - Tailored Activity Program (activity engagement)
  - COPE (care challenges)
- Best practices for people with IDD and dementia
- Enhancing clinical relevance
  - Targeting
  - Tailoring
State of Dementia Care Research
Recent Reports on Dementia Care


  - Gitlin, Jutkowitz, Gaugler – Summation of interventions for caregivers
  - Gaugler, Jutkowitz, Gitlin – Summation of interventions for people living with dementia


- **Best Practice Caregiving – Family Caregiver Alliance/Benjamin Rose:** [https://bpc.caregiver.org/#home](https://bpc.caregiver.org/#home)
Lessons Learned From Hundreds of Clinical Trials

- Support programs for carers are highly effective; Evidence for programs for people living with dementia more inconsistent

- Most effective programs are multicomponent combining counselling, support, education, stress, mood management, skills training

- No one program is effective for all desired outcomes

- Need to select an approach based on desired outcomes
Pathways for Supporting Quality of Life in People with IDD and Living with Dementia

**Person**
- Etiology
- Disease Stage
- Physical Health
- Cognitive functioning
- Preferences

**Caregiver**
- Relationship
- Closeness
- Gender/Race/ethnicity/culture
- Employment
- Life course
- Readiness, Style, Hours caregiving

**Care setting**
- Behavioral, Cognitive, Mood
- Skills, Health, Resources, Financial

**Delivery Modalities**
- in person
- video-chat
- telephone
- online platforms/apps
- in healthcare systems, care homes, home

**Targeting Tailoring**

**Caregiver Outcomes (Formal/Family)**
- Mood
- Quality of life
- Efficacy
- Skills
- Upset/burden
- Physical health

**Person with IDD and Dementia Outcomes**
- Mood
- Behaviors
- Quality of life
- Function
- Engagement
- Physical health
- Aging in place

**Environment**
- Safety
- Under/over Stimulation
- Wayfinding

**Pathways for Supporting Quality of Life in People with IDD and Living with Dementia**

Gitlin & Hodgson, 2015

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**Pathways for Supporting Quality of Life in People with IDD and Living with Dementia**

Gitlin & Hodgson, 2015
Promising Interventions to Support Quality of Life
DICE APPROACH
Managing Challenging Behavioral and Psychological Symptoms
What are Behaviors?

- Rejection of care; “Extreme stubbornness”
- Arguing
- Repetitive verbalizations/questioning
- Wandering
- Hoarding/rummaging
- “Inappropriate” behaviors (screaming, spitting, sexual behaviors)
- Sleep problems (day-night reversal)
### Behaviors are Bad for Everyone

<table>
<thead>
<tr>
<th>Person Living with Dementia</th>
<th>Caregivers</th>
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<tbody>
<tr>
<td>• More rapid declines</td>
<td>• More time providing care</td>
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<tr>
<td>• Increased hospitalizations</td>
<td>• Increased depression and distress</td>
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<tr>
<td>• Poorer quality of life</td>
<td>• Distressing to person</td>
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<td>• Trigger for residential placement</td>
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<td>• Rejection from care facilities</td>
<td>• Increased care costs</td>
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</table>
Why do behaviors occur?

**Neurodegeneration**

**Modifiers***
- Genes
- Reserve
- Resilience
- Comorbidities
- Other
*Some of these are also potentially modifiable

**Disruption in brain circuitry**

**Circuits Involved**
- Monoamines
- Salience network
- Limbic system
- Circadian system
- Other

**Behavioral Effect**
- Loss of executive/inhibitory control
- Impaired threat assessment
- Mood instability
- Sensory impairment
- Sleep-wake disruption
- Stimulus bound/goal directed behavior
- Impaired information processing
- Other

**Behavioral and Psychological Symptoms (BPSD)**
- Agitation
- Psychosis
- Depression
- Apathy
- Sleep disruption
- Other

**Environmental Factors**
- Over or under-stimulation
- Safety issues
- Lack of activity or structure
- Limited light exposure
- Residence and neighborhood
- Other

**Caregiver Factors**
- Emotional state (distress, depression, fatigue)
- Loss of mastery/stress
- Communication challenges
- Unrealistic expectations
- Caregiving style
- Limited resources (human, financial)
- Other

**Patient Factors**
- Acute medical illness
- Pain threshold/expression
- Premorbid personality
- Premorbid psychiatric disorder
- Unmet needs: fatigue, poor sleep, hunger, fear, boredom
- Other

**Vulnerability to stressors/triggers**

**Kales, Gitlin & Lyketsos, JAMDA, 2019**
• **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

https://diceapproach.com/
Example of DICE APPROACH

Describe

Resident (Mrs. J)
- Trying to leave the facility; Blocking door; Screaming and striking out; Escalating aggression with staff intervention

Caregivers
- Worried Mrs J might escape; Concerned about impression of new residents and families at entrance; Worried that Mrs J would fall; Staff concerns about being hurt

Environment
- Noisy music group; Saw front door when she exited; Surrounded by staff and residents as they left concert

Investigate

Resident
- Recent move from another part of building; Due to anxiety, had recent increase in meds; Functional and cognitive fluctuations of Parkinson’s; Moderate dementia, poor executive function; History of rape as a teenager

Caregivers
- Taken off guard by sudden uncooperativeness; did not know her well; Communication style inappropriate; Fear and embarrassment increased their stress and led to physical intervention

Environment
- Over-stimulating; Routine was changed by move; Seeing door gave her a view of outside
Create

**Resident:**
- Rule out acute medical issues; Decrease SSRI back to original dose; Avoid antipsychotics which could worsen Parkinson’s;
- Consider ways to decrease anxiety (e.g. music, exercise); Use of 4-wheeled walker for stability

**Caregivers**
- Identify less overstimulating activities; Use simple calm communications; Avoid evoking memories of sexual assault;
- Inform and explain any need for touch or direction; Educate staff about her history; If tries to leave event, walk with her, calmly redirect her back into facility when less agitated

**Environment**
- Create routines that are safe, not overstimulating and meaningful; using signage to redirect and cue

Evaluate

**Resident:**
- Monitor behavior change once SSRI is decreased; Evaluate effect of each strategy; Monitor anxiety levels

**Caregivers**
- What approaches did staff try? Were there any that they were resistant to? If so, why?; What worked? What didn’t?; Any unintended consequences or “side effects” noted?

**Environment**
- What changes were made? Were new routines instituted? Any issues with that?
Clinical Trajectory

Pre-Clinical

Prevention

No Impairment

Mild Cognitive Impairment

Early Stage

Mild Dementia

Middle Stage

Moderate Dementia

End Stage

Severe Dementia

COPE Program

- Person with dementia
  - Lives at home
  - Functional dependence
  - Behavioral symptoms
  - Caregiver distress

COPE Treatment Goals

- Person with dementia
  - Reduce functional disability
  - Prevent/manage behavioral symptoms
- Caregiver
  - Enhance knowledge and skill

McKhann et al., 2011, Albert et al., 2011, Sperling et al., 2011 and Jack et al., May 2011

Alzheimer's & Dementia: The Journal of the Alzheimer's Association
COPE Program

Phase 1: Assessment
- Person
- Caregiver
- Environment

Phase 2: Implementation
- 3 Care challenges
- 1 Activity
- 4 COPE Prescriptions

Phase 3: Generalization
- Modify for future
- Use strategies for other problems

- Strength based (what a person can do)
- Caregiver-centric (identify what matters)

Gitlin et al., JAMA 2010
COPE Nurse Visit

- Provide caregiver education (Pain, Dehydration, Infection, Constipation, Polypharmacy, Talking to doctor, Talking to family and others)
- Discuss strategies for self-care self (respite, health habits, sleep)
- Physical exam
  - Medication review
  - Blood and urine
  - Results shared with caregiver
## COPE Prescription

### What is the problem?

### How do I want the situation to change?

### Why the problem may occur:

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<th>Caregiver</th>
<th>Environment</th>
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### Person’s Abilities:

1. ________________________________
2. ________________________________
3. ________________________________
4. ________________________________

### Strategies:

1. **Communicate effectively**
   - What to do:
     - □ __________
     - □ __________
   - What to avoid doing:
     - □ __________
     - □ __________

2. **Modify your home and make it safe**
   - What to do:
     - □ __________
     - □ __________
   - What to avoid doing:
     - □ __________
     - □ __________

3. **Simplify the way you set up daily activities**
   - What to do:
     - □ __________
     - □ __________
   - What to avoid doing:
     - □ __________
     - □ __________

4. **Enhance activity participation**
   - What to do:
     - □ __________
     - □ __________
   - What to avoid doing:
     - □ __________
     - □ __________

### Strategies for You:

- □ ________________________________
- □ ________________________________

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Jefferson College of Health Professions
Caregiver-identified Problems in the COPE Assessment Phase, by Percent of Problems (N=409)

- **Activity Engagement**
  - Engaging person with dementia in meaningful/familiar activities
  - 13.9%

- **Behavioral Symptoms**
  - Addressing behavioral symptoms in person with dementia
  - 32.3%

- **Caregiver Concerns**
  - Taking care of self, handling care coordination, communicating with family members, feeling overwhelmed, and understanding/accepting dementia
  - 30.3%

- **Daily Activities**
  - Assisting the person with dementia with self-care activities (e.g. bathing, dressing, grooming), and other daily activities (e.g. medication management, financial management, meal preparation)
  - 23.5%

Funded by the National Institute on Aging (AG044504)
Level of Resolution of Problems at End of COPE-Connecticut by % Problems (N=314)

- Eliminated, 21% (66)
- Reduced, 75% (234)
- Got Worse, 4% (14)

Funded by the National Institute on Aging (AG044504)
For Persons Living with Dementia

- Improved caregiver confidence
- Reduced targeted problem area
- Reduced physical dependence
- Enhanced activity engagement

For Caregivers

- Improved caregiver wellbeing
- Less Upset

And for Health Systems, cost savings

Select sources: Gitlin et al., 2010; Fortinsky et al., 2020
Tailored Activity Program (TAP)

An evidence-based program that improves quality of life of people living with dementia and their caregivers.

It uses activities tailored to abilities and interests of people living with dementia, instructs caregivers in setting up and using activities, and provides disease education and stress reduction techniques.
Tailored Activity Program (TAP) is Local and Global

- England and Scotland
- Eastern and Western Europe
- Russia
- M.E Asia
- Africa
- M.E Asia
- Hong Kong
- Australia
- South America
- North America
- South America
- Brazil
- Chile
- Maryland, Utah, Texas, Arizona, Missouri, Pennsylvania, North Carolina; Nevada
- Italy
- Eastern and Western Europe
- Russia
- Tailored Activity Program (TAP) is Local and Global
TAP ADAPTED FOR AND TESTED IN DIFFERENT SETTINGS AND AROUND THE WORLD
WHY ACTIVITY?

• It matters to people and caregivers
• Associated with life quality
• Lack of activity associated with behavioral and psychological symptoms
• Provides sense of purpose, connectivity, a role, relief from situational stress and anxiety
• May have physiological benefits
Phase I of TAP

1. Assess Person with Dementia
   - Interests, previous roles
   - Abilities, sensory and physical function, executive function, mobility, behavioral symptoms

2. Assess Caregiver
   - Readiness
   - Stress
   - Communications
   - Daily Routines
   - Cultural Norms
   - Employment
   - Other Roles

3. Assess Environment
   - Lighting
   - Seating
   - Clutter
   - Accessibility
   - Visual Cues
   - # Persons
   - Ambient Noise

4. Create Activity Prescriptions
   - Early
     - Goal Oriented
     - Multi-Step
     - Sequencing
     - Problem-solving
     - Independent
     - Minimal Set-up
   - Moderate
     - 2-Steps
     - Cueing
     - Repetitive motions
     - Not goal oriented
     - Some supervision
   - Severe
     - Sensory
     - Single-step
     - Supervision
     - Brief engagement
     - Cueing
Phase II = Instruct Caregivers in Use of Activities

Caregiver learns person’s capabilities, activity is demonstrated, and activity prescription provided.

Caregiver learns stress reduction techniques, tries activities & adjustments made if necessary.

Phase III = Generalization

Caregiver learns to modify activities for future declines and how to use strategies (communication, simplification) for other care challenges.
More time for self

For Caregivers

Improved confidence

For Persons Living with Dementia

Improved Caregiver confidence

Reduced behavioral symptoms

Reduced physical dependence

Fewer health events

And for Health Systems, cost savings

Select sources: Gitlin et al., under review; Gitlin et al., 2008; 2010; 2014; 2017; Novieli et al., 2018; O’Connor et al., 2017)
Tailored Activity Program  
(n=250; Gitlin et al., under review)

Health-Related Events

48.8% improvement in # of health-related events in TAP for PLWD

63.6% improvement in # of hospitalizations in TAP for Caregivers

Tailored Activity Program (n=250; Gitlin et al., under review)
Activities
Best Practices for People Living with IDD and Dementia
Best Practices:

**Strength-based**
- Identify what a person can do and build on strengths
- Optimize environments to support daily function and activity engagement
- Attend to preferences and values

**Support of quality of life**
- Prevent excess disability
- Maintain function
- Predictable routines
- Support activity engagement (purpose, meaning, roles)

**Caregiver (staff; family) training**
- Communicating effectively
- Setting up activities
- Dementia (Behaviors not intentional)

**Multi-component**
- Tailoring to needs
- Targeting care challenges
- One size does not fit all
- Education, skills training, coping, environmental simplification, activity engagement
Best Practice

Assess
- Strengths/Deficits
- Behaviors, Function
- Interests, Preferences
- Previous roles
- Environment
- Unmet needs

Implement
- Strategies tailored to care challenge and living context
- Communication
- Cueing
- Establish routines
- Meaningful activities
- Environmental simplification

Evaluate
- What works/what does not
- Simplification of tasks, communications, environment
- Prepare for future declines
- Repeat assessments with change in abilities
Enhancing Clinical Significance: Who and What to Target

- Family, staff-identified need or care challenge
- Depression/burden
- Communication styles
- Number of hours providing care
- Behavioral symptoms
- Excess disability
- Poor relationship
Considerations in Tailoring

Caregiver readiness

Caregiver styles (Leggett et al, 2021):

- Externalizer - symptoms of dementia volitional; responds with frustration and anger
- Doer - view only one solution forward
- Learner - approaching adaptability but keep getting stuck
- Adapter – use trial and error & keeps trying
- Cheerleader - other-focused; express positive emotions

Risk profiles

Culture, care preferences, values

Resources, Environmental context
Take Home Points

• Adapt evidence for people with IDD and dementia
• Nonpharmacological strategies are front line
• “Many ways to Many” – one size does not fit all
• No one “magic pill”
• Considerations include disease trajectory, etiology, life course, familial and living context, unmet needs, pre-morbid abilities, interests
• Evidence for multi-component approaches
• Principles for intervening:
  • Person/family centered
  • Tailoring, consideration of preferences
  • Problem-solving
Resources for Families and Health Providers

“Sometimes you just need a checklist.” (Washington Post)

Living with Dementia: Impact on Individuals, Caregivers, Communities and Societies
Massive Open Online Course (MOOC)

Drs. Nancy Hodgson and Laura Gitlin lead the MOOC, an international educational forum for health professionals, students, family caregivers, and anyone affected by dementia.

SIGN UP TODAY! www.coursera.org/course/dementiacare

https://www.amazon.com/Caregivers-Guide-Dementia-Activities-Strategies/dp/1933822902/ref=sr_1_1?ie=UTF8&qid=145459837&sr=1-1&keywords=gitlin+and+piersol

Better Living With Dementia
Implications for Individuals, Families, Communities, and Societies

Laura N. Gitlin
Nancy A. Hodgson

https://www.amazon.com/Better-Living-Dementia-Implications-Individuals-ebook/dp/B07DLRQY4G